

**“It felt like there was a piece missing from me.”: An IPA Exploration of the
School Experiences of Adolescents with an Autistic Sibling**

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Brooke, thank you for being my biggest support system and best friend. In the times where things felt the darkest, you either held the light or sat with me in the dark. I can never thank you enough for all you are and all you do.

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Abstract

Sibling relationships have been described as the ‘marathon runner’ of human connections – beginning before those with significant partners and outlasting those with one’s parents (Green, 2013). Despite the acknowledged importance of sibling relations and growing research into the experiences of having an autistic sibling, the literature into neurotypical sibling experiences within school has received little focus to date. This paper seeks to highlight the lived experiences and individual voices of young people navigating the UK school system, whilst also exploring their roles within their sibling dynamics. To explore this, the following research qualitatively examines the school experiences of young people with an autistic sibling, aged between 14-18 years old using Interpretative Phenomenological Analysis. This paper situates itself within research around disability and sibling relationships, drawing on the Siblings Embedded Systems Framework (Kovshoff et al., 2017) and The Social Relational Model of Disability (Connors & Stalker, 2007) to make sense of the experiences shared by neurotypical siblings. Sibling roles of parentification, caregiving and protection are shared, as well as feelings of loss and confusion around transitioning away from a sibling in school. Consideration is given to the role of gender with respect to caregiving expectations, as well highlighting the development of a sense of self enmeshed with the needs of a sibling. Avenues for providing further space for neurotypical sibling perspectives are discussed, as well as implications for the roles of school-based staff and Educational Psychologists.

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Abbreviations

Attention Deficit Hyperactivity Disorder (ADHD)

Autism Spectrum Condition/Disorder (ASC/ASD)

Child and Adolescent Mental Health Service (CAMHS)

Children and Young People (CYP)

Diagnostic and Statistical Manual of Mental Disorders (DSM)

Educational Psychologist (EP)

Free Association Narrative Interview Methodology (FANIM)

General Data Protection for Children (GDPR)

Interpretative Phenomenological Analysis (IPA)

Local Authority (LA)

National Autistic Society (NAS)

Neurotypical Siblings (NTS)

Social Model of Disability (SMD)

Social Relational Model of Disability (SRM)

Special Educational Needs (SEN)

Siblings Embedded Systems Framework (SESF)

Thematic Analysis (TA)

Trainee Educational Psychologist (TEP)

Typically Developing (TD)

1. Introduction

1.1. Chapter Overview

This qualitative research explores the school experiences of children and young people (CYP) who have a sibling diagnosed with Autism. This chapter provides the context for the current research by first outlining the experiences of siblings, and in particular siblings of those with a disability. This chapter will then outline theoretical frameworks which form a basis for conceptualising disability within the current research, and finally, will outline personal motivations and experiences behind this research. The chapter aims to give a broad overview of sibling experiences, with a specific focus on CYP with autistic siblings to follow in Chapter 2.

1.2. Sibling Relationships, National and Legislative Context

Sibling relationships have been described as the ‘marathon runner’ of human connections, outlasting those with parents and beginning before those with significant partners (Green, 2013). It is therefore crucial to consider the life experiences of individuals with disabled siblings, particularly as the majority of those with additional needs rely on the support of close family members (Seltzer, 1992).

According to Sibs UK (2024a), half a million CYP and approximately 1.7 million adults are siblings to those with disabilities. As research suggests the experience of having a disabled sibling varies regarding the impact and can span multiple contexts that a young person exists within (e.g., home, school, the local community), their experiences require close attention and research (Sibs UK, 2024a). According to the 2021 census, there are approximately 120,000 young carers aged 5 -18 in England, half of whom are estimated to be caring for a sibling (Office for National Statistics, 2021; My Family Our Needs, 2021). In a recent survey, children described how these home experiences influenced their school life, including difficulties being recognised

as individuals, challenges concentrating after difficult mornings, ongoing worry for their siblings, and experiences of bullying linked to their sibling's disability (Kassa & Pavlopoulou, 2024)

Despite this known context, siblings are not mentioned specifically within the Special Educational Needs (SEN) Code of Practice (Department for Education, 2015), despite guidance stating the need to pay attention to the family unit when providing support to a child with SEN. What is clear however, from the Children and Families' Act (Department for Education, 2014), is all children have a right to have their voices heard and receive help where needed. This sentiment is echoed by the 'Every Child Matters' documentation (Department for Education, 2003), which indicates the need to involve CYP in consultation about their needs, and by Article 12 from the Convention on the Rights of the Child (United Nations, 1989) which further outlines the need to involve children in decisions concerning them. Highlighting the voices of CYP who have disabled siblings is therefore an important area for exploration.

1.3. Conceptual and Theoretical Frameworks

1.3.1. Social Models of Disability

The term 'disability' is used throughout this research and so it is first important to outline that it is being used in alignment with the 'Social Model of Disability' (SMD). The SMD positions disability within the context of the barriers created by society, rather than solely by individual impairments or differences (Shakespeare, 2006). Taking this further, the Social Relational Model of Disability (SRM) has discussed how it relates to the lived experiences of children specifically (Connors & Stalker, 2007). The SRM proposes that difference exists but are then perceived and maintained as disability by social opinions and barriers. It highlights that as well as

disability existing as a result of societal barriers, it is also rooted in unequal social relationships. The SRM highlights a 'social imposition of restrictions of activity' on those who are seen as disabled and that this can take the form of 'barriers to doing' or 'barriers to being' (Connors & Stalker, 2007, p. 21). The former refers to the physical barriers to equity as outlined by the SMD, while the latter, refers to behaviours from others which impact the self-esteem of those who are disabled. This is termed by the model as 'psycho-emotional disablism'. In acknowledging these models and how they may relate to the experiences of NTS, this research draws on the concept of 'disability by association' (Burke, 2010), whereby CYP with disabled siblings may perceive themselves as disabled simply by living with their sibling (Naylor & Prescott, 2004). However, it is important to attend to the position I adopt as a researcher. While my thinking aligns with the SRM and the SMD, when sharing the views of siblings from previous research, I am conscious of any implications that disabled siblings are seen as a burden to others. This highlights the tension between how disability may be seen from the outside, versus experienced by the individual siblings. As a researcher, I am aiming to not position autistic and disabled siblings as burdens. However, it is important to acknowledge that NTS may sometimes perceive their autistic siblings through the lens of societal and relational barriers which can foster challenging experiences.

1.3.2. Siblings Embedded Systems Framework (SESF)

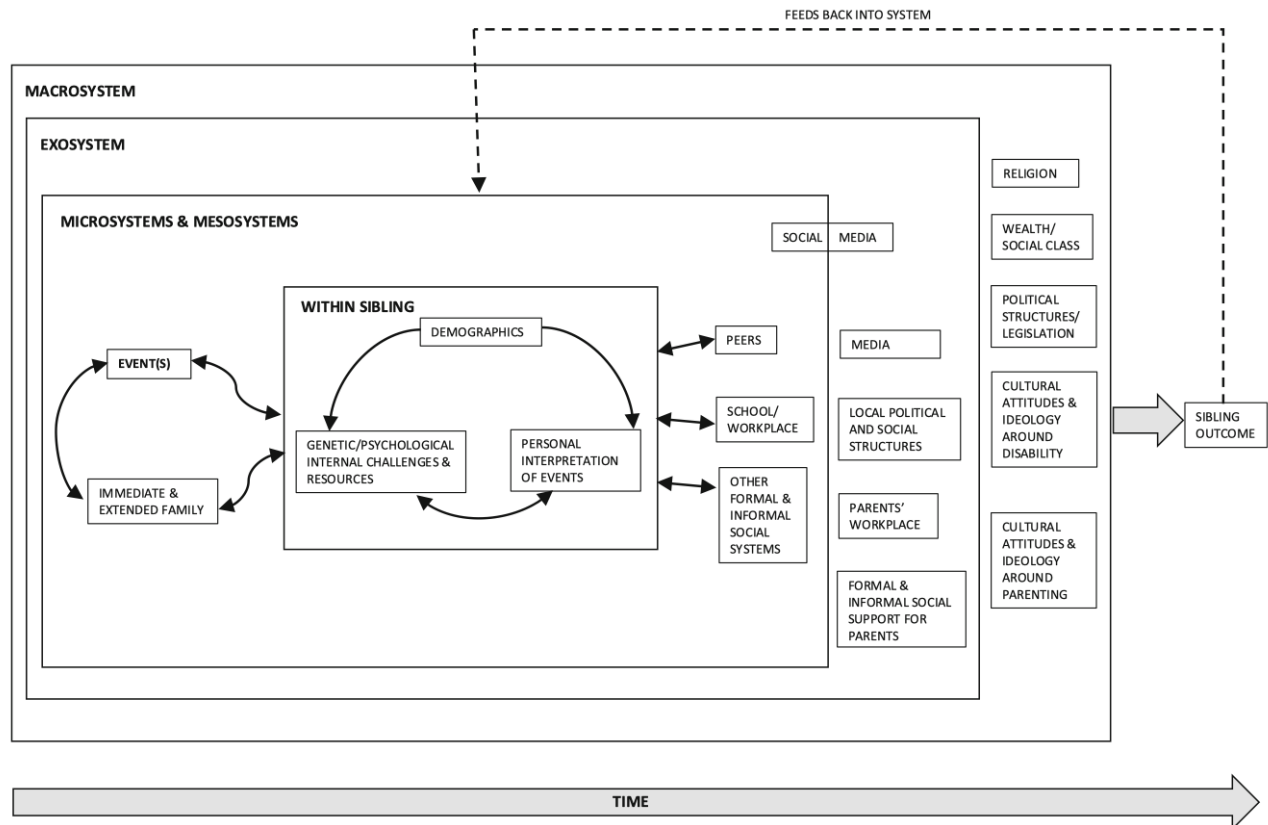
In line with the position outlined above, this research will utilise the SESF (Kovshoff et al., 2017) to understand the embedded nature of sibling experiences. While the SESF was not originally designed specifically for studying siblings of disabled children, it has been effectively applied in research exploring sibling relationships involving autistic children (Kovshoff et al., 2017). The SESF is being

used to explore the experiences of siblings as it acknowledges the multiple systems a sibling is embedded within and allows an exploration of intersecting contexts. As this research is focused on looking at the school experiences of siblings, this framework allows a model for exploring the interplay between experiences.

The SESF shown in Figure 1 outlines a model in which the sibling - here, a neurotypical sibling (NTS) - is placed at the centre of nested levels. In line with Bronfenbrenner's (1979) Ecological Systems Model, the SESF suggests that understanding an individual requires considering the multiple contexts and environmental settings they encounter, both directly and indirectly. At the 'within sibling' level, the framework proposes that an 'event', in this case having an autistic sibling, is interpreted individually and interacts with demographic and physiological factors. This aligns with the Diathesis-Stress Model (Zuckerman, 1999), which examines how genetic predispositions and environmental stressors influence outcomes (Orsmond & Seltzer, 2009; Zuckerman, 1999). While drawing on Family Systems Theory (Von Bertalanffy, 1950), which promotes a holistic view of families, the SESF does not position the autistic sibling as inherently stressful. Instead, it frames the sibling or a specific behaviour as an 'event', accommodating both positive and variable experiences over time. Like the ABCX Model (McCubbin & Patterson, 2014), it considers each family member's responses individually. This resonates with the SRM, which emphasises the role of individual relationships and responses in shaping sibling experiences

Figure 1

The Siblings Embedded Systems Framework (SESF)



Note. The SESF as retrieved from Kovshoff et al. (2017).

Within the micro and mesosystemic levels of the model, siblings are not only impacted by 'the event', but also by systems they are a part of. This may include extended family, peers, school experiences, and for siblings of autistic children, may consider the responses these systems have towards autistic young people and their siblings. Kovshoff et al. (2017) outlines that this level, particularly in relation to an interplay between home and school environments, is where current research is lacking.

At the exosystemic level, the SESF explores the impact of media, social structures and parent support on the siblings, with the most research focused on how parental support influences sibling adjustment (Hastings & Petalas, 2014). At the macrosystemic level, the SESF outlines the impact of culture and religion on sibling outcomes – this may be in relation to family narratives around seeking

support and diagnoses and/or cultural views on Autism. The framework also outlines that sibling outcomes are fed-back into the system. For example NTS who have positive emotional and behavioural outcomes due to individual, peer, family and cultural factors, may be more likely to interact differently with their autistic sibling, with research suggesting there is a correlation between NTS behaviour and autistic sibling behaviour (Kovshoff et al., 2017). The final element of the SESF is 'time', emphasising that many of the factors within the framework will change over time, with earlier experiences shaping later ones and with tools such as social media, and wider socio-political landscape and attitudes to Autism potentially influencing NTS.

The current research will use this theoretical framework to make sense of the experiences of NT children with autistic siblings, with a particular focus on school within the microsystemic level and its interaction (mesosystemic level) with home life for individuals.

1.4. Researcher Background

Interest in this area of research has, in part, stemmed from my own lived experiences of having a sibling with diagnosed neurodiversity. Although my older sister has a diagnosis of ADHD rather than Autism, this inspired a personal wish to explore the school experiences of others who have a neurodivergent sibling. For me personally, my close relationship with my sister formed a large part of my school experience, particularly as we attended both the same primary and secondary schools together. As a Trainee Educational Psychologist (TEP), I was prompted to consider this further through my work within an Autism Diagnostic Service in CAMHS. When working within this team and facilitating groups for parents whose children had been diagnosed as autistic, the common questions were around the experiences of their other children, the NTS. Parents often asked 'What about her

sibling? How can we support her too?', and upon researching to support the parents, it became apparent that further research was needed. In essence this research arose from a sense of a 'felt difficulty' (Dewey, 2003) that gave pause for reflection and prompted further exploration.

1.5. Chapter Summary

This chapter has outlined the national context around disability, as well as started to highlight the experience of having a disabled sibling within the frameworks provided. The next chapter will outline an initial scoping of the literature in relation to Autism specifically to provide a rationale for the current research. Following the subsequent scoping chapter, this paper will provide a systematically informed literature review, an outline of the methodological approaches taken for data collection and analysis, illustrate a detailed exploration of the research findings and then conclude with a discussion around the school experiences for CYP with autistic siblings. This research will continue to be framed within the literature, context and frameworks provided.

2. Context: Initial Scoping and Locating the Research

2.1. Chapter Overview

Following the previous chapter's exploration into the context and theoretical frameworks for understanding sibling relationships, an initial scoping search was completed ahead of a systematically informed literature review (see Chapter 3). The purpose of this search, which will be outlined in the chapter below, was to hone the focus of the current research. This chapter will first outline the specific context of Autism in the UK, before exploring the findings of the scoping search.

2.2. Autism and Sibling Experiences

Before exploring Autism and the current research more specifically, it is acknowledged here that the language around Autism is a highly personal decision and each individual, including siblings and wider family members, may use different terms at different points in their lives. For the purpose of this research, the guidance around language from the National Autistic Society will be used. This guidance is based on research from Kenny et al. (2016), who discussed preferred language with those diagnosed as autistic. The preferred terms for the majority of those diagnosed were 'Autism' and 'autistic', rather than the use of person first language such as 'person with Autism'. Although there is no universally accepted term for all those diagnosed, these generally preferred terms will be used throughout this paper.

Autism, as outlined by the Diagnostic and Statistical Manual (DSM), is defined as 'persistent deficits in social communication and social interaction, across multiple contexts' (American Psychiatric Association, [APA] 2022) and involves difficulty in interpreting the behaviour and intentions of others, difficulties in engaging in reciprocal conversation, differences in non-verbal communication, difficulties in

changes to routines and specific and specialised interests. A full description of Autism as outlined in the DSM, can be seen in Appendix A.

The autistic population in the UK is currently said to encapsulate as many as 1.2 million people, and when taking their families into account, there may be as many as 2.8 million people in UK who live with Autism as part of their daily lives (Danby, 2023; National Autistic Society, 2023). Research has reported on a 787% exponential increase in the recorded incidence of Autism between 1998 and 2018 within the UK and explored that this has been greater for the diagnosis of females (Russell et al., 2022). This increase has been hypothesised to be due to increased reporting and diagnosis, increased awareness of differences in female presentation of Autism, and an increase in clinicians who can diagnose. Regardless of the reasons for the increase in prevalence, exploring the experiences of the wider family network, including the siblings, becomes an ever more crucial area for research.

To begin exploring the lived experiences of CYP with autistic siblings, a scoping search was completed. This scope was conducted using Google Scholar to explore the field of research, producing more than 300 papers for review. These papers were explored pragmatically by reading the first page of results and exploring their references sections. This was completed until saturation was reached in terms of new theme emergence. A summary of the findings of these papers has been outlined below.

2.2.1. Reported Challenging Experiences

Much of the literature into the lived experiences of NTS describes a “different normality” in family life (Tozer et al., 2013), where day-to-day experiences diverge from peers without autistic siblings.

One prominent difference is the emotional toll of navigating public responses to Autism. NTS frequently report feelings of shame or embarrassment, particularly in response to perceived judgement from others (Hwang, 2009; Keirse, 2016; Mascha & Boucher, 2006; Tsai et al., 2018). The reactions of others are often described as lacking understanding or empathy, which leads to feelings of anger, frustration, and disappointment (Petalas et al., 2012). As a result, some siblings withdraw socially, avoid sharing information about their sibling, or even resort to protective behaviours such as physical retaliation (Petalas et al., 2012). Family-wide withdrawal from community spaces has also been documented, with families opting to stay at home to avoid judgement, particularly in the absence of respite care (Hall & Graff, 2010). This judgement was often related to unpredictable behavioural outbursts (Iannuzzi et al., 2022), which, alongside emotional strain, contributed to heightened vigilance among NTS both at home and in public.

Increased responsibility is another well-documented theme. While caregiving may be experienced positively by some, research frequently frames it within the concepts of young caregiving and parentification, which can be associated with negative outcomes. Parentification refers to a reversal of roles, where a child assumes responsibilities beyond what is developmentally appropriate (Haxhe, 2016). This can lead to stress, isolation, and disrupted education and can also expand out to parent-focused caregiving - attempting to shield their parents from stress, alongside caring for their sibling (Nuttall et al., 2018; Tsai et al., 2018). Over time, this dynamic can lead to patterns of 'compulsive caretaking', where the individual seeks to control social dynamics or assumes they know what is best for others (Nuttall et al., 2018). Worries about the future due to their caring roles also emerged throughout the literature. For example, NTS often anticipated taking on caregiving roles in

adulthood, particularly after the death of parents (Corsano et al., 2017; Iannuzzi et al., 2022; Pavlopoulou & Dimitriou, 2020). These concerns sometimes manifested in the present, particularly around worries about a sibling's transition to higher education or the evolving expectations around care (Petalas et al., 2012).

Gender and age can shape these experiences further. Older siblings, particularly girls, often report stronger feelings of resentment linked to caregiving expectations (Hennon, 2013). In one study, a typically developing (TD) sister described being seen as the family's 'shining star' in contrast to her autistic sibling, which led to her own learning difficulties being missed (Pavlopoulou & Dimitriou, 2020). In other cases, siblings described shaping their behaviour to appease their autistic sibling - such as allowing them to lead play - sometimes at the expense of their own needs (Papacek, 2012).

Social lives and friendships are also impacted. Many NTS report hesitancy in inviting friends over, fearing their sibling might experience a crisis (Corsano et al., 2017). In one case, a sibling described life with an autistic brother as a form of "persecution" that demanded constant personal sacrifice, especially in relation to social opportunities. This theme of sacrifice also extends to family dynamics: where differential parental attention, often skewed toward the autistic child, can strain relationships between the NTS, their parents and sibling (Benini, 2022; Hall & Graff, 2010; Hennon, 2013).

2.2.2. Reported Positive Experiences

To provide a holistic view of NTS experiences, as well as contrasting perspectives, some research outlines no significant differences in emotional and behavioural functioning between NTS aged 7-17 and CYP without an autistic sibling (Hastings & Petalas, 2014). NTS also describe close sibling relationships and a strong sense of

pride in their sibling's progress (Chu et al., 2023; Macedo Costa & Pereira, 2019) and many shared having gained skills such as empathy, compassion, and emotional attunement (Iannuzzi et al., 2022; Keirse, 2016). Others express an appreciation of gifts that others may take for granted (Schall, 2000), and report higher personal, social, and spiritual growth than peers with non-autistic siblings, along with greater tolerance and acceptance of difference (Findler & Vardi, 2009; Costa, 2019).

Research also indicates elevated perspective-taking and empathy in NTS, with greater perspective-taking linked to more positive feelings towards their autistic sibling (Shivers, 2019). NTS often voiced wishes for their families rather than themselves, and this family-oriented focus was linked to stronger familial connections and closer sibling relationships than those reported by CYP without autistic siblings (Hennon, 2013).

In conclusion, the experiences of NTS of autistic children appear to be a unique experience for each individual, sibling and family (Hennon, 2013), encompassing both positive and negative impacts - the nuance of which is important to hold in mind.

2.3. Research Rationale

The scoping review demonstrates an impact on the home and community experiences of those with an autistic sibling; an impact that may be positive, negative, neutral, or a combination. While much of the research highlights this impact, very little is known about how having an autistic sibling impacts CYP experiences within the UK education system. From the hundreds of papers explored as part of the initial scoping search, only a small selection focused on school experiences for these children. As children spend roughly 32.5 hours in school per week (equating to ~1235 hours in a school year), it is pertinent to investigate their

views of how their school experience may or may not be influenced by growing up with their autistic sibling. Siblings school experiences are not only neglected throughout the literature, but as noted in Chapter 1 they are not mentioned specifically within the Special Educational Needs (SEN) Code of Practice (Department for Education, 2015), despite guidance stating the need to pay attention to the family unit when providing support to a child with SEN. Although there are some recent investigations into the school experiences of siblings, this has tended to be of those whose brother or sister is disabled, rather than exploring Autism specifically (Sibs UK, 2024b). As professionals aim to provide differentiated support to children with a variety of needs, (e.g. Autism, Down Syndrome, ADHD), their siblings may also require individualised support as Autism may poses unique challenges and benefits for the family. To address this discrepancy this research will focus on hearing the voices of CYP with autistic siblings, exploring their school experiences in depth.

Considering the impact for EPs specifically, understanding the experiences of siblings within school may allow a deeper understanding of the systemic influence of Autism, and therefore may support the identification of specific risk and resilience factors, for children who may have previously been overlooked. EPs may also be in a position to highlight the specific needs of siblings within consultations, integrate NTS experiences into formulation, and may have a greater appreciation of where school training needs to be targeted. Within broader government policy, EPs may be able to advocate for siblings within policy change, specifically in relation to the individual sibling policy within medical, health and social care (Meltzer, 2021), and within educational policy. Holding the potential implications in mind, this research will focus on hearing the voices of CYP themselves with the sentiment of ‘nothing about

us without us' (Charlton, 1998), It is hoped their voices will add further insight into NTS experiences across different contexts, and how best to support and understand their experiences in schools.

The following chapter will outline a focused, systematically informed literature review regarding what is currently known about the school experiences of CYP with autistic siblings.

3. Literature Review

3.1. Chapter Overview

This chapter provides a comprehensive synthesis of the current literature exploring the school experiences of CYP with an autistic sibling. The chapter will first introduce the literature review purpose and outline the systematic search strategy. It will then describe the inclusion and exclusion criteria, and frameworks of quality appraisal used. The identified literature will then be critically reviewed and synthesised thematically to provide a clear view of the existing landscape of the research in this area. Finally, the reviewed literature will be considered as it relates to the original review question and what this means for the current study and subsequent methodological decisions.

3.2. Literature Review Purpose and Questions

A literature review using a systematic approach was used to evaluate the current landscape of research in the area. A literature review aims to draw conclusions about key principles and issues, while also explaining how and why existing studies fit together (Cherry et al., 2023). This allows for an exploration into gaps for future research, and emerging themes within the field (Siddaway et al., 2019). The aim of the literature review was to answer the following question:

What does the literature tell us about the school experiences of CYP with an autistic sibling?

A systematic approach to answering this review question was deemed as appropriate as this method allows for an in-depth exploration into a specific area in an exhaustive and non-biased manner (Siddaway et al., 2019). The aim was to

address the research question through a replicable and staged approach, based on clear inclusion and exclusion criteria - an approach outlined below.

3.3. Review Method

3.3.1. Search Strategy

An initial review of the literature using the search terms and process outlined below took place in May 2024. The search was re-run in November 2024 to ensure a comprehensive search had taken place and all papers, including those published recently, were included in the review. The searches took place via the EBSCOhost online research platform within which a number of databases specific to psychology and education were selected. In line with recommendations from the Cochrane Collaboration, more than one database was searched in order to reduce the likelihood of publication bias, while also understanding that searching across 6 or more databases can increase the likelihood of research duplication (Lefebvre et al., 2008). The searches were therefore undertaken across 5 databases: PsycINFO, APA PsychArticles, Psychology and Behavioural Sciences, Education Source and Education Resource Information Centre. In order to ensure the relevance of papers identified through database searching, the searches were based on the titles and abstracts of papers. The search returned 275 items of literature, and eight were included in the final review. Figure 2 illustrates the process of elimination during the review process.

3.3.2. Search Terms

The search terms were derived from the literature review question, with considerations being given to alternative words and word endings to ensure a comprehensive search of the area. The search terms utilised can be seen in Table 1,

where asterisks show how words were truncated to ensure alternative word endings could be explored. All individual search terms were connected by the Boolean operator 'AND' to ensure the searches were specific and narrowed in focus, and in line with the inclusion and exclusion criteria (Table 2). All alternative search terms were joined using the Boolean operator 'OR' to ensure all searches remained broad and open to alternative words and word endings (Cherry et al., 2023).

Table 1

Literature Review Search Terms

Search Terms	Alternative Search Terms	Field
Sibling	sibling* OR brother* OR sister*	Title and Abstract
Autism	autism* OR autistic OR autism spectrum condition OR autism spectrum disorder OR asd OR asc	Title and Abstract
School	school* OR college* OR educat*	Title and Abstract
Child	child* OR adolescen* OR youth*	Title and Abstract

Initially, the terms 'experiences OR perceptions' were included as search terms. However, adding in these terms significantly reduced the number of papers returned by the searches and were excluding quantitative explorations into the topic area. Removing these terms broadened the scope of the search while still ensuring papers remained specific to the search at hand.

3.3.3. Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria (Table 2) were formulated prior to the initial search taking place and were chosen to ensure relevance to the literature review question. The criteria, along with justifications for their implementation can be seen in the table below.

Table 2

Literature Search Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Justification
Focus is on the non-autistic sibling – other perspectives and information can be incorporated but sibling views are the main focus.	Focus only on wider family perspectives e.g., parents.	To ensure the literature reviewed is appropriate for the review question around non-autistic sibling experiences.
CYP have an autistic sibling	CYP have a sibling with complex needs e.g., medical needs, Down Syndrome Both children are autistic	To ensure the literature reviewed is appropriate for the review question in that it specifically explores experiences of NTS who have an autistic sibling.
Paper accessible in English (including requested translations)	Only accessible in a language other than English	English is the language spoken by the researcher
Published after 1980 (when Autism was added to the DSM)	Published prior to 1980	To ensure that research was within the context of Autism being a diagnosable need.

Peer reviewed journal article (including grey literature)	Books, reports, opinion pieces, conference proceedings.	Grey literature included to reduce publication bias. Books and reports not included to ensure that empirical research and the findings are synthesised.
NTS aged between 4-18	Focus on adult siblings or preschool siblings	To ensure that the experiences of school and college age young people were explored – maintained focus on a specific population.
School experiences as the focus.	Home or community life experiences as the focus, papers exploring interventions given to NTS or papers exploring symptoms of Autism in non-diagnosed siblings.	To ensure the literature reviewed is appropriate for the review question around school experiences.

Limiters and expanders were also applied to the searches in line with the inclusion criteria in Table 2. An additional expander ‘apply equivalent subjects’ was also used to ensure literature could be retrieved that may not have been previously identified based on the keywords chosen – this expander was chosen to ensure the search was as exhaustive as possible. It was decided the search would not be focused solely on research published in the UK, as when this limiter was applied, only two papers were returned for review. Based on the current scope of research in the

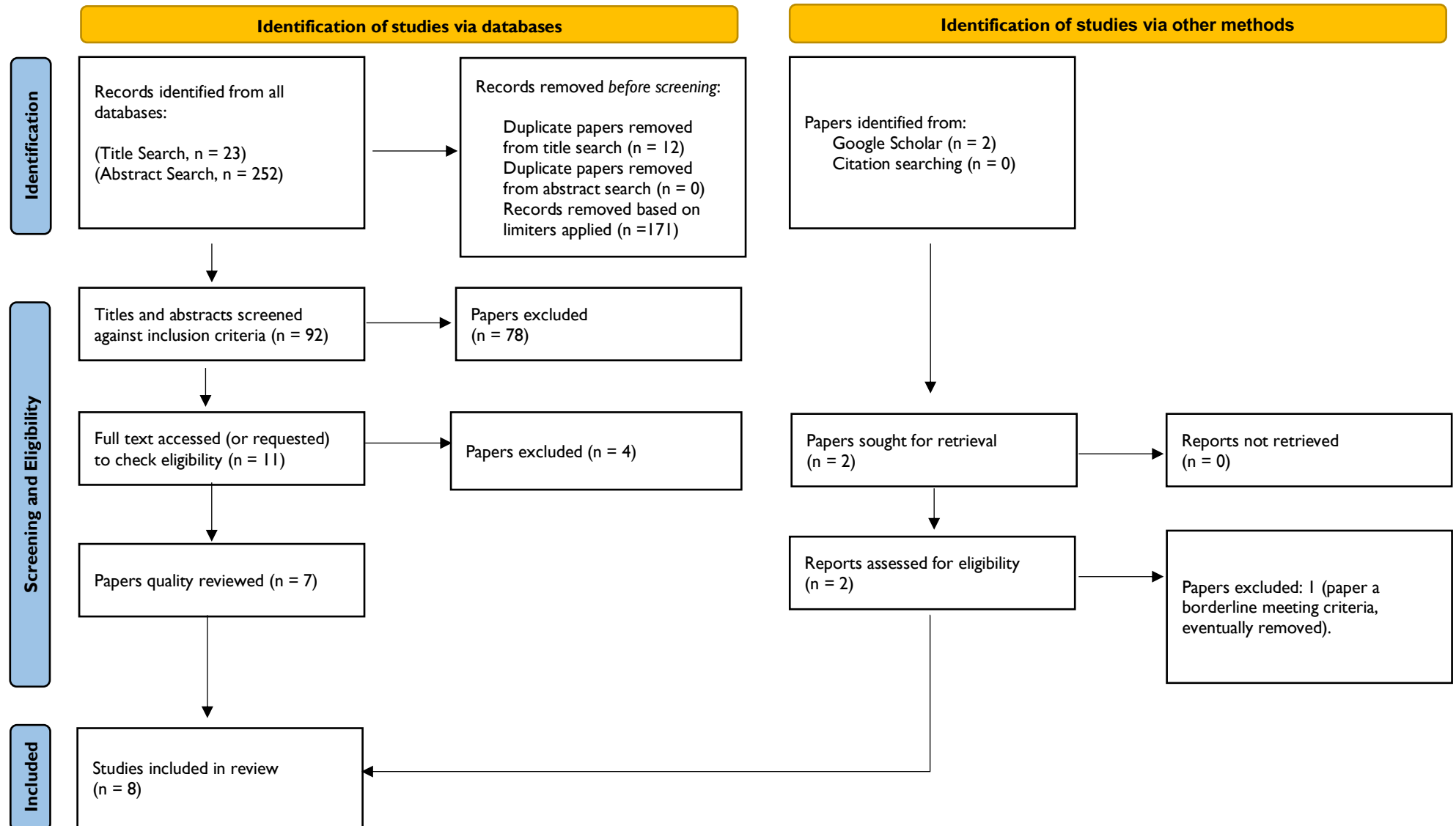
United Kingdom, there was not enough research as yet to limit the search by location.

3.3.4. Selection Process

The study selection process for the systematically informed literature review followed the methodology outlined by Cherry et al. (2023), as depicted in the PRISMA flowchart (Figure 2).

Following the use of search terms within the selected databases, the first step was the removal of duplicate papers (Cherry et al., 2023). All papers were then screened against the inclusion and exclusion criteria, with those clearly not meeting the criteria for inclusion, being removed at this stage. This included research from Gangi et al. (2021) and Greenslade et al. (2019) whose research looked at social communication needs in school-age children with autistic siblings, but did not look at school experiences or outcomes. The rationale for all papers excluded at this stage can be seen in Appendix B.

The next step was to obtain all papers passing this initial screening (Cherry et al., 2023). These papers were then read in depth, with more papers being excluded here based on not meeting the inclusion criteria. At this point, access was requested for 3 papers via the Tavistock and Portman NHS Trust library. One paper was obtained (Mates, 1990), and another two were not. From the two that could not be obtained, one was grey literature in the form of a thesis, and the published journal article version was included in this review (Mates, 1990). This left only one paper which could not be included within this review (Matthews, 2014). At this point screening, a further paper was removed as it was a thesis version of a later publish research paper (Gregory et al., 2020) – the decision was made to appraise the published article.

Figure 2*PRISMA Flowchart*

Additional papers were then located via 'handsearching' within Google Scholar using the same literature review question as used in the database search. The titles and abstracts of papers were then screened against inclusion criteria, and if further exploration was needed, the paper was obtained for detailed appraisal against the criteria. This stage yielded two additional papers for inclusion within the review. The method of 'citation chaining – backwards searching' was also used here to ensure a comprehensive search (Cherry et al., 2023) – this search within the references and bibliography sections of relevant research resulted in two additional papers for review.

There were several borderline papers which appeared to meet criteria and have relevance to the review question, but for whom a school-based focus was not the main premise. Careful consideration was given to these papers and the decision to include the papers or not is acknowledged as a highly subjective task in this case. Papers were read and re-read, and the inclusion criteria were consistently applied. This resulted in the exclusion of research from Nowell et al. (2014) and Stampoltzis et al. (2014) – where the focus of the papers remained on general NTS experiences, with a brief acknowledgement of school experiences and peer relationships. In both cases the information around school experiences was deemed too brief to include fully in a literature review. A third borderline paper from Ben-Yizhak et al. (2011) was included in the review. Although this paper does not focus solely on the school experiences of NTS, there is an examination of academic attainment. It was deemed inclusion of this paper would add to the understanding of academic attainment of NTS and so this paper was included for review. Appendix B can be viewed for a table with individual rationale for borderline papers.

3.3.5. Approach to Review

In order to organise the literature review, a data extraction document was created to explore the eight papers that met the inclusion criteria, in more depth (Appendix C). The focus for extraction was on gathering information around; aims, location and population, school type, methods of data collection and analysis, findings, and lastly the strengths and limitations of each paper. When reading each paper for data extraction, critical appraisal using quality assessment tools was taking place simultaneously. The tools used and the approach to critical appraisal is outlined in more detail within the next section of this chapter.

3.3.6. *Quality Appraisal*

Engaging with critical analysis allows a researcher to become familiar with the context of the field in greater depth and allows the noticing of meaningful connections across papers already published in the field (Cherry et al., 2023). In addition, critical appraisal allows insights into the strengths and limitations of research in the area, as well as an appreciation of the relevance and quality of research available. The hope is that with not only a comprehensive understanding of the literature, but an awareness of its quality, the current research is more able to provide a meaningful contribution to the knowledge base. It is recommended (Cherry et al., 2023) that specific quality appraisal tools are used to review the literature, based on the methodological approaches taken by individual researchers. Therefore, for this literature review, the following different appraisal tools were used:

- The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Critical Appraisal Skills Programme, 2018).
- The Mixed Methods Appraisal Tool (MMAT) Version 2018 (Hong et al., 2018).

- The Holland and Rees Tool – Quantitative Research Appraisal Tool (Holland & Rees, 2010)

Additionally, grey literature in the form of a thesis was also included for appraisal and review. The abstract, methodology, results and discussions sections were read and were then appraised using a tool generated independently for the purpose of appraising a thesis. As this thesis was a mixed methods exploration, the tool was created using prompts from the MMAT, but questions were adjusted to reflect the unique nature of a thesis. All appraisal tools can be seen in Appendix D.

3.4. Critical Appraisal of the Literature

This section sets out a comprehensive, critical appraisal of the literature. It does so by reviewing the aims and methodology of papers included, the participants and sampling, the data collection and analysis, and finally, an appraisal of researcher reflexivity.

3.4.1. *Aims and Methodology of Reviewed Literature*

The literature in this review explored various concepts under the umbrella of school experiences. Four quantitative papers examined school achievement and academic outcomes of CYP with autistic siblings (Ben-Yizhak et al., 2011; Chien et al., 2017; Mates, 1990), as well as their sense of school belonging and academic self-concept (Gregory et al., 2020). The impact of having an autistic sibling was also considered in relation to the behaviour of NTS in school (Barak-Levy et al., 2010; Chien et al., 2017; Mates, 1990), often framed as ‘psychological adjustment’ (Gregory et al., 2020). In contrast, three papers explored more general school experiences by considering how home life with an autistic sibling influenced school life (Cridland et al., 2016; Herman, 2013; Pavlopoulou et al., 2022). Cridland et al.

(2016) and Pavlopoulou et al. (2022) used qualitative approaches, while Herman (2013) employed mixed methods. These studies aimed to highlight broader experiences, unlike the more targeted focus of the quantitative studies. Two papers examined specific sub-groups: Mates (1990) considered the impact of gender and family size, while Cridland et al. (2016) focused on neurotypical girls with autistic younger brothers. Of the eight papers, four used quantitative methods, two qualitative, and two mixed methods. While all methodologies were appropriate for their aims, Herman's (2013) mixed methods paper may have been stronger as a purely quantitative study, given its focus on grades and extracurriculars. Similarly, Barak-Levy et al. (2010) intended to add qualitative depth but did not clearly articulate the rationale for doing so.

3.4.3. Participants, School Context and Sampling

Of the eight papers included in the review, six explored the school experiences of NTS through triangulation of perspectives, including parent views (Barak-Levy et al., 2010; Ben-Yizhak et al., 2011; Chien et al., 2017; Cridland et al., 2016; Gregory et al., 2020; Mates, 1990), with two also incorporating teacher perspectives (Gregory et al., 2020; Mates, 1990). While triangulation allowed for a breadth of perspectives, it often limited in-depth exploration of NTS voices. Only two papers focused solely on child views - one qualitatively (Pavlopoulou et al., 2022) and one using mixed methods (Herman, 2013). The inclusion of multiple perspectives is not a limitation per se, but rather the reduced opportunity for deep, nuanced exploration of neurotypical siblings' experiences within studies that incorporate multiple viewpoints.

Regarding the types of educational settings attended by NTS and their autistic siblings, papers varied around if this was addressed or not. NTS attending mainstream secondary schools were the target population of participants in Herman

(2013), and Cridland et al. (2016)'s research. However, while Gregory et al. (2020) and Pavlopoulou et al. (2022) outlined that participants were attending schools in the UK, there were no explicit statements around if these were mainstream settings or otherwise. Research from Ben-Yizhak et al, (2011), Mates, (1990) and Chien et al. (2017) did not acknowledge the type of school NTS were attending at all. This lack of information affects the quality of comparisons that can be drawn across the research. Of the eight papers included in the review, only one (Barak-Levy et al., 2010) commented on the schools attended by the autistic siblings (specialist settings). Additionally, regarding the context of the research, two of the eight papers shared information around if the siblings had experienced an overlap in their school time with their autistic sibling (Herman, 2013; Pavlopoulou et al., 2022). Research from Gregory et al. (2020) highlighted that this information was not gathered, but for the other five papers this remains unclear.

The gender split of NTS within the research base was generally even, with seven papers exploring the perspectives of both male and females, and one paper exploring the specific perspectives of females (Cridland et al., 2016). Regarding age, quantitative and mixed methods studies looked at NTS aged between 8-19 years old and did so with large number of participants (between 33-66) (Barak-Levy et al., 2010; Ben-Yizhak et al., 2011; Chien et al., 2017; Gregory et al., 2020; Herman, 2013; Mates, 1990). All of these papers used control groups to draw comparisons around the specific experience of NTS with an autistic brother or sister.

In the qualitative papers (Cridland et al., 2016; Pavlopoulou et al., 2022), NTS participants ranged from 6–17 years old, but with most in Pavlopoulou et al. (2022) being of primary school age (6–11). Both studies used purposive sampling and snowballing, which are appropriate for exploring specific phenomena. Generally,

across the literature however, the steps taken for participant recruitment are unclear. For example, Ben-Yizhak et al. (2011) mentions selecting participants from a research consortium but do not explain how or why it was chosen. Similarly, recruitment via schools lacks detail - it is unclear whether schools were targeted based on known NTS or if recruitment was open regionally. In contrast, Herman (2013) outlines clear recruitment steps and provides materials for appraisal.

Lastly, in relation to the participant pool, although there is some variation by nature of the location in which the research took place (America: Mates (1990), and Herman (2013); Israel: Barak-Levy et al. (2010); and Ben-Yizhak et al. (2011); Taiwan: Chien et al. (2017), The UK: Gregory (2020) and Pavlopoulou et al. 2022; and Australia: Cridland et al. (2016)), the majority of participants were White British. Where there are participants of different ethnic groups (Mates, 1990), very little detail is given beyond stating they are 'non-white'. There are also no reflections within any of the research around how different cultural backgrounds may influence sibling experiences. Similarly, when research outlined the socio-economic status of different participants (Barak-Levy et al., 2010; Gregory et al., 2020; Pavlopoulou et al., 2022), there were no comments in the papers around the impact this may have on NTSs, their family dynamics, and school experiences.

3.4.4. *Methods of Data Collection and Analysis*

3.4.3.1. Data Collection. Both the quality and methods of data collection varied across the papers included in this review. Quantitative studies used a range of self-report questionnaires and tests of school achievement, including the Strengths and Difficulties Questionnaire (Gregory et al., 2020), Motivation and Engagement Scale (Herman, 2013), Weschler Intelligence Scale for Children (WISC) (Ben-Yizhak et al., 2011), and Social Adjustment Inventory for Children and Adolescents (Chien et al.,

2017). A common limitation was the lack of detail around test administration—none of the four papers described the training of the administrators or the testing context. This lack of transparency makes it difficult to evaluate confounding variables. Regarding the various measures used, there is little to no acknowledgment of reliability and validity (Ben-Yizhak et al., 2011; Gregory et al., 2020; Mates, 1990), and from Ben-Yizhak et al. (2011), no reporting of issues around translation of the Social Communication Questionnaire, WISC, WRAT-III Test of School Achievement the Diagnostic Battery of Reading Processes into Hebrew. In contrast, research from Chien et al. (2017) clearly outlines the reliability and validity of the tools used, as well as outlining the process of translating all measures into Chinese. Further critique around the tools used and the reporting of data collection lies in the area of cultural responsiveness. None of these four quantitative papers outline the challenges of using standardised assessments across cultures and languages or acknowledge if and how the assessments were adjusted to consider the bias present when comparing children's results to the normative samples. Three of these papers used control groups from the local area which may have counteracted this bias, however this is not explicitly explored.

Qualitative data collection centred on semi-structured interviews to explore the views of CYP with autistic siblings; Cridland et al. (2016) also interviewed parents. Pavlopoulou et al. (2022) employed participatory methods, including a sibling advisory group and photo elicitation, using child-centred approaches. These papers clearly outlined interview questions, with Cridland et al. (2016) noting adjustments made after piloting.

Across papers, some qualitative data were lost, particularly in mixed methods research. For example, Barak-Levy et al. (2010) converted quotes into themes and used descriptive statistics for group comparisons. This data was also shaped by

potentially leading parent questions (e.g., what troubles you most about your child?). Similarly, although Chien et al. (2017) state a semi-structured tool was used, this is not reported, and the paper focuses solely on quantitative findings.

3.4.3.2. Data Analysis. A range of different methods for data analysis were used across the eight papers, all of which were described in varying depths. For qualitative analysis, Pavlopoulou et al. (2022) utilised Reflexive Thematic Analysis (RTA), and although the individual steps were not outlined, the study demonstrates a strength in providing the themes and subthemes, each illustrated with quotes from individual interviews. The opposite pattern can be seen in the qualitative research from Cridland et al. (2016), whereby although authors outlined the software used for analysis (NVivo), and the steps of Inductive Coding (Braun & Clarke, 2017), thematic analysis is not named as the official form of analysis. Regarding the analysis of the qualitative data from mixed methods papers (Barak-Levy et al., 2010; Herman, 2013), this was a weakness of the research. Information from open ended survey questions (Barak-Levy et al., 2010) were themed and then statistical analyses were used to compare theme occurrence descriptively, rather than leaning into the qualitative nature of the data. Additionally, no information was provided around how themes were derived, although some quotes from parents were provided. Mixed methods data from Herman (2013) displays a similar picture whereby qualitative information was not analysed using a formal method but quotes were provided from CYP.

Across the quantitative data, various statistical tests were used, though only one paper (Chien et al., 2017) specified the software employed. Most studies compared results across different groups (e.g., control vs. experimental, or normative samples), using tests such as ANOVAs (Mates, 1990), t-tests (Gregory et al., 2020), PROC

mixed models of variance (Chien et al., 2017), Mann-Whitney U tests (Barak-Levy et al., 2010), and MANCOVA/ANCOVAs (Herman, 2013). Ben-Yizhak et al. (2011) mentioned variance analyses but did not specify the type. Correlational analyses were run by Ben-Yizhak et al. (2011) and Gregory et al. (2020), while Barak-Levy et al. (2010) presented descriptive statistics. Gregory et al. (2020) also used Chi-squared tests and regressions. Five of the six studies using statistical analysis employed both control and experimental groups, with the remaining study comparing to a normative test sample. Effect sizes were reported in three papers (Chien et al., 2017; Gregory et al., 2020; Herman, 2013). Only two studies (Gregory et al., 2020; Mates, 1990) outline issues around non-response bias and reference 'cleaning up the data'.

3.4.5. Reflexivity and Ethics

Ethical considerations and researcher reflexivity are considered to varying degrees within the literature but are considered a general weakness of the literature.

Firstly, there are no considerations given within the literature to the impact on the children involved in the research, or how this was mitigated. For example, there is no acknowledgment of the fatigue likely to be experienced when completing multiple standardised assessments, or the potential emotional impact of sharing difficult experiences via semi-structured interview. Furthermore, none of the research included in this review outlined the ethical considerations needed specifically for researching with children, and no authors outlined procedures for gathering assent from CYP included in their research.

Regarding researcher reflexivity, none of the papers mention relationships or power dynamics between researchers and participants. For example, in studies recruiting via existing organisations (Ben-Yizhak et al., 2011; Mates, 1990), no

details are given about researcher affiliations with the groups or consortiums. Similarly, in school-based recruitment (Barak-Levy et al., 2010; Cridland et al., 2016; Gregory et al., 2020; Pavlopoulou et al., 2022), there is no information on prior relationships with schools, limiting the ability to assess potential bias or influence. While Gregory et al. (2020) disclose offering a £5 voucher, its impact on findings is not considered. None of the literature discusses personal researcher experiences and motivations for exploring the within this field – these limits the transparency and trustworthiness of papers presented.

Regarding the value provided by the papers included in the review, all research appraised adds new information into the field and supports a further understanding of the experiences of CYP with autistic siblings. Authors clearly state how their research links to practice for teachers and EPs (Chien et al., 2017; Cridland et al., 2016; Gregory et al., 2020; Herman, 2013; Pavlopoulou et al., 2022), and highlight areas of future research, namely exploring CYP views in more depth (Barak-Levy et al., 2010).

The majority of papers state that the research received formal ethical approval from a research board (Chien et al., 2017; Cridland et al., 2016; Gregory et al., 2020; Herman, 2013; Pavlopoulou et al., 2022), but research from Mates (1990), Ben-Yizhak et al. (2011) and Barak-Levy et al. (2010) did not share the same information. Regarding steps taken to protect the wellbeing and anonymity of participants, Pavlopoulou et al. (2022) shared pseudonyms used and Cridland et al. (2016) stated all participant names were removed from the paper, something also outlined by Herman (2013). The majority of research, however, did not outline the steps taken to protect participant identity (Barak-Levy et al., 2010; Ben-Yizhak et al., 2011; Chien et

al., 2017; Gregory et al., 2020; Mates, 1990), and only one paper mentioned a debriefing procedure for participants (Gregory et al., 2020).

3.4.6. *Quality Appraisal Summary*

Overall, the quality of the literature included within this review is variable and some general overall strengths and limitations must be recognised. By way of strength, the literature generally triangulates the views of multiple individuals within the young people's lives, providing a breadth of understanding. Authors also generally acknowledge the strengths and limitations of their own research and make strong statements around avenues for further research. Implications for teachers and those supporting siblings professionally were also often made throughout the literature. However, across the literature there is a recurring issue around missing information – for example, schools attended, or time spent at the same school as their sibling. Where information is collected (gender, age gap, race and ethnicity), the information is largely not included within the analysis. The literature also generally lacks evidence of researcher reflexivity and any potential biases in data collection are not transparently explored. These methodological constraints are considered when interpreting the findings as they may influence the strength of conclusions drawn from the literature.

3.5. Literature Review Themes

Following a critical appraisal of the eight papers included in the literature review, a thematic approach was used to identify and organise the key ideas reported across the studies. Informed by Thomas and Harden (2008)'s approach to thematic synthesis of qualitative research, the findings and discussions of each paper were read again, and the key themes were extracted. Themes were identified by reading

each paper in detail and highlighting recurring ideas, concepts and findings relevant to the research question. This process drew on both the data reported in the findings sections (such as participant quotes) and the authors' discussions and interpretations. A mind map was then created to organise and group these ideas, drawing on the data extraction document developed earlier in the review process. The themes were then refined and discussed in supervision to check they captured the main points across the papers and provided a clear and balanced synthesis of the literature.

The themes were then grouped across papers in order to present a cohesive synthesis of the literature in the area (Figure 3). Due to the small number of papers included in the review, themes were included if they were present across at least two papers (20% of the review). However, in a small number of cases, themes are presented if they occur in only one paper. The decision to include a theme present in one paper was based on the weight given to the theme within the original paper. If the theme was discussed as a key finding in the original paper, it is included within this review. As previously discussed, although the focus of the review is around the school experiences of NTS, many of the papers included also share home-based experiences of the children. These themes are included below so as to reflect the overlapping nature of the lived experiences of NTS. The themes to be illustrated within this section are relationships, classroom experiences, experiences beyond the classroom (sleep and extracurriculars, for example), stigma, emotional responses, and an exploration of role (see Figure 3).

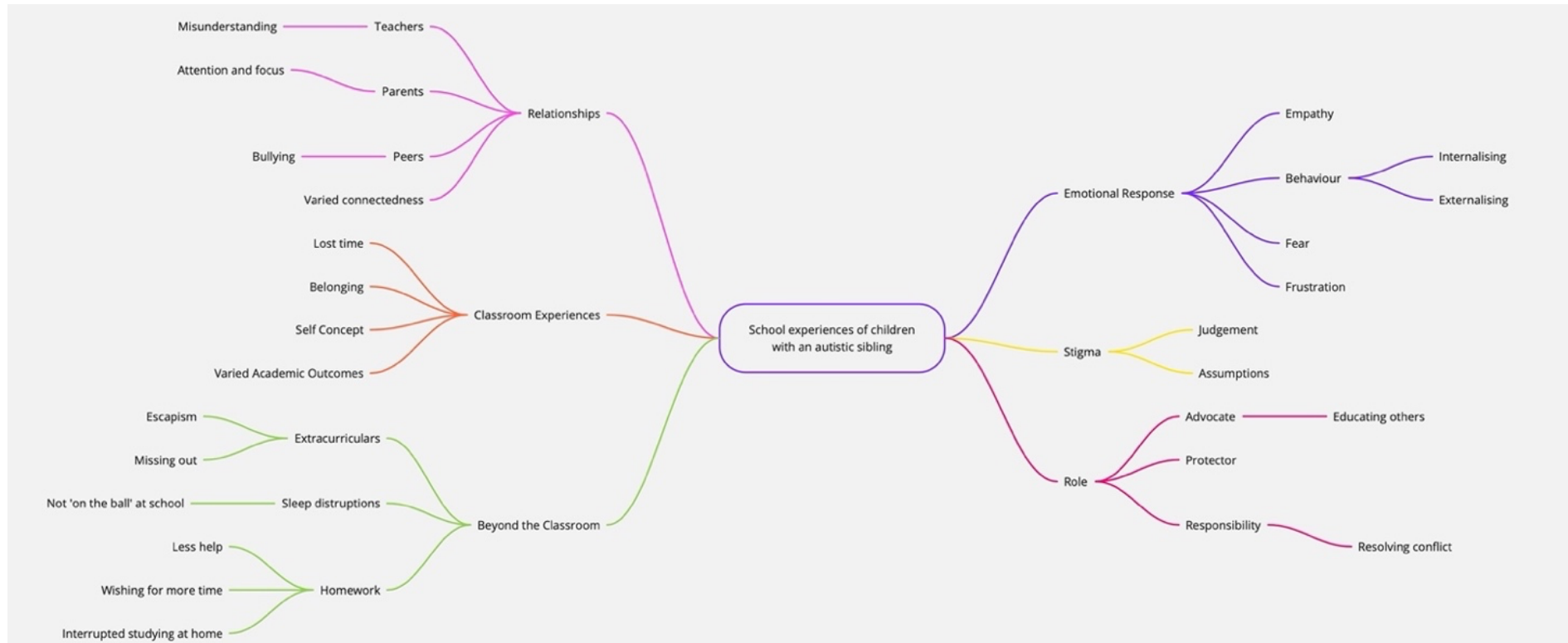
3.5.1. Relationships

3.5.1.1. Parents. Three of the papers included in the review identified findings around the relationships between NTS siblings and others, with Cridland et al.

(2016), focusing specifically on the parent relationship. All of the NT sisters included within this research described a feeling of 'cherishing' family time but feeling this time could be quickly impacted by their autistic sibling. It must be noted however, an explanation of what the 'impact' would look like, was not stated. The sisters in this study did, however, share the importance of quality 1:1 time with their parents, especially the wish to 'just talk and talk – just me and her [mum]' (Cridland et al., 2016, p.201). A reduction in parental attention was also shared by these sisters, along with feelings that their autistic sibling received more attention from their parents than they did. The sisters within this research shared they wished they could speak to someone outside of their family about the challenges of having an autistic sibling.

Figure 3

A Visual Summary of the Literature Review Themes



Note. This visual presents the themes from the literature review. These themes are split into 6 main groups: emotional responses, stigma, role, beyond the classroom, classroom experiences and relationships. The visual also displays the subthemes present within these overarching groups.

3.5.1.2. Peers and Teachers. Research also explored the peer and teacher relationships of NTS. Pavlopoulou et al. (2022) found siblings had mixed experiences with peers. Many reported that having an autistic sibling did not affect their willingness to invite friends' home, while others described a "phobia in bringing friends over" (Pavlopoulou et al., 2022, p.6) due to previous sibling behaviour. Some participants described bullying at school linked to peers' limited understanding of Autism. As a result, some children felt they could form better friendships after school transitions - either their own or their sibling's. Chien et al. (2017) also found social challenges may relate to lower school social interaction scores in unaffected siblings, potentially due to lower social communication abilities in their autistic sibling. Teacher relationships were also complex (Pavlopoulou et al., 2022) where some NTS did not feel comfortable sharing home difficulties due to concerns about teacher misconceptions or observed inflexible responses to autistic peers. Many wished teachers better understood their sibling's needs, so they themselves could be supported. However, both peer and teacher relationships could also offer "powerful school support." Children who connected with autistic peers, or with those linked to Autism, felt more understood, reassured, and heard

3.5.2. Sibling Role

3.5.2.1. Advocacy and Protection. The roles siblings of autistic children take up at school was also highlighted across four of the papers included in the review. Of particular note was the role NTS would take in advocating for their autistic sibling with their teachers and peers. When family members were asked how they would conceptualise the roles taken by the NTS, labels such as 'mother hen', 'protector' and 'bodyguard' were used (Cridland et al., 2016). It was also noted these roles were not perceived as extending to the home environment where one mother

hypothesised that her NT child felt her autistic brother was safer and well cared for at home. Although the NTS themselves did not use these terms to describe their roles, they discussed the need to protect their sibling from bullies in school and highlighted their role in educating their sibling about how to manage experiences of bullying (Cridland et al., 2016). NTS were often positioned in the role of educating not only their sibling on how to navigate social relationships but educating their peers about Autism and advocating for their siblings' needs with peers (Cridland et al., 2016; Pavlopoulou et al., 2022). Educating others also extended to educating their teachers about Autism (Cridland et al., 2016). The emotional response attached to this role varied across CYP, with some feeling this role made school difficult for them, while others shared educating others helped them to 'feel good'. The role of educator often took the form of conflict resolution between peers and their autistic sibling during the school day. NTS shared the importance of them being at the same school as their sibling in order to 'make sure things were okay' (Pavlopoulou et al., 2022). The emotional response and interpretation of these labels, however, is not explored within this research.

3.5.2.2. Responsibility. In addition to taking on roles of advocacy and protection, the research also highlights the additional responsibilities taken by NTS in supporting their autistic siblings in school – a role with mixed reactions and experiences from individual siblings. NTS reported recognising that their autistic siblings had less opportunities for socialising with others and so invited them to social scenarios with their own friends (Pavlopoulou et al., 2022). Some of the children shared feelings of pride and enjoyment in relation to this experienced responsibility, while others shared the difficulties associated with attending social situations themselves (Pavlopoulou et al., 2022).

NTS also shared feeling that they needed to check on their autistic sibling throughout the school day to ensure they were 'comfortable and happy' and explained that being responsible or 'in charge' of their sibling meant that they missed out on opportunities in school, such as extracurricular activities (Pavlopoulou et al., 2022). Being responsible also looked like liaising between teachers and their parents on behalf of their sibling (Cridland et al., 2016). When exploring what attending time at the same school as their sibling was like, it was highlighted by one participant that they (as NTS) would often be informed about their sibling's behaviour 'as if they had control over it.' (Herman, 2013).

The role of responsibility for NTS was also highlighted by parents (Barak-Levy et al., 2010), where 60% of them reported that the most positive attributes of their NT child was that they were helpful and responsible for their autistic sibling. These same parents also highlighted their worries around what their NT child would do if their autistic sibling needed help when they were no longer around as parents in the future. This highlights a parental hope for ongoing responsibility throughout the NT child's life (Barak-Levy et al., 2010).

Regarding supporting their autistic sibling with school related work at home, NTS were reported to be no more likely to help their sibling with their homework, compared to a control group (Herman, 2013). Researchers highlighted that parents took on the additional responsibility themselves and so appeared to protect the NTS from this additional role.

3.5.3. Emotional Response and Behaviour

3.5.3.1. Emotional Reaction. The emotional responses from NTS in relation to seeing their autistic sibling at school were reported to be varied, and complex.

Feelings of frustration were experienced by NTS in relation to repeatedly intervening

in conflict throughout the school week (Pavlopoulou et al., 2022), and in relation to their autistic siblings seemingly not taking their advice in navigating peer relationships (Cridland et al., 2016). The latter research shared NTS frustration not only to their sibling but to their peers too. NTS shared feelings of annoyance that others would continue to take advantage of an autistic sibling. Others reported emotional responses were those of embarrassment at seeing their brother in school, preoccupation with worry during the day, and the fear associated with unpredictable school based 'meltdowns' (Pavlopoulou et al., 2022). NTS also shared the 'emotional pain' related to seeing aggressive behaviours from their autistic sibling to others in school (Pavlopoulou et al., 2022). Children also shared feeling less rested after a school holiday where they felt 'drained' from more time with their autistic sibling (Pavlopoulou et al., 2022).

In contrast, mothers reported feelings of pride when thinking of their NTS (Cridland et al., 2016), and authors suggested an increased resilience in the children involved in their research, and a greater perspective on life. Furthermore, although the results were not statistically significant, NTS displayed higher scores on measures of self-concept, interpersonal and caretaking skills (Mates, 1990). NTS also reflected positively on the transition to different schools, explaining that they gained independence and that both themselves, and their autistic sibling were able to make their own friends when apart (Pavlopoulou et al., 2022).

3.5.3.2. Behaviour. The impact on sibling behaviour was also highlighted across five of the papers included in the review. Both parents and NT children reported higher levels of externalising behaviours in school, with parents also reporting higher NTS internalising behaviours. Parental reports around 'bad behaviour' (Barak-Levy et al., 2010) and 'severe school behavioural problems' (Chien et al., 2017) were also

reported within the literature. Behavioural difficulties were reportedly related to ADHD-like symptoms within the NTS, and social difficulties that overlapped with features of Autism.

Aside from behavioural challenges, the literature also reports increased self-reliance, autonomy and independence - particularly in relation to NTS studying habits (Herman, 2013). Authors hypothesised this may be due to the increased sense of responsibility as highlighted earlier in this review. In addition, research illustrates reduced levels of judgement towards others in school, and an increased sense of understanding of others' needs (Cridland et al., 2016; Herman, 2013).

3.5.4. School Academics and Belonging

3.5.4.1. Academic Experiences. Regarding academic attainment, there is a mixed picture across the research included within this review. It has been reported that NTS of autistic children, experience higher academic difficulties than siblings within a control group (Barak-Levy et al., 2010; Herman, 2013). However, these academic difficulties have not yet been reported to affect school performance across general abilities (Chien et al, 2017; Herman, 2013), including reading, spelling, mathematics, school adjustment, and language skills (Ben-Yizhak et al., 2011; Mates, 1990). Academic underachievement appeared more related to NTS own needs, for example those who displayed symptoms of inattention performed more poorly across measures of academic underachievement (Chien et al., 2017), as did NTS who presented with 'Broad Autism Phenotype (BAP)' – sub-clinical Autism. (Ben-Yizhak et al., 2011). BAP was also related to higher overall IQ scores in children with autistic siblings.

Aside from the attainment-based impact for NTS, their emotional experience in school was also explored within the literature. NTS cited that their day at school is

fully dependent on their sibling's day at school, and that disruptions were generally related to being asked by teachers to support their autistic sibling (Herman, 2013; Pavlopoulou et al., 2022). Across the literature, NTS attitudes to school were also explored. NTS displayed lower academic self-concept (Gregory et al., 2020), feel that school is less important (Herman, 2013), and report 'more negative' attitudes towards their schoolwork (Chien et al., 2017), compared to peers with NT siblings. NTS also shared that while they felt able to approach their teachers for support with their academic work, they were unsure about the support available to them in relation to the emotional experience of having an autistic sibling (Pavlopoulou et al., 2022).

However, when comparing children with TD siblings with those with autistic siblings, there was no significant difference reported regarding wanting their grades to be higher, feeling like they need to perform better than their sibling in school, or their grade related satisfaction (Herman, 2013). Furthermore, when CYP were asked how their autistic sibling positively influenced their school experience, NTS shared a motivation to work hard, and having inspirations for their artistic and essay-based assignments (Herman, 2013).

3.5.4.2. Belonging. Two papers included in the review also explored a sense of school belonging in NTS. A sense of school belonging was reported to be significantly lower in children with autistic siblings (Gregory et al., 2020) and this was hypothesised as related to increased levels of stigma and bullying experienced by peers in school, or an overall sense of feeling 'different' from peers. Although belonging was not explicitly measured in research from Herman (2013), researchers hypothesised that school belonging is likely impacted by less participation in extracurricular activities and less investment in a school-based social life. However,

some children shared being with their autistic sibling in school allowed for shared friendships, and experiences (Herman, 2013).

3.5.5. *Beyond the Classroom*

3.5.5.1. Homework. Within the literature, NTS also shared their experiences of completing homework and how this may or may not be impacted by living with their autistic sibling. NTS were reported to experience less parental support in completing their homework (Herman, 2013; Pavlopoulou et al., 2022), and this was related to the parent's time taken up by supporting their autistic sibling at home. NTS shared feeling that if their parents helped with homework, they would experience higher attainment in school (Herman, 2013). Additionally, although there was no statistically significant difference in the number of hours spent on homework across siblings of unaffected siblings, compared to CYP with autistic siblings, the latter were more likely to complete their homework (Herman, 2013). Herman (2013) also reported no significant difference between siblings of autistic children compared to a control group, regarding the amount of time they spent helping their sibling with school related work at home. However, they found the more time spent doing so, was positively correlated to the extent to which siblings wished they had more time to complete their own school-work and home-based studying. NTS in this research also highlighted their autistic sibling interrupting their studying at home (Herman, 2013).

3.5.5.2. Extracurricular Activities. The research highlights the mixed experiences around participation in extracurricular activities for NTS. For some children, participation in groups and clubs felt like an escape and was described as a key part of socialising outside the classroom (Pavlopoulou et al., 2022). Many of the participants involved in research from Pavlopoulou et al. (2022) felt that access to

extracurriculars was not impacted by their sibling's needs, however one young person shared that her autistic sister affected her attendance at clubs. This picture was shared across many other NTS, as reported by both themselves and their parents (Barak-Levy et al., 2010; Herman, 2013).

3.5.5.3. Sleep. One paper also highlighted difficulties with sleep in NTS (Pavlopoulou et al., 2022). The participants shared issues with the quality of their sleep and shared that even if they have a separate room from their autistic sibling, their sibling's reluctance to go to sleep, restlessness, or sleepwalking, left them either wary of sleeping away with their backs to the door, or experiencing interrupted sleep. When discussing the impact of this on their school life, NTS expressed the impact of tiredness as it related to 'not feeling on the ball' for learning.

3.5.6. Stigma

Another theme from the qualitative side of the research was around the fear of stigma from peers and teachers in school. Siblings shared a fear of being stigmatised themselves when sharing about their sibling and cited limited understanding about their siblings' special interests and behavioural patterns as the potential reason for any negative reactions. NTS also shared experiences of assumptions made from teachers and peers, about their own behaviour. Children explained that peers and staff 'assume I have ASD and treat me like I do', they explained experiences of being treated like a 'lower class student' (Herman, 2013, p.35). This experience of misunderstanding and judgement was also shared by children who explained that staff would 'try and get me excluded as well' (Pavlopoulou et al., 2022, p.7).

3.6. Emerging Patterns and Insights

By drawing these papers together, this review offers new understanding in several important ways. First, it highlights how challenging it is to separate home and school life for non-autistic siblings (NTS); their family roles, emotional experiences, and sense of responsibility often spill into and shape their school worlds. Secondly, it reveals a recurring tendency in existing research to explore sibling experiences indirectly through the perspectives of parents, teachers, or professionals - rather than privileging the voices of siblings themselves. Importantly, the synthesis also illuminates patterns that may be less visible when studies are viewed in isolation: for instance, the recurring role of NTS as protectors and educators emerges across different contexts and methods, suggesting this is not an isolated finding but a common thread shaping school experiences.

Bringing together findings from qualitative and quantitative research further demonstrates that NTS school experiences are deeply varied, complex and personal, influenced by individual meaning-making alongside broader systemic and relational factors. There also appears to be a recent, but still limited, shift towards qualitative exploration, reflecting a growing recognition of the importance of understanding these lived experiences in greater depth. This review, therefore, not only maps what is currently known but clarifies why an idiographic, qualitative exploration of older adolescents' school experiences - centred on their own voices - is needed. It shows the value of moving beyond broad comparisons to explore how these young people themselves make sense of their everyday school lives within the specific social, cultural and educational context of the UK.

3.7. Literature Review Summary

This literature review aimed to answer the question – ‘What does the literature tell us about the school experiences of CYP with an autistic sibling?’. By exploring this question using the systematic approach detailed within this chapter, the following themes were identified in relation to NTS experiences: the impact on relationships (teachers, parents and peers), classroom experiences (belonging and academic abilities), an impact beyond the classroom (extracurricular activities, sleep disruptions and homework), emotional responses (including behaviour), stigma and the role taken by NTS (protector, advocate, responsibility). The review and the exploration of these themes has provided a deeper, contextualised understanding of the current knowledge in the area. This exploration has allowed for the identification of clear gaps in the knowledge base and therefore has helped to highlight a clear rationale for the current research.

The current literature review highlights a dearth of research into the school experiences of CYP with autistic siblings in the UK. Of the studies located, only two explore the school-based experiences of NTS in the UK (Gregory et al., 2020; Pavlopoulou et al., 2022), and only the latter focuses solely on the voices of CYP. Although international research (from the USA, Australia, Taiwan, and Israel) illustrates both commonalities and differences, it becomes difficult to explore how CYP in the UK specifically make sense of their experiences within the UK school system. In view of the Social Relational Model of Disability and the Siblings Embedded Framework, UK-based research is needed to explore how ‘barriers to being/doing’ within the UK school context may influence the experiences of NTS. Where UK research exists (Gregory et al., 2020; Pavlopoulou et al., 2022), it includes CYP aged 6–15 (mean age around 12), suggesting opportunities to explore

experiences beyond this age range. In research involving young people over 15, school experiences tend to be only a subsection of broader studies (Cridland et al., 2016).

Much of the existing literature uses quantitative methodology. While this is valuable, the focus is often on comparing NTS of autistic children with those who have NT siblings, rather than exploring individual lived experiences. Where qualitative or mixed-methods research exists, the triangulation of views often reduces CYP perspectives to a small part of a wider sample

Finally, findings across the literature are often mixed and complex, with varied experiences and perspectives. This suggests that identifying overarching themes may not be the most suitable methodological approach. A more idiographic design, giving space and value to individual experiences, is currently missing from the literature.

While the studies reviewed provide a comprehensive outline of the current knowledge base in relation to siblings of autistic children, there is an emerging gap related to the qualitative school experiences of young people over the age of 14, within the UK. The current study will address these gaps in the literature by taking a qualitative approach to exploring the lived experiences of NTS between ages 14-18 years old. The age group has been highlighted by research as an important group for further exploration due to the unique educational pressures facing young people at this time point (GCSE's and A Levels) (Pavlopoulou et al., 2022). It is also an age where young people transition from childhood to adulthood, and an age whereby social connections become increasingly important (Dumontheil, 2016). The focus of this research will be on exploring the depth of individual lived experiences, delving into siblings meaning and sense making of their school lives so far. Beginning to

address this gap may provide a deeper insight into the lived experiences of a group of young people within a specific age range, and at a pivotal time in their adolescence and school lives.

4. Methodology

4.1. Chapter Overview

This chapter will provide an overview of the research methodology used, and the methods for data collection and analysis. In doing so, it will first outline the research aims and questions, the ontological and epistemological positions taken in order to answer the questions and will then explore the use of IPA methodology for data analysis. This chapter will conclude by sharing details of participant demographics, recruitment, research quality, and how ethical considerations were addressed.

4.2. Research Aims and Questions

The literature review highlighted a gap in understanding the school experiences of adolescent CYP with autistic siblings, therefore the research question is as follows:

What are the school experiences of CYP, aged 14-18, with an autistic sibling?

Due to the limited research in this area within the UK, this study will take a broad approach, focusing on building an understanding of the lived experiences of adolescents with an autistic sibling. It will explore how these experiences impact their social, emotional, and academic lives.

4.3. Research Orientation

In conducting research and choosing methodological approaches to explore the research questions, decisions are underpinned by researcher assumptions about the nature of reality and knowledge, and how it can come to be known (Guba & Lincoln, 1994). In doing so, the researcher must explore the ontological and epistemological positions taken with regards to the phenomenon being explored, and outline the stances adopted.

4.3.1. *Ontology*

As described by Crotty (1998), ontology is the study of being and is concerned with the form and nature of existence, along with what it is possible to know about it (Al-Saadi, 2014; Guba & Lincoln, 1994). A key ontological question is whether there is a social reality that exists independently of human interpretation (Al-Saadi, 2014). In taking a stance on the nature of knowledge and existence, different researchers embrace different realities (Creswell & Poth, 2016). The two ontological positions to be discussed here are realism and relativism – positions which can be considered as existing on opposite ends of a spectrum. In taking a realist position, there is an assumption that there is one true reality that can be discovered, and that there is a cause and effect relationship between the world and the objects within it (Moon & Blackman, 2014; Willig, 2013). This position is rejected within this research because there is not an assumption that there is one singular truth about the experiences of having an autistic sibling.

Instead, a relativist position is adopted within this research. This posits that reality is constructed through social meaning-making rather than existing externally and independently (McBeath & Bager-Charleson, 2020). This position values the diversity of interpretations individuals apply to their experiences' (Willig, 2013) and fits with the idiographic focus of the research (Grace & Priest, 2015). By taking this ontological position, the research holds that there are multiple realities (Mertens, 2010), and that the reality of having an autistic sibling will be interpreted by each individual. As a researcher, I will have access to individual perspectives, understanding individuals as they 'appear to me', rather than 'as they are' (Grace & Priest, 2015).

4.3.2. *Epistemology*

As discussed by Willig (2013) and Al-Saadi (2014), epistemology is concerned with the theory of knowledge and 'how' it is possible to find out about the world. It involves understanding how knowledge can be produced and acquired, and what the scope and legitimacy of the knowledge is. This research takes an interpretivist epistemological stance.

Interpretivism posits that all knowledge is grounded in individual lived experiences and emphasises the importance of a researcher understanding the meanings made by individual participants (Hiller, 2016). Particularly in line with the methodological approach of IPA, interpretivism highlights that there is a searching for subjective views which are co-created by both the researcher and the researched (Lincoln & Guba, 1985). This results in an 'interpretive explanation of the experience by both participant and researcher, informed by societal culture and is historically situated' (Bennett, 2023, p. 55). This highlights that experiences are not simply described, they are interpreted, the meaning ascribed is shaped by broader cultural norms, and that the interpretation has been shaped over time.

Alternative epistemological positions, positivism and critical realism are therefore rejected. A positivist epistemology assumes that an objective, knowable truth exists and can be uncovered through research, often using quantitative methods and statistical analysis (Al-Saadi, 2014; Guba & Lincoln, 1994; Madill et al., 2000). This research is not focused on uncovering a 'truth' and is instead focused on exploring interpretations of individual lived experiences. Critical realism was considered for this research but was ultimately dismissed. This position acknowledges that the real world exists but that there the processes by which we come to understand it (e.g., language and perception) that are subject to variation, rather than providing an objective mapping (Grace & Priest, 2015). This position was

considered due to a wish to acknowledge both the individual experiences and structures in place (for example the realities of the school system, and societal views on Autism). However, this position was dismissed as critical realism still maintains that there is an element of 'truth', even if it is said to be influenced by perspectives and social structures. While there may be truths around the structures in place, I believe that the way these are experienced will be individual, based on unique lived experiences and how individuals interpret this external world.

In summary, by adopting a relativist ontology and interpretivist epistemology, this research acknowledges the idiographic nature of the individual lived experiences of participants, while also taking the view that there is no 'one' reality and knowledge is not fixed. This focus is instead on the individual interpretations made within personal and social contexts.

4.4. Methodological Choices and Rationale

4.4.1. Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative research methodology that is invested in an examination of the sense that individuals make of a lived experience (Smith et al., 2022). The approach acknowledges that while experience is a complex concept, IPA researchers aim to explore what happens when an everyday experience in an individual's life, takes on an element of significance for them. The IPA researcher aims to understand what is happening for the participant, and as they do so, makes their own interpretations of the reflections shared by each participant.

The need for an interpretative and idiographic approach to exploring the individual experiences of CYP with autistic siblings, was central to the choice of using IPA as a methodological approach. Furthermore, this methodological approach aligns with the

way in which I am conceptualising knowledge and how it can come to be known. For example, IPA aligns with the relativist ontology taken as it recognises the varied and idiographic nature of existence, and the absence of 'one truth'. It also aligns with the interpretivist epistemological view that knowledge is grounded in individual lived experiences, with IPA being recognised as an inherently interpretative endeavour (Eatough & Smith, 2017)

4.4.2. Theoretical Underpinnings of IPA

Smith et al, (2022), describes IPA as an approach to qualitative, experiential, and psychological research which draws its key elements from three key areas of philosophy: phenomenology, hermeneutics and idiography. It is argued that by negating to engage with these underpinnings, IPA is not able to achieve the depth of analysis that is available, not being able to 'capture qualitative and experiential dimensions' while 'dialoguing with mainstream psychology' (Smith et al., 2022, p.17). This research will therefore outline the three key philosophical concepts involved with conducting IPA and will acknowledge how they remain consistent with the current study.

4.4.2.1. Phenomenology. Phenomenology, founded by Husserl, is the philosophical study of lived experience, focusing on how individuals perceive and reflect on their experiences (Smith et al., 2022). Husserl emphasised examining experiences in their own terms to uncover essential features, introducing the concept of 'bracketing' - setting aside preconceptions to attend to participants' perspectives through a series of 'reductions' (Husserl et al., 1964; Smith et al., 2022). Heidegger built on this, arguing that researchers are always situated in context and cannot fully detach from the world they are part of. He introduced the idea of intersubjectivity -

understanding experiences through relatedness to others - which informs IPA's hermeneutic approach (Smith et al., 2022).

IPA also draws on Merleau-Ponty, who highlighted the importance of embodiment and affect in how we make sense of the world (Merleau-Ponty & Bannan, 1956). Accordingly, IPA attends closely to emotional responses and language during analysis. Sartre's ideas further support IPA's attention to the relational nature of experience, shaped by the presence or absence of others (Smith et al., 2022).

The current research into the school experiences of CYP with an autistic sibling is consistent with this phenomenological approach. Not only is there an exploration of the CYP's lived experiences as they see them themselves, but there is an attention to embodied experiences, relational contexts, and what it means for the researcher to interpret the perspectives shared within this context.

4.4.2.2. Hermeneutics. The second theoretical concept underpinning IPA is hermeneutics – the theory of interpretation led by three main theorists: Schleiermacher, Heidegger and Gadamer. For Schleiermacher, interpretation involves both 'grammatical' and 'psychological' interpretation, where grammatical refers to consideration to the objective text or information shared about a lived experience, while psychological refers to the unique influence of the author (Palmer, 1969; Schleiermacher, 1998; Smith et al., 2022). For the IPA researcher, this involves acknowledging the objective information shared, and a detailed psychological interpretation that may 'offer a meaningful insight which exceeds explicit claims from our participants' (Smith et al., 2022, p.18). An IPA researcher may therefore offer a perspective to the text/information shared which is not offered by the participant, without claiming that our analyses are truer than the participants

themselves. In other words, the researcher attempts to make sense of the sense that participants are making of their own experiences (Hood, 2016).

IPA also draws on ideas from Heidegger, who viewed phenomenology as an interpretive activity whereby the lived experiences of an individual are understood through interpretation and where things that were previously unknown can come to light. These interpretations are likely to always be founded upon what Heidegger termed as a 'fore-conception' (prior experiences, assumptions, and biases), with the researcher likely to interpret any new information through these fore-conceptions (Heidegger, 1962). In interpretation however, emphasis should be given to the new information shared, rather than preconceptions – the researcher makes sense of the information given about a lived experience and makes sense of it in light of the information known beforehand. This is extended with the suggestion that researchers may also project a meaning onto the text when attempting to make sense of it – highlighting the complex relationship between the interpreter and the interpreted (Gadamer et al., 1989). This encourages an extension of the idea of bracketing in IPA whereby it is much more of a cyclical process whereby one notices the projections and preconceptions during the interpretation, rather than beforehand, acknowledging that this cyclical approach can only be partially achieved.

4.4.2.3. Idiography. The third concept underpinning IPA is idiography. This is concerned with the study of individual cases, rather than typical psychological research which tends to focus on population level analyses. It is important to note that while idiography allows an exploration into experiences at the individual level, there is still an acknowledgement that experiences are relational and occur within contexts (Smith et al., 2022). Therefore, analysis using IPA can be seen as a method

of exploring a participant's unique insight into *their relationship* to the phenomena, rather than the experience being the participant's objective property.

In summary the main philosophical assumptions for IPA are in alignment with the following:

- There is an understanding of the participants world and lived experiences using an idiographic approach.
- The researcher elicits and engages with the personal accounts shared while engaging with recognising their own assumptions and biases.
- The researcher makes interpretations as part of a double hermeneutic while still maintaining the commitment to ground these in the participants views.

4.4.3. A Critique of IPA

The use of IPA within this research is not without an acknowledgement of its limitations. For example, Willig (2013), questions the idea that information shared can be seen as a true representation of an individual's lived experiences, as it relies on an individual being able to convey their sense making of a phenomenon by using language. Willig (2013) argues by using IPA, a researcher may not gain true insight into the lived experience, but instead be able to understand how an individual talks about their experiences (Hood, 2016).

In addition, Sousa (2014) termed IPA as an 'anything goes' approach whereby the trustworthiness and credibility are likely lacking, something echoed by Giorgi (2011) when highlighting concerns about the scientific integrity of a flexible approach and one in which there are no clearly defined steps (Dennison, 2019). However, within the parameters of IPA, the focus is on the interpretative insights offered by a researcher and therefore a clearly staged approach may be seen as restrictive and limit the depth of analysis that can be achieved (Smith et al., 2022). Instead, IPA

allows a researcher flexibility when exploring phenomena that require an adaptable approach. Further to the idea that IPA is not scientific, counterarguments have been made around the idea that science is culturally defined and socially embedded itself. Just as IPA has evolved, so too does the idea of what it means for something to be scientific (Dennison, 2019).

Finally, Willig (2013), suggests that while IPA allows for a detailed exploration of a phenomena, it is limited regarding its ability to provide explanations. However, as this study has only an exploratory focus rather than an explanatory one and IPA does not deem to offer explanations, IPA remains well suited for this research.

4.4.4. *Alternative Approaches*

During the process of selecting the appropriate methodology to answer the research questions, alternative methods for data analysis and collection were considered. The first of which was thematic analysis (TA). TA is concerned with identifying themes and patterns across cases (Braun & Clarke, 2021), rather than taking an idiographic approach like IPA. Within TA, as the researcher develops codes across participants it is suggested to produce a breadth, rather than depth of analysis. Braun and Clarke (2021) suggest that TA is appropriate when the research questions are focused on something other than lived experiences, the data comes from a method different to individual interviews, the research interest is focused on wider socio-cultural contexts, and the research is focused on deriving 'actionable outcomes' (Sandelowski & Leeman, 2012). As these are not aligned with the focus of this research, TA was deemed as inappropriate for use as a method of data analysis.

The second approach considered was the Free Association Narrative Interview Method (FANIM) – a psychoanalytically informed model of research interviewing. The assumption is that each participant is 'defended', and there becomes a focus on

the unconscious processes taking place within the interview (Archard, et al., 2024). However, this method requires multiple meetings with each participant, and aside from time constraints and emotional toll involved in interviewing young people more than once, as a researcher I also wanted to honour the meanings shared by each participant, rather than following the notion that defended subjects cannot access their own meanings readily (Archard, et al., 2024).

4.4.5. IPA Summary

In contrast to alternative approaches, IPA allows a level of creativity and depth which is appropriate approach for ‘complicated situations and experiences’ (Willig, 2001). In the case of this research, there is not an aim of generating a theory, exploring defences or exploring group wide themes – there is instead a commitment to a detailed exploration of individual lived experiences and the meanings shared by individual young people. IPA was deemed as appropriate for this as there is an idiographic approach which analytically delves deeply into each data set, exploring the lived experiences of having an autistic sibling. The aim as an IPA researcher is to ‘walk along with the local inhabitants, asking questions which lead subjects to tell their own stories of the lived worlds and conversations’ – in doing so I am ‘wondering together with them’ (Kvale, 1996 as cited in Eatough & Smith, 2017 p.30).

4.5. Research Method

4.5.1. Participants

4.5.1.1. Participant Sampling and Homogeneity. In order to explore a specific phenomenon, participant sampling must be purposive (Smith et al., 2022). This refers to sampling whereby participants are selected because they can provide insight into the particular experience under exploration. In line with these

recommendations, purposive sampling was utilised within this research, and most often this took the form of opportunistic sampling via referral from other EPs within the local authority (LA) (see section 4.5.1.2). Smith et al. (2022) also highlight the need for a homogenous sample in order that the research questions can be answered in a meaningful way. Homogeneity refers to how ‘uniform’ the participants within a sample are, particularly in relation to clear social and theoretical factors in order that conclusions can be drawn in answer to the overarching research questions. Within this research, the main factor to ensure homogeneity was that all CYP had a sibling diagnosed as Autistic, and they themselves, were not. Additional inclusion and exclusion criteria to ensure further homogeneity can be seen within Table 3. The need to ensure a homogenous sample was balanced with an appreciation of the idiographic approach to IPA in that while homogeneity allows insight into the broader questions being asked, each participant will have their own story which deserves detailed exploration.

Table 3

Sampling Criteria for Participation

Participant Inclusion Criteria	Exclusion Criteria	Justification of Criteria
Has a sibling with a diagnosis of Autism.	Sibling on the pathway for an assessment or has self-diagnosed as autistic.	To ensure that the participants had autistic siblings and therefore could reflect on the phenomenon being explored.
Participants aged between 14 – 18 years old.	Participants aged under 14 or above 18.	To allow an exploration into the school experiences at an age identified as a gap in the literature. A relatively

narrow age range also allowed for greater homogeneity.

Currently attending school, college or higher education institution in England.

Participants being educated via home schooling or in schools outside of England.

To ensure that participants were able to reflect on the phenomenon being explored and to ensure homogeneity.

Participants are aware of their sibling's diagnosis of Autism.

Participants are unaware of their sibling's diagnosis.

This was an ethical consideration to ensure that all participants were giving informed consent and to ensure that the researcher was not disclosing information not previously known.

Able to speak and understand English with the required proficiency to share and reflect on their experiences (including children with English as an additional language).

Participants who would need access to an interpreter to access the interview.

To ensure that participants were able to share their experiences verbally as part of an interview, and to ensure the researcher could interpret and explore the answers, with less chance of misunderstanding.

Participant does not have a diagnosis of Autism, nor are they on the pathway for an assessment for a diagnosis.

Participants who have a diagnosis of Autism, or those who have been

To ensure that the phenomenon of having an autistic sibling, while not

referred for an Autism
assessment.

being autistic themselves,
could be explored.

The following were considered as additional inclusion or exclusion criteria:

- Gender of either the NTS or autistic sibling
- The age gap between siblings
- Length of time siblings spent in the same school (if at all)
- Birth order of the siblings
- Type of educational provision participants autistic sibling was attending.

As this study is one of the first UK based qualitative research explorations into the school experiences of CYP with autistic siblings, there was very little research to draw upon to formulate a rationale for controlling for factors such as birth order or gender. It is hoped this research will provide further rationale for specific follow up studies (see Chapter 6). Specifying the type of educational provision autistic siblings attended was also considered. However, narrowing the participant pool to only those with an autistic sibling at specialist provision for example, does not allow for participation from CYP whose sibling would ideally have a space at specialist provision but cannot attend due to specialist school's being oversubscribed. There would also be an implied assumption that all children in specialist provision have the same level of need, compared to those in mainstream. It was therefore decided that the kind of educational provision would not form part of the sampling criteria.

4.5.1.2. Recruitment Process. Following ethical approval (see Appendix E), participant recruitment began in April 2024 and ended in September 2025. The recruitment strategy took a staged approach with any interested participants being

screened against the inclusion and exclusion criteria and then being accepted on a first come first served basis. The staged approach was as follows:

1) The EP team within the LA was contacted via email to begin recruitment.

EPs were asked to contact any families they felt had a child who met the inclusion criteria for the research, with whom they had had contact with within the last 18 months. 18 months was decided as the cut off in consultation with the Principal Educational Psychologist, as after this time, EPs would routinely request further consent for any more involvement. EPs asked the families for consent to pass on their contact details with me before I could then follow up and share more information.

2) School SENCOs within the LA contacted regarding the research via email or during in-person meetings.

This started with my own linked schools and then progressed to sharing with other schools within the LA. This approach was taken to ensure that the study was not initially opened too broadly, potentially resulting in the need to refuse participants. Although the initial request was that SENCOs identified children who fit the inclusion criteria who attended their schools, occasionally staff members shared potential participants within their personal lives. These were screened in line with the criteria as per all other methods of recruitment.

3) The LA Autism Service contacted via email. The Autism service was forwarded a flyer and information sheets (see Appendices G and H) to share with families with whom they were working.

4) Recruitment via social media. This involved posting the recruitment flyer on X (formerly known as Twitter), Facebook groups, and EPNET (Appendix F)

Regardless of the recruitment channel used, all participants were provided with the appropriate information sheet (see Appendix G) to ensure informed consent could be provided. Appendix H can be seen for individual consent forms. All participants were recruited via recruitment stages 1 and 2, and therefore came via professional contacts in the EPS, or within schools.

4.5.1.3. Sample Size and Participant Information. With regards to sample size, it is recommended that qualitative research samples are both large enough to allow discovery of new and rich understanding, and that they remain small enough to allow a deep, case-by-case analysis of individual lived experiences (Sandelowski, 1995). Historically, qualitative researchers were making use of larger samples to fall in line with quantitative research sample sizes, but over time and as the approach has matured, the central issue has shifted towards quality over quantity (Smith et al., 2022). With regards to number of participants suitable for IPA specifically, anywhere from a single case study to 10 participants has been suggested as suitable, but the exact number depends on the level of commitment to individual analysis, the richness of the data, and the organisational constraints they are bound by. In the case of this research, 4 participants were interviewed, falling in line with recommendations of completing a focused analysis on a small number of cases. Smith et al. (2022) have encouraged a shift away from the idea that larger samples are better, even suggesting with more than six in-depth interviews, the analytic process can be inhibited. It was deemed that the sample size utilised in this research would enable an idiographic approach to understanding the phenomena being explored, guided by rich and detailed individual accounts. Additional information relating to each participant can be seen within Table 4.

Of particular note within this research, were barriers to recruiting more participants than the 4 that consented to take part due to their siblings Autism. A number of parents of potential participants reached out in the initial stages of recruitment but then explained that due to the needs of their Autistic child, finding time to support their NT child to take part in the research was a challenge, particularly over the summer period where the majority of recruitment took place.

4.5.2. Data Collection

4.5.2.1. Participant Interviews. Smith et al. (2022) outlines the importance of asking the participant where they would like to be for the interview, as this level of autonomy in the process is likely to facilitate feelings of comfortability and safety. Within this research, participants were given the choice of meeting at their school/college, the EP offices or at their home. In all places the emphasis was that interviews would be conducted in quiet, 1:1 environment due to the personal and potentially sensitive nature of the conversations. As illustrated in Table 5, three participants chose to complete the interviews in school, and one at home. When contracting a time and space for the interviews to take place, all participants were informed the expectation was of an interview around one hour.

Although signed consent forms had been completed prior to the interview, no assumptions were made around the participants expectations of being involved in the research. Therefore, prior to starting the recording, the research aims, process, anonymity, and confidentiality were outlined - including reasons confidentiality may be broken in the event of concerns around participant safety. Participants were given the opportunity to ask questions and were asked for their verbal consent before the audio recording started. Part of the importance for this initial discussion involved rapport building and setting the pace for the interview (Smith et al., 2022). For

example, participants were informed the interview may feel like a one-sided conversation at times. In addition, I made a conscious effort to slow down participant

Table 4*Contextual Information of the Participants and their Autistic siblings*

Name (pseudonym)	Age at the time of interview	Age when sibling was diagnosed	Gender	Ethnicity	More than one sibling (Y/N)	Living with birth family (Y/N)	Educational Setting Attended	Autistic Sibling Age	Sibling Gender	Siblings attended same school (Y/N)
Cassandra	17	~11	Female	White British	Y	Y	Mainstream	14	Male	Y (5 years) – Primary School
Lilly	17	~6	Female	White British	Y	Y	Mainstream	16	Male	Y (11 years) – Primary and Secondary School
Blue-Moon	17	~12	Female	White British	Y	N	Mainstream (1 year in Social Emotional, Mental Health (SEMH) school)	18	Male	Y (4 years) – Primary School
Rian	14	~12	Male	White British	Y	Y	Mainstream	9	Male	Y (3 years)

Note. This information was accurate at the time of interview. The symbol ‘~’ indicates when information is approximate. All time spent in the same school as their siblings took place in mainstream school

thinking and response times, modelling pauses to reflect the desired approach for participants to take when answering later questions. All interviews were audio recorded via secure NHS Trust issued Zoom accounts whereby the cameras remained off to ensure only the audio was captured.

Interviews conducted by an IPA researcher are seen as ‘a conversation with a purpose’ (Smith et al., 2022), whereby the purpose is informed by the research questions under exploration. Smith et al. (2022) outlines that for the most part, the participants talk, while the researcher listens and facilitates their sharing around a relevant topic. In order to hold space for both following the participants lead, and answering a desired question, it was deemed that the use of a semi-structured interview schedule was appropriate, a method which is said to align well with research of an exploratory nature (Mertens, 2008). Within a semi-structured interview schedule there is scope to be present, involved and responsive, remaining a naïve and curious listener while entering the participants lived experiences with them. Guidance from Smith et al. (2022) suggests an hour is needed for an in-depth exploration within an interview. The average interview length within this research was 50 minutes which is appropriate when adjusted for adolescents.

Table 5

Logistical Information Relating to Each Interview

Name (pseudonym)	Interview Location	Interview Length (minutes)
Cassandra	In person (school)	53
Lilly	In person (school)	61
Blue-Moon	In person (home)	57

4.5.2.2. Semi-Structured Interview: Design and Schedule. At the beginning of the interview, demographic and orienting questions were asked of the participant (see Appendix I for schedule). This was part of ‘getting the participant comfortable with talking’ (Smith et al., 2022), as well as building up a picture of the participants experiences so far. During the initial gathering of information, the participant was supported to construct a visual timeline (see Appendix J), plotting the important educational transitions along it. The aim here was to take a temporal sequencing approach as outlined by Smith, (2009) with the goal of orienting the participant to consider the entirety of their experience, rather than a sole focus on the here and now.

Following this timeline creation and in line with the exploratory nature of the research, participants were offered the chance to complete a drawing to support their gathering of thoughts about their sibling and lived experiences. The use of drawings has been suggested as a helpful facilitative approach when conducting research and CYP (Fargas-Malet et al., 2010; Søndergaard & Reventlow, 2019). It is suggested to bridge a gap between the understanding of children and adults, and to be a rapport building stepping stone for engaging in a potentially more emotive topic. The drawing task was provided as an optional activity for all participants as it was a stage aimed at building rapport, and it was understood that not all young people may find this helpful. This option was not taken up by any of the participants.

The semi-structured interview schedule that followed was created based on the guidance from Smith et al. (2022). The questions were sequenced with the knowledge that over the course of the interview, participants move from descriptive

to the affective, and from the superficial to the disclosing (Smith et al., 2022 p.65), and were therefore ordered in a way that allowed a working towards more emotive questions. For example, the schedule started with an exploration into their siblings needs, allowing a sharing of a more descriptive 'scene setting', before moving to questions around their emotional responses. Based on the literature review and therefore an understanding that lived experiences across contexts are inextricable, a second question was then asked around sibling's home experiences. The purpose of this was in effort to continue the transition from the descriptive to the affective, and in order to support an exploration of the impact of home life, on school experiences.

At all times I remained committed to being an 'active listener' (Smith et al., 2022) as guided by Rogers (1957) principles. This involved careful monitoring of participant body language as well as verbal signs of the participant's emotional state. Smith et al. (2022) also outlines several types of interview question which support the gathering of rich data which were used during careful consideration of how to word questions within the 'funneling' approach. These suggestions were incorporated into the interview schedule (see Appendix I) and held in mind during interviews when asking follow-up questions.

- *Descriptive*: Participants were asked to expand on the detail of their answers to ensure the researcher was able to understand the experience being shared. For example, 'Tell me what that was like for you.'
- *Narrative*: These were to support the building of connections across the participants experiences at both home and school. For example, 'How has this changed over time?'

- *Contrast*: These questions supported participants to reflect on differences within their experiences. For example, 'How was that similar or different to your experience at primary school?'
- *Evaluative*: These questions encouraged participants to share their emotional reactions to parts of their experiences. For example, 'How did that feel?'
- *Comparative*: These questions encouraged participants to share and reflect on different experiences they may have had compared to their peers and/or siblings. For example, 'How would that be different if your brother was not autistic?'
- *Prompts*: Participants were often asked 'Can you tell me more about that?' or 'Can you give me an example?' This supported participants to share more detailed accounts of their experiences.
- *Probes*: Participants were asked clarification on things they shared. For example, 'What does it mean if you feel lost?'

By contrast, Smith et al. (2022) shared a poor interview is one which takes a rapid pace, uses closed questions, offers judgement and utilised leading questions. The following kinds of questions were avoided within each interview, based on guidance from Smith et al. (2022):

- *Over-empathetic*: 'I can imagine it is so hard being at the same school as your sibling'.
- *Manipulative*: 'You described it as feeling lost. Is it even worse than that?'
- *Leading*: 'I suppose it must have been really rewarding helping your brother at school.'
- *Closed*: 'So that was different then?'

4.5.2.3. Pilot. In order to support the finalisation of the semi-structured interview questions and build competence and confidence with being in-role as a researcher, a pilot study was conducted (Ismail et al., 2017). It was deemed important the participant was within the desired age range being recruited for the study, so as to assess the quality and accessibility of the question being asked, but as the data was not to be included in full analysis, the participant did not need to meet all inclusion criteria. For this pilot, Bella met all inclusion criteria aside from her sibling having a formal diagnosis of Autism, instead, her brother was on the waiting list for an assessment at the time of interview. The interview with Bella took place online over Zoom and additional information can be seen in Table 6 below.

Table 6

Pilot Participant Information

Name (pseudonym)	Age (at time of interview)	Gender	Ethnicity	Sibling Age	Sibling Gender	Siblings attended same school (Y/N)
Bella	14	Female	White British	11	Male	Y (5 years)

Note. This information was accurate at the time of interview.

Following the pilot, a reflective log was completed to reflect on both the personal experience of being in role as researcher, and potential adjustments to the interview protocol (see Appendix I). Subsequent reflections around allowing time and space for reflection, developing skills with asking open questions to increase data quality, and pre-empting the idea of a ‘one sided conversation’, as per guidance from Smith et al. (2022), were all woven into the interviews.

4.5.2.4. Reflecting on Interviews. There is an acknowledgement that an element of subjectivity is likely to be present in any research and this can affect data collection and later analysis. This subjectivity may be the result of a combination of personal experiences, assumptions and biases. This dual interpretation is accounted for within IPA's theoretical framework as named the dual hermeneutic. Darawsheh (2014) share a balanced view that while bias must be acknowledged, it can be celebrated and seen as enriching, rather than something akin to a 'contamination' of the data and subsequent analysis. This was taken forward by way of keeping a reflective log during both data collection and analysis (see Appendix K). Within this log there is an attempt to notice assumptions and biases while allowing an exploration into personal emotional experiences and early interpretations. These reflections were then taken to supervision to support the exploration of alternative perspectives.

4.5.3. Data Analysis

Following each interview, the audio recordings were transcribed verbatim and then initial themes were identified from the data for sharing back with each participant as part of a visual summary of the topics discussed – a step taken to ensure credibility of the research (Guba, 1981) (see Chapter 5). Following the sharing of the visual summaries with each participant, and any subsequent amendments, the data was then analysed using IPA. Data analysis was completed by hand and through the use of Microsoft Word to structure reflections and interpretations (Appendix L). Although IPA can be described by the process of moving from the descriptive to the interpretative, and through commitment to understanding individual perspectives (Smith et al., 2022), it must be noted there is 'no one prescriptive account' of using IPA. The overarching essence of IPA is to focus our analytic skills on the participants

attempts to make sense of their experiences. Despite this variation, there are a set of common processes which can be applied flexibly based on the specific analysis.

These processes are part of an iterative and inductive cycle which will be outlined below.

1. ***Reading and re-reading:*** At this stage of analysis, the researcher becomes immersed within, and familiar with, the data from one participant. I therefore began by reading and re-reading the transcript and did so at least once with the audio recording – a step which supports a more complex analysis later on (Cherry et al., 2023). At this stage, I noted recollections of the interview itself, along with some initial thoughts and feelings about the transcript. To support this stage, I collated the information shared into a simple timeline, illustrated by comments with numbers alongside the analysis document (see Appendix L). I also noted changes across the interview over time as rapport and comfort built.
2. ***Exploratory noting:*** At this stage, I began an exploratory examination of the semantic and linguistic content of the transcript. This step involved making ‘exploratory notes’ alongside the data in a Microsoft Word document (Appendix L), which were grouped into: descriptive, linguistic, and conceptual comments.
 - *Descriptive Comments:* Comments which stay close to the participants explicit meaning (for example descriptions of the important and the meaning of those things for the participant).
 - *Linguistic Comments:* An exploration into the language used by participants – a stage of annotation which became more reflective and hermeneutic. This involved an exploration into pronoun use, pauses,

laughter and functional aspects of the language used (for example, tone, fluency). I also began to attend to my own emotional response to reading the data, pausing to explore when the shift occurred, and what meaning the participant was making.

- *Conceptual Comments:* Interrogative noting where I asked explicit questions about the data. This also involved personal reflections and started to form a dialogue between pre-existing or experiential knowledge, and the initial insights into the participants world.

3. *Constructing experiential statements:* At this stage, the exploratory noting was analysed in order to identify experiential statements. These statements shift away from the original transcript, while staying true to the participants experiences, and combine both the original words, and researcher interpretation under an experiential statement. This becomes one example of a hermeneutic cycle, a process that continues through the whole transcript.

4. *Searching for connections across experiential statements:* Following the creation of experiential statements, the focus shifts to how the experiential statements fit with one another. The forming of clusters of statements was completed manually by physically moving cut out statements around to form cohesive groups (see Appendix L). At all times throughout this process, I returned to the participant experience, asking if the connections beginning to form were reflective of the experience shared (Smith et al., 2022).

5. *Naming the personal experiential themes (PETs) and consolidating them into a table:* At this stage, each cluster of experiential statements was given a title which became the participants PET. They are so called because they are 'personal' to the participant, 'experiential' because they relate to the lived

experiences of the participant and ‘themes’ because they are no longer tied to individual lines within the transcript. PETs were recorded in bold uppercase to reflect that they are the highest level of organisation, and then sub-themes within the PETs were given lower case bold titles. Alongside each subtheme are the individual experiential statements along with illustrative quotes (Appendix L).

6. *Continuing the individual analysis of other cases:* At this point, steps 1-5 began again with the second transcript. While it is likely our fore-conceptions have changes as result of the previous analysis, there was an attempt to treat the next transcript as an independent and separate data set, keeping in line with the idiographic nature of IPA.

7. *Working with PETs to develop group experiential themes across cases:*

The aim here is to create group PETs based on the individual PETs created – these are termed ‘Group Experiential Themes (GETs)’. This allows both an exploration of the convergence and divergence of experience and must not be mistaken for searching for a group norm as this is not the focus of IPA. The formation of GETs was completed using a cross-case analysis as suggested by Smith et al. (2022), whereby each participants’ PETs and PET subthemes were colour coded and physically moved around to create GETs. Although there is no strict rule for forming a GET, I decided to work within the parameters shared by Smith et al. (2022) in that the GET must consist of contributions from at least half of the participants. Some PET subthemes were divided across multiple GETs at this stage. In line with guidance of high-quality IPA analyses (Smith et al., 2022), a focus was retained on individual,

idiographic expression of experiences, during the process of forming larger themes in the form of GETs.

4.6. Research Quality

As qualitative research cannot be judged against the same measures of validity and reliability as quantitative research, there are often critiques about the qualitative research rigour (Shenton, 2004). There are, however, several recommendations regarding how qualitative researchers can ensure similar levels of trustworthiness in their own research. These recommendations from Guba (1981) are around ensuring the following:

- **Credibility:** This is defined as a measure of how congruent the findings are with reality and can be seen as similar to the idea of 'internal validity' in quantitative research.
- **Transferability:** May be considered as similar to the concept of 'external validity' as discussed in quantitative research and can be thought of as an ability to demonstrate findings may be applicable to other situations and populations. Although when exploring individual lived experiences, each case is unique, it has been suggested each participant is still within a wider group and so transferability should not be immediately rejected (Denscombe, 2017).
- **Dependability:** This can be seen as similar to 'replicability' in quantitative research. Dependability is indicated through the provision of a clear research design and a detailed exploration of the implementation of research.
- **Confirmability:** While quantitative research may look towards ensuring objectivity, qualitative research acknowledges that researcher bias cannot be fully removed but must instead be acknowledged. The concept of

confirmability addresses ensuring as far as possible that findings are the experiences of participants, rather than the preferences of the researcher.

The ways in which these are addressed within this research are outlined in Table 7.

Table 7

Research Quality Criteria

Quality Criteria	Guidance	Steps Taken
Credibility	Qualitative researchers should adopt research methods which are well established.	Research into the lived experiences of phenomena has been extensively conducted using IPA (Johnson, 2016; Smith & Osborn, 2015), and has been used to explore the perceptions of CYP as well as adults (Kimura & Yamazaki, 2013; Sravanti et al., 2022).
	Frequent debriefing sessions between a researcher and a supervisor to widen perspectives and reduce blind spots.	Monthly supervision sessions were held during this research, and these were more frequent during analysis and interviewing.
	Using 'member checks' with participants to ensure participants views have been captured accurately.	Visual summaries of the topics discussed were shared with each participant. These visual summaries were also shared in supervision to again check for bias, and to consider the emotional impact for each participant (see Chapter 5)
	Use of a reflective journal to support 'progressive subjectivity' and track how	See Appendix K. Insights from the reflective journal supported later analysis and findings.

	researcher perspective evolves over time.	
	Ensuring the honesty of participants is important – there should be the chance to consider and potentially withdraw.	Participants were informed that the exploration was around their personal views, and that the researcher would allow space for those, rather than leading them. Participants were also given 2 weeks from the interview to ask for all information stored to be deleted, and to withdraw their participation. It was also made clear to each participant that all information they shared would be kept confidential unless there were concerns related to their safety or the safety of others.
	Random Sampling	Not utilised in this research as it was critical that the researcher was able to select participants with the particular lived experiences under exploration (Smith et al., 2022).
	Triangulating Information (e.g., through observation as well as interviews)	Not utilised here as the individuals were the sole informants about their lived experiences. There was a respect and understanding that it is the participants' interpretations that are not only important, but true to them, rather than confirming their interpretations from other sources.
Transferability	The following must be shared:	All of these are shared within Chapter 4 of this thesis.

	The context of the research location.	
	The number of participants involved and any limitations around participation.	
	The data collection methods used.	
	The number and length of data collection sessions	
	The time period over which data collection took place.	
Dependability	Dependability is indicated through the provision of a clear research design and a detailed exploration of the implementation of research	Illustrated throughout Chapter 4.
	A depth of reflective appraisal within the written research.	This can be seen in the Discussion Chapter (6), and in Appendix K for reflective journal entries.
Confirmability	The findings are the experiences of participants, rather than those of the researcher.	Although IPA addresses the dual interpretation of an experience via the concept of double hermeneutics, a number of measures are outlined by Guba, (1981) that support an

acknowledgement of researcher bias and the preservation of participant views within the double interpretation:

- 1) Researcher bias and personal experiences are addressed throughout this paper (see Chapter 1 and Chapter 6).
 - 2) Excerpts of individual transcripts were shared in supervision to ensure an expansion of perspectives and interpretations, as well as to reflect on any biases in assumptions made.
 - 3) The concept of the hermeneutic cycle is shared within Chapter 4 for transparency around the addition of researcher interpretations.
-

Note. This table shows the criteria to ensure quality qualitative research from Guba (1981), and the ways in which these were met within this research.

4.7. Ethical Considerations

This research was approved by the Tavistock and Portman NHS Trust Research Ethics Committee. In addition, this research was also approved by the Children's Services department in the LA in which data collection would take place. In order to gain approval to conduct this research in the LA, a full research proposal was reviewed by the Head of Children's Services and was approved by the senior leadership team within the EP Service (Appendix E for ethical approval letters).

The researcher abided by the guidelines set out within both the BPS Code of Human Research Ethics (The British Psychological Society, 2021), and the HCPC guidelines in relation to being an ethical and responsible researcher. Detailed ethical considerations taken at all stages of this research can be seen in the subsequent sections.

4.7.1. *Researching with Children*

Of particular note within this research, are additional considerations about what it means to be an ethical researcher when working with children. At all stages throughout this research, decision making was guided by the reflexive tool provided by Graham et al. (2013). This tool poses reflexive questions to the researcher to ensure ethical decision making is upheld throughout the research, while outlining that it is the responsibility of all those engaged in research with children to work out how ethical principles apply. All steps taken to ensure ethical research are outlined below.

As part of respecting the autonomy and life stories of all participants (Graham et al., 2013), the CYP were involved as ‘active participants’, having some control over the journey of the interview, as their lead was followed through the semi-structured interview (Alderson., 2005). Considerations were also made with regards to the imbalance of power likely present between CYP and researcher. The BPS (2021) outlines how child compliance is expected and reinforced in schools, and therefore to what degree a potential participant may feel able to say no or ask to withdraw from the research. The BPS (2021) suggests researchers make ‘special efforts’ to establish a different position, where the child is a free agent. In this case, all participants were given information sheets and consent forms prior to meeting in school to ensure they had time and opportunity to consider and ask any questions.

This offer was made to ensure that participants were able to fully consider taking part in the research without being face-to-face with the researcher, where asking questions or opting out may feel more challenging. CYP were also given choices throughout the interview process in an effort to hand over as much autonomy as possible. For example, CYP had the choice to engage in a drawing task before the interview and were offered an initial choice of where to conduct the research.

4.7.2. Minimising Harm and a Duty of Care

Harm is referred to as ‘anything which may cause distress to a participant as a result of taking part in research’ and this may include the potential that suppressed feelings may be uncovered (NSPCC, 2023). Although efforts should be made to reduce harm for all participants, particular care must be taken when researching with vulnerable groups, in this case those under 16 and those who are being asked to share potentially difficult experiences. One recommendation to support this is the appointment of ‘gatekeepers’, those who are around at the time and location of the research. The idea of a ‘gatekeeper’ (in this case more appropriately referred to as a ‘safe adult’) was utilised to ensure the safety of all participants (British Educational Research Association [BERA], 2024). If at home, regardless of participant age, an adult over the age of 18 was requested to be present to ensure that someone could be contacted for support both during and after the interviews if needed. For interviews in school, a named adult was chosen by the participant and again, if the interview needed to be paused or terminated, there was still someone designated and in proximity. Before starting all interviews, participants were also asked to name a person they wished to be informed if they or the researcher felt the participant needed emotional support following the interview. For under 16’s this needed to be a parent or carer.

Additionally, participants' emotional responses were closely monitored. In line with BERA (2024) recommendations, if a participant became distressed during the interview, professional judgment would be used alongside participant input to decide whether to continue, pause, or withdraw. Regardless of the decision, participants were informed their named contact would be told elements of the interview were distressing. If an interview was ended due to distress, the named individual would be contacted again a week later to check on the participant's wellbeing and remind them of support organisations listed in the debrief sheet, if necessary. This was not necessary for any of the interviews conducted.

After all interviews, participants received a debrief in line with British Psychological Society (2021) guidance. This included checking how the participant experienced the interview and how they felt afterwards. This enabled the addressing of any unforeseen distress or misconceptions and gave participants the chance to ask follow-up questions. Participants were also given information about how to access further support and follow up information.

Careful consideration was also made around how the nature of the relationship between the siblings would be handled. The aim for this research was to explore the participant's experiences, rather than providing support to link experiences together or reach new perspectives. However, due to the potential this may happen through the very nature of reflection, the start of each interview was prefaced with a transparent reminder of the research purpose and aim, rather than contracting for a therapeutic space.

During the interview, every effort was made to follow up any comments around their experiences with open questions to ensure full understanding of their thoughts, rather than leading the young person, or indicating agreement/disagreement with the

participant about their experiences. Finally, an additional question was added to the interview schedule that would not be used for analysis purposes but to encourage reflection around the positives of their sibling and sibling relationship. Research suggests ending an interview by asking the participant to share the positive parts of their experiences, is an important part of sensitive, qualitative interviewing (Dempsey et al., 2016), and that it may serve to provide a ‘well-rounded ending’, associated with positive memories of an experience (Schwörer et al., 2020).

4.7.3. Confidentiality and Anonymity

Participants were informed via the information sheet, and then again at the start of the interview that the content of the conversation would not be shared with anyone in their personal lives (for example teachers or parents) unless they made a disclosure that caused concern for their safety, or the safety of others. It was discussed with each participant who they would wish to be contacted in this case, for example a parent/carer or a teacher if a concern also needed to be shared with the young person’s school (for example if a disclosure was made about bullying). Additionally, no matter the location of the interview, the arrangements were made to ensure quiet, distraction free spaces for the interview to take place. In two cases, recruitment had been via parental contact, however the young person wanted to meet in school. In this case a discussion with parents was held to gain consent to share the content of the research with school, to arrange a time to visit. In both cases, the information sheet was shared with the school following verbal consent from the parents and participants.

4.7.4. Data Storage and Security

Children participating in research require specific protection when their personal data is processed, collected, and stored, because they may be less aware of the risks (Information Commissioner's Office, 2018). Additional steps were therefore taken to keep the young people safe. For example, the guidance recommends only collecting and storing the minimum amount of data necessary for the intended purposes, as well as placing access restrictions on the data. In this research, recordings and any participant information were password protected and stored on an encrypted hard drive. Therefore, only I had access to the data. Participants were also provided with clear, age-appropriate information around the storage and security of their data (see Appendix G). This information included informing participants that all information relating to their involvement would be stored in accordance with the Data Protection Act (2018) and under the pseudonym they had chosen. In line with the Research Council's UK (RCUK) guidance, participants were informed that following transcription, audio recordings would be disposed of securely, and written transcripts would be stored for 6-10 years. Participants were also informed the name of their sibling or the school/college they attend would be removed from any transcripts or data gathered. As the UK General Data Protection for Children (GDPR) also asserts all data processing must be transparent and fair, participants were informed that while all efforts would be made to ensure they could not be identified, there was a chance people who know them may be able to identify their answers upon reading the research, due to the small sample size.

4.7.5. *Informed Consent*

As the participant age range for this research was 14–18, three different consent forms were created. For participants under 16, both the parent/carers and the young person were involved: the parent/carers received an information sheet and consent

form, while the young person received an adapted information sheet and assent form. Participants over 16 received the information sheet and consent form directly. All CYP materials were adapted using visuals and accessible language with explanations where appropriate. Participants were also informed how their data would be used, stored, analysed, and when it would be destroyed. After sending these forms, a face-to-face meeting or phone call was offered to discuss the research in more detail and answer questions. One face-to-face meeting and three phone calls were arranged.

To protect participants and ensure transparency, one inclusion criterion required that participants were already aware of their sibling's Autism diagnosis. This helped ensure no unknown information was disclosed to participants, while allowing the phenomenon to be explored openly. Participants were informed they could contact the researcher within two weeks of their interview to withdraw their data if they wished.

Finally, consent was viewed as an on-going process, rather than seeing it as a singular event (Morrow, 2008). This was ensured by starting the interview with an outline of the process and checking again for consent, as well as checking for consent during interviews and reminding of the right to withdraw at the end. Additional consent was sought as needed from either parents (if under 16), or the participants (if over 16), for example to contact participants via email to share the final copy of the research as requested on a case-by-case basis.

5. Findings

5.1. Chapter Overview

This chapter presents the findings from the data collected, in relation to the research question:

‘What are the school experiences of CYP, aged 14-18, with an autistic sibling?’

In line with IPA and the emphasis on the individual lived experiences, this chapter will focus first on each participant, their PETs and researcher reflections on each interview. Subsequently, the chapter will explore the GETs produced from the PETs, illustrated with quotes from participants, and interpretations of their experiences. Finally, a summary will be presented as an answer to the research question above.

5.2. Personal Experiential Themes (PETs)

This section will provide an overview of each participant’s PETs’ and researcher reflections. Demographic information related to each participant can be seen within Table 4 but are not explored in additional depth here so as to preserve participant anonymity. The experiential statements as well as the individual quotes which comprise each PET can be seen in Appendix L.

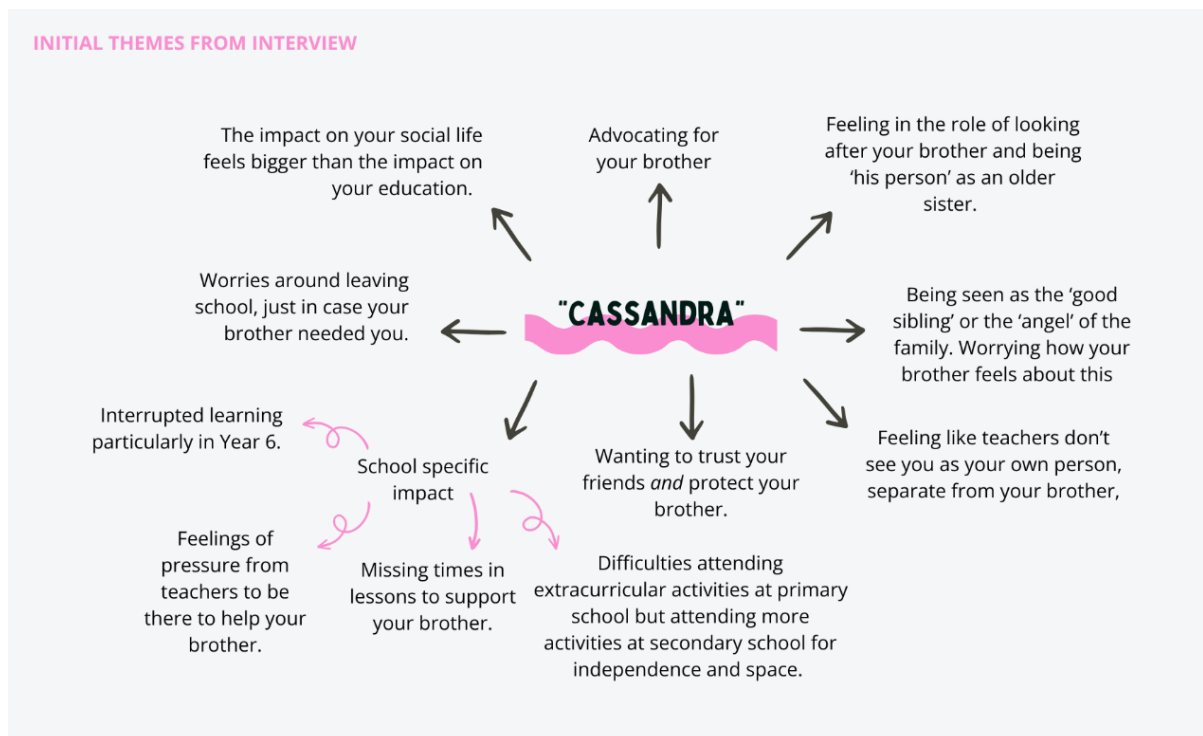
5.2.1. *Cassandra*

Following the interview with Cassandra, a visual summary of topics discussed was created (Figure 4) and shared with her via email prior to formal IPA beginning. The sharing of draft findings with participants is not uncommon where research utilised qualitative interviews and is often used as an indicator of research quality (Archard et al., 2024). The visual summary created was based on an initial re-read of the transcript in conjunction with the audio recording. The visual summary (and those for

subsequent participants) is not to be considered as the first stage of IPA analysis, but as a means to ensure that subsequent interpretations of Cassandra's lived experiences could remain as true to her experience as possible.

Figure 4

A Visual Summary of Cassandra's Interview



After the visual summary was shared with Cassandra and no edits were required, IPA began. Following stages 1-5 of IPA analysis, the following PETs in Figure 5 were identified. The PETs presented are closely aligned with the visual summary yet explore the initial themes in more depth following the IPA process.

Throughout the interview, Cassandra shared her experiences of being labelled as the "good sibling" and "angel of the family" and reflected on experiences of taking up these roles at school, both with her brother and others. She shared being an educator, protector and advocate for her brother, and during the interview these roles became present in response to my questioning. For example, Cassandra often

shared difficult emotions or experiences and then followed them up with an explanation of her brother's needs or descriptions of his 'positive' traits. A sense of having her own feelings and experiences enmeshed with her brothers was also woven throughout the interview. When asked questions about her experience Cassandra often shared her brother's emotional response or used 'we' rather than 'I' or 'me/mine'. As this was my first interview, I also found it challenging to guide her back to her own experience and found myself pulled into neglecting her own experience with her at times. There may have been a duality of 'firsts' here in that there was a sense this was the first time Cassandra had fully shared her experiences in this way. Throughout the interview, Cassandra also reflected extensively on the social and emotional impact on her school experience, as related to her brother. She articulated a multitude of conflicting emotions, particularly in relation to gaining more independence during adolescence, for example a joy in freedom and a guilt around feeling this at all. Further to the social impact for Cassandra, she explored feelings of paranoia and mistrust in others' motivations and shared a lasting impact on her ability to trust the relationships she maintained in school.

Figure 5.*Cassandra's PETs*

CASSANDRA'S PETS

C1. TRANSITIONS AND CHANGES OVER TIME: SHAPING EXPERIENCES	C2. ROLES, RESPONSIBILITIES AND EXPECTATIONS OF SIBLINGS IN SCHOOL.	C3. BALANCING ACADEMIC RESPONSIBILITIES AND SIBLING SUPPORT	C4. NAVIGATING SIBLING SUPPORT AND ISOLATION IN THE SCHOOL ENVIRONMENT.	C5. LABELS AND IDENTITY	C6. INDEPENDENCE: FINDING SPACE FOR JOY	C7. SOCIAL CONNECTIONS AND TRUST: CHALLENGES IN SCHOOL FRIENDSHIPS	C8. DISAPPOINTMENT IN SELF AND OTHER
N/A	C2.1. Taking responsibility for uncovering the truth in school and peer conflict C2.2. Actively facilitating calm: the responsibility of supporting school dynamics C2.3. Parenting and protection: The expected role of being an older sister. C2.4. Selfless Advocate and Educator	C3.1. Putting his needs first C3.2. Looking for balance C3.3. Academic Impact	C4.1. Other people in school do not understand. C4.2. The unique role of sibling support. C4.3. Isolation vs seeking calm	C5.1 The role of the 'good sibling': performance and relationships. C5.2. The conflict between being seen as one vs constant comparison. C5.3. Guilt and confusion	C6.1 Gaining independence and the importance of friendships. C6.2 Finding time for fun and relaxation.	C7. 1 A social life put on hold C7.2 Trusting others and sharing vulnerability	C8.1 Feeling that she let her brother down. C8.2 Feeling let down by the school system

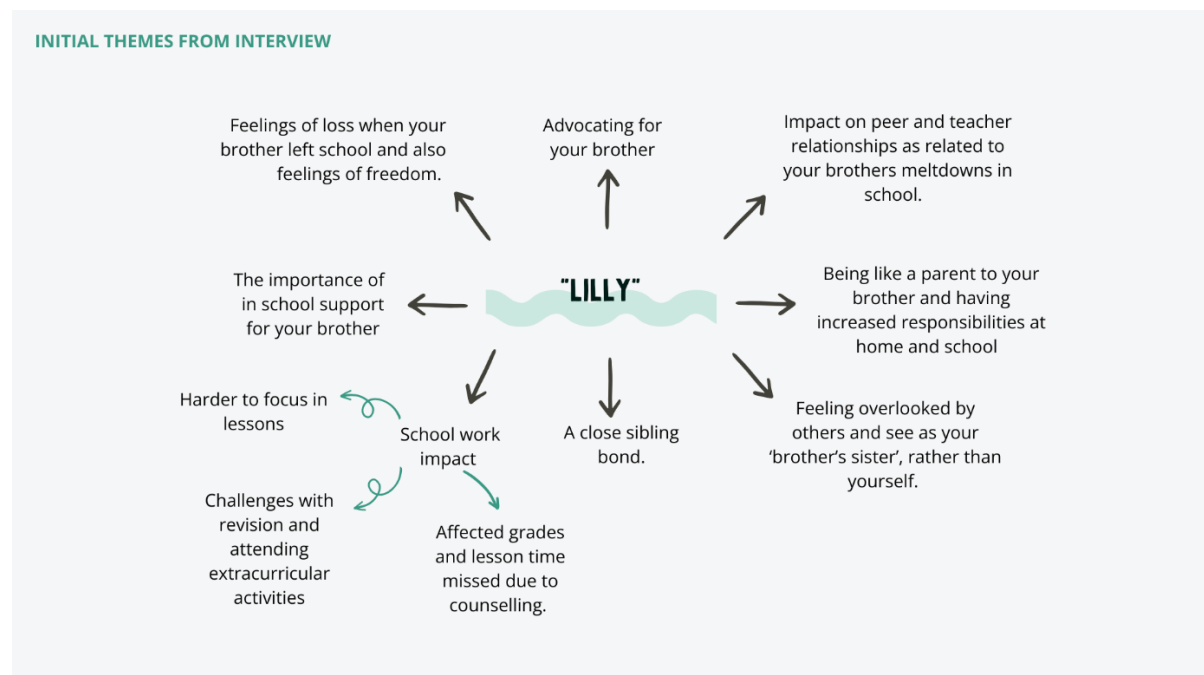
Note. The figure shows the 8 PETs created from stages 1-6 of IPA. N/A indicates where there were no identified subthemes.

5.2.2. Lilly

In line with the practice outlined in relation to Cassandra's interview, a visual of Lilly's interview was created for checking with her that the initial summary of her experience was true to her words. This summary can be seen in Figure 6.

Figure 6.

A Visual Summary of Lilly's Interview



After the visual summary was shared with Lilly and no edits were required, IPA began. The following PETs in Figure 7 were identified.

For Lilly, being a “young carer” in school, was a focus of much of the interview. Just one academic year apart, she described herself as an additional parent to her autistic brother, with their school lives deeply entwined. Lilly shared how she took on the role of educating others about her brother's needs, while also guiding him in social situations and helping him organise his revision. This level of responsibility left her feeling as though she was “not living much” during her school years.

Throughout the interview, Lilly displayed deep empathy - not just for her brother, but for her peers and school staff too. She reflected on why her friends might have reacted negatively and why teachers might have overlooked her, often justifying their behaviour. This role of caring and a deep understanding for the motivations and perspectives of others appeared so engrained for Lilly that she took this role up seemingly automatically in response to questions I asked of her. Regularly when I asked about her own experience, Lilly shared her brother's perspective and feelings and appeared to find it challenging to separate out their differing lives. This difficulty also appeared to be shared by school-based staff who Lilly shared would often ask about her brother, rather than her. This left Lilly feeling invisible and overlooked.

Lilly discussed how her own school life was supported when her brother had adequate school-based support and that this took the weight off her. Without this support, Lilly was constantly in role as mediator and calming presence for her brother and peers. Lilly also shared the difficulties she experienced with balancing her time between supporting her brother's revision and her own during exam season.

Figure 7*Lilly's PETs*

LILLY'S PETs

L1. BALANCING SOCIAL RELATIONSHIPS IN SCHOOL	L2. FOSTERING CONNECTION THROUGH GIVING AND RECEIVING SUPPORT	L3. THE COMPLEX ROLE OF CAREGIVING IN SCHOOL: BALANCING PROTECTION AND ADULTIFICATION	L4. THE CHALLENGE OF INVISIBILITY: A SISTER'S ADVOCACY FOR RECOGNITION	L5. NAVIGATING DIFFERENCES AND MISSED OPPORTUNITIES	L6. ENTWINED IDENTITY AND A SENSE OF SELF	L7. AVOIDING JUDGEMENT THROUGH EMPATHY AND PERSPECTIVE TAKING	L8. THE EMOTIONAL LANDSCAPE OF CHANGE IN EDUCATION: EMBRACING FREEDOM AMIDST LOSS
L1.1. Peer and teacher dynamics. L1.2. Balancing jealousy, mediation and blame.	L2.1. A close sibling relationship. L2.2. The importance of connection and understanding.	L3.1. Adultification and parentification L3.2. Hypervigilance and protection L2.3. Responsibility, caregiving and educating.	L4.1. Feeling invisible at school L4.2. Isolation in knowledge: a sister's role	N/A	L6.1. Being 'one person' L6.2. Self-neglect and guilt	N/A	L8.1. The difference in role across time in education L8.2. The emotional landscape of change

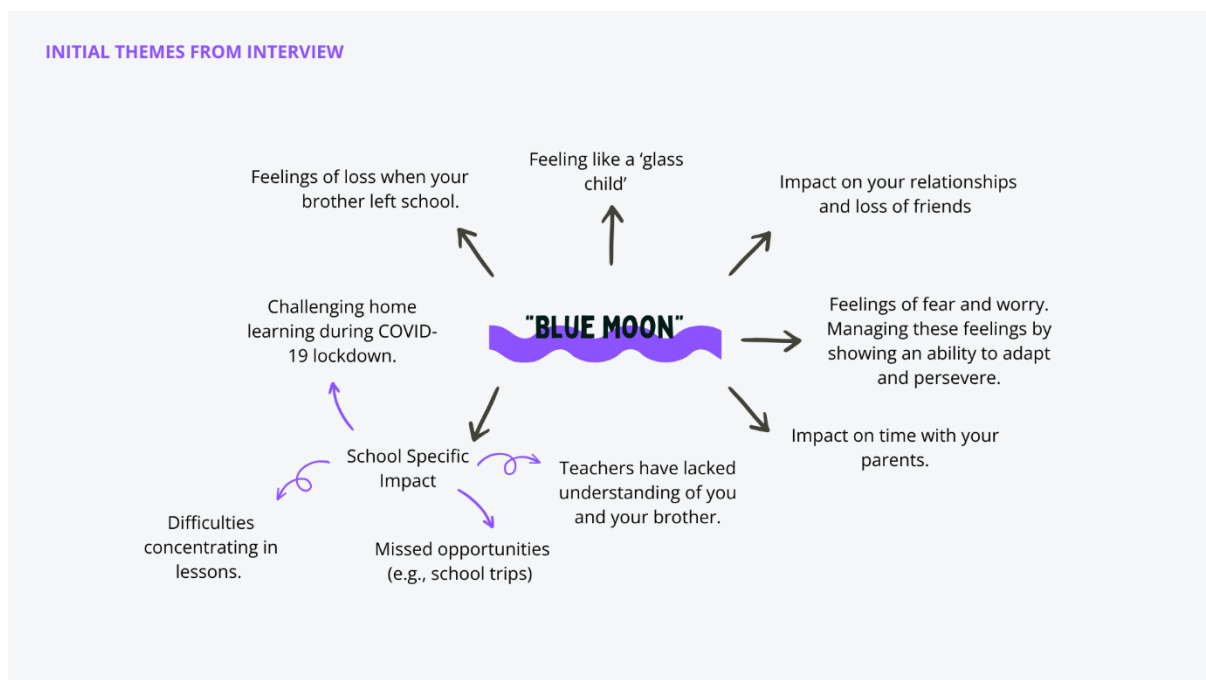
Note. The figure shows the 8 PETs created from stages 1-6 of IPA. N/A indicates where there were no identified subtheme

5.2.3. Blue-Moon

In line with the previous participants, a visual summary of her interview was shared with Blue-Moon before IPA analysis began. The visual summary (see Figure 8) is closely aligned with the PETs presented in Figure 9, although the PETs explore the nuances of the interview in more depth.

Figure 8.

A Visual Summary of Blue-Moon's PETs



No edits were made to the visual summary following sharing it with Blue-Moon and so stages 1-5 of IPA analysis began. PETs were identified and can be seen in Figure 9.

Throughout the interview, Blue-Moon shared her experience of feeling like a "Glass Child". This was defined by Blue-Moon as being "seen through", with people just seeing her brother instead of her, or being "reflected off" as if by a mirror. In response to this experience, Blue-Moon shared difficult experiences throughout her time in education, sharing the impact of her brother's exclusion on her, as well as her

own transfer to an SEMH provision for a year. Blue-Moon explained her behaviour escalated due to a build-up of her needs – after years of being a ‘glass child’. She expressed feelings of anger and frustration about being left alone to cope in school and explained the steps she took in school to regain a sense of control. Feelings of loss were woven through the thread of Blue-Moons interview – when her brother left school, when she was left behind and missed out on school opportunities, and when her teachers left school. For Blue-Moon, comparisons with her brother were made which saw others assuming she would present with the same behaviours as him, and therefore she felt judged before she was ever understood.

Blue-Moon shared experiences of remaining aware of potential physical altercations that could occur between her brother and her parents while she was studying at home during the COVID-19 pandemic. Blue-Moon shared feelings of fear and worry around the physical damage done to their house when her brother was dysregulated. As this interview took place in Blue-Moon’s home, the impact of seeing this damage around me cannot be underestimated. The warm data in the room (Bateson, 2017) – that is the emotional feelings provoked by being in the space with Blue-Moon – held a significance in that not only did I hear about her experiences, but I could also see them. This understanding added a reality and understanding that guided my questioning when I explored with her where this sense of self protection showed up in school also.

Figure 9.*Blue-Moon's PETs*

BLUE MOON'S PETS

BM 1. LIVING ON ALERT: SELF PROTECTION IN SCHOOL	BM 2. ASSUMPTIONS AND LOSS OF INDIVIDUALITY	BM 3. TRYING TO KEEP UP AT SCHOOL: WORK, FOCUS AND FUN	BM 4. A LACK OF UNDERSTANDING	BM 5. BEING FORGOTTEN	BM 6. PUTTING OTHERS FIRST	BM 7. SUPPORT IS ELSEWHERE: BEING A GLASS CHILD	BM 8. LOSS AT TRANSITION
BM1.1. Self-protection BM 1.2. Hypervigilance	N/A	BM 3.1. Difficulties with focus BM 3.2. Inconsistent schoolwork support BM 3.3. Missing out at school	N/A	N/A	N/A	BM 7.1. Isolation in school BM 7.2. Being a 'glass child' BM 7.3. The build-up of need and lacking attention	N/A
BM 9. DRIFTING APART FROM FRIENDS	BM 10. A BALANCING ACT BETWEEN CHAOS AND CONTROL IN SCHOOL						
BM 9.1. Embarrassment BM 9.2. A loss of friendships	BM 10.1. Losing control BM 10.2. Searching for control in school						

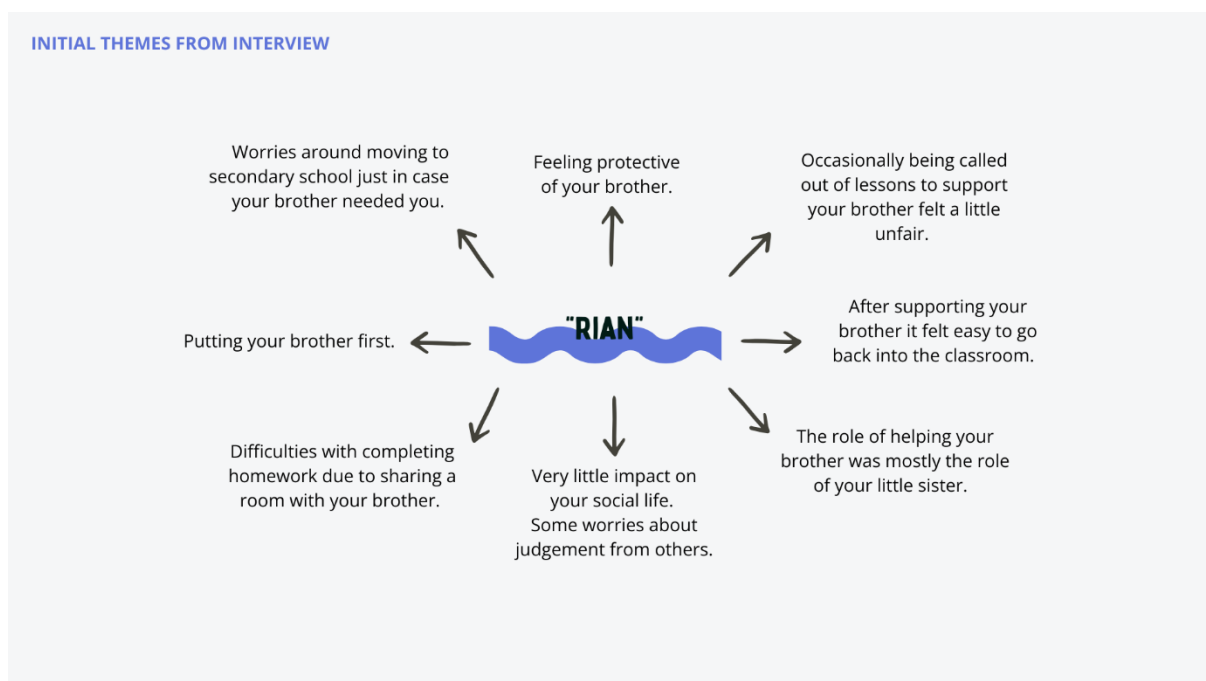
Note. The figure shows the 8 PETs created from stages 1-6 of IPA. N/A indicates where there were no identified subthemes.

5.2.4. Rian

A visual summary of Rian's interview can be seen in Figure 10. As with the other participants, this was shared with Rian before IPA began, in order to ensure the following stages of analysis remained true to his lived experiences.

Figure 10.

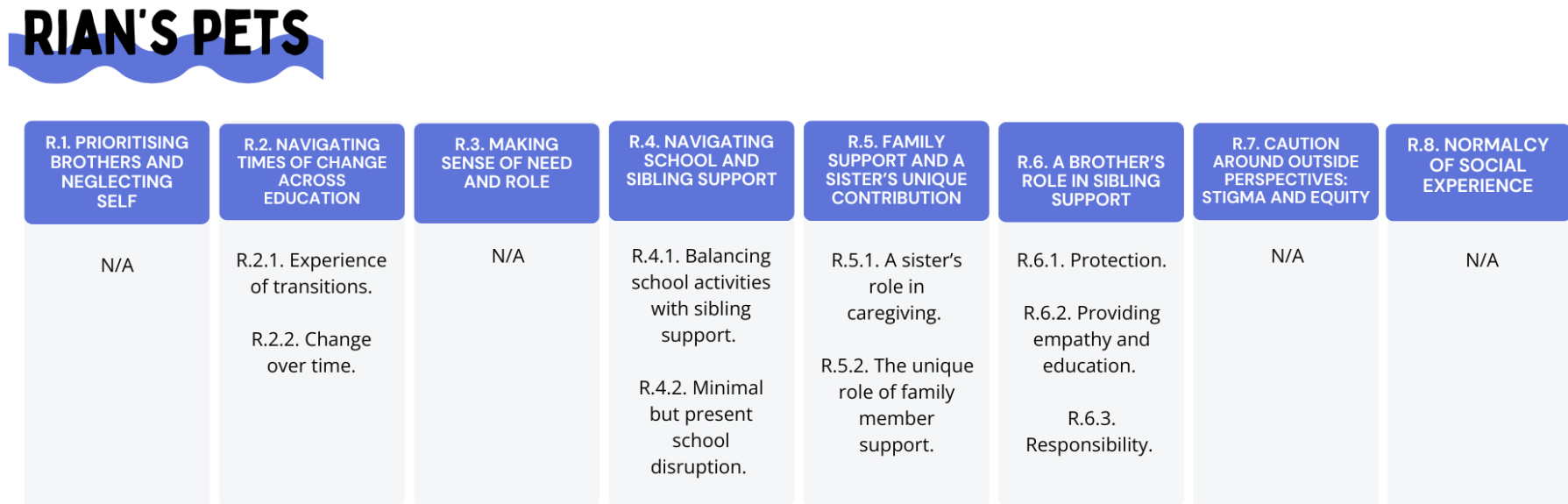
A Visual Summary of Rian's Interview



No edits were made to the visual summary following sharing with Rian and so stages 1-5 of IPA analysis began. The PETs that emerged from this analysis can be seen in Figure 11. As with previous participants, the PETs remained closely aligned with the visual summary, but with added analytic depth.

During the interview with Rian, he shared experiences of his role as an older brother, explaining his sense of being protective and how challenging it can feel when other people judge him and his family. Rian also shares being positioned as responsible for his brother in school but reflected this was more his younger sister's

role, then his. For Rian, the impact on his school life was shared to be minimal and he explored a sense that his school life would have been very similar with or without his brother. Throughout the interview, Rian shared an experience of grappling to understand both his brother's needs and his own role in supporting him – I wondered if this was related to being the youngest participant in the research and may have reflected his higher levels of uncertainty. He shared a variety of different emotional experiences such as guilt, confusion and frustration and voiced putting his brother's feelings above his own. Rian reflected on transitioning away from primary school where his brother remained and shared worrying about how he would be supported without him there. In general, the interview with Rian felt different from the other three participants, potentially because the impact he shared felt less - this made for shorter answers. As an interviewer, I tried to ensure I maintained a balance between pushing for more depth to his answers, while also accepting his shorter answers around there being many parts of his school life that were not influenced by his brother. This required me to regularly return to my goal of highlighting the participants' voices' and not being guided by personal expectations and previous literature.

Figure 11.*Rian's PETs*

Note. The figure shows the 8 PETs created from stages 1-6 of IPA. N/A indicates where there were no identified subthemes.

5.3. Overview of GETs

Following individual case by case analysis, GETs were created to identify convergence and divergence across participant experiences (Smith et al., 2022). Appendix L, (Table L6) can be seen for a comprehensive table which includes an illustration of which PETs and subthemes comprise each GET. This section provides an analysis of each GET illustrated by verbatim quotes from individual participants.

To support with reading, the following features have been used:

- Verbatim quotes embedded within the text are shown within speech marks “”.
- Where participants shared speech from others or from memory, this is within separate quotation marks within the speech marks “...’speech’...”
- Where text has been removed, square brackets are used with ellipsis [...].
- Where words have been added for context or ease of reading, they are within square brackets [].
- Any significant intonation changes, laughter or sighing is indicated within brackets for example (laughs).

An overview of GETs to be explored in more detail can be seen in Figure 12.

Figure 12

A Visual Overview of GETs



Although quotes from participants have been grouped into individual PETs, and then into GETs, it is important to note that overlap can often be seen across the groups. This is due to the complex and intertwined nature of lived experiences. Therefore, occasionally, quotes have been used to illustrate more than one theme, with the overlap between themes acknowledged where appropriate. Across all GETs to be explored below, a colour coding system is used to make it clear which PETs and subthemes come from which participants. This is as follows: **Cassandra**, **Lilly**, **Blue-Moon**, **Rian**.

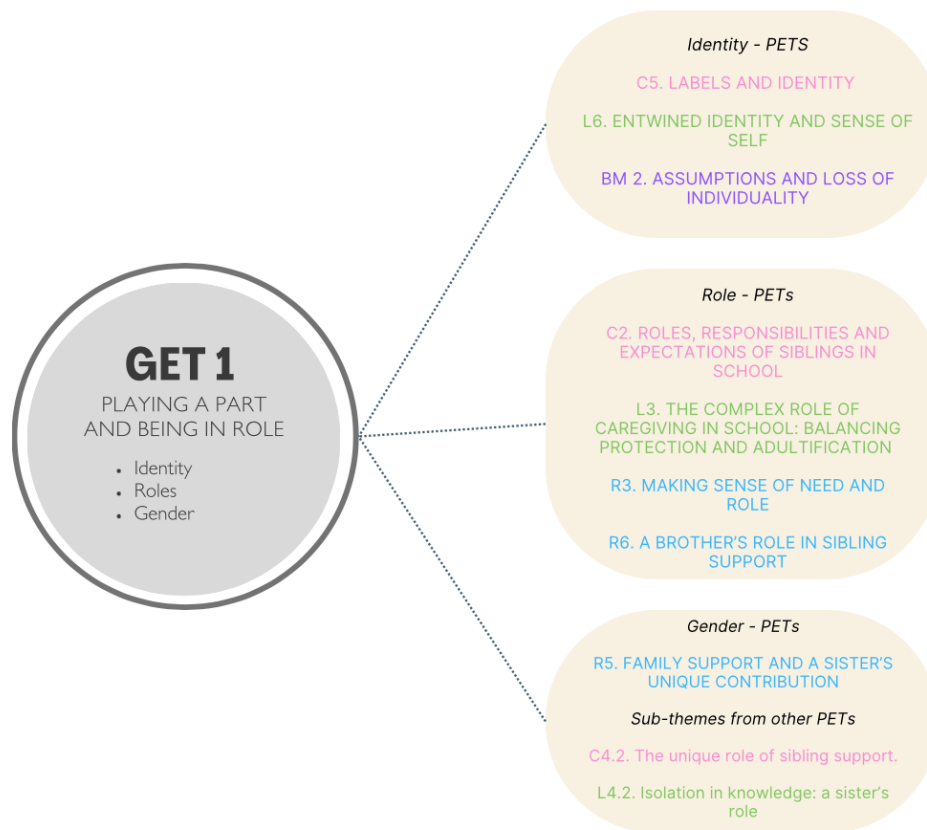
5.3.1. GET 1: *Playing a part and being in role*

This GET illustrates the young people exploring their own identities and role at school, and an exploration into the role gender plays across these roles. This GET was reflected in the accounts of all four participants, across eight PETs and two

additional subthemes from other PETs. As illustrated in Figure 13, this GET encompassed three subthemes: identity, role, and gender.

Figure 13.

GET 1 – Playing a Part and Being in Role



5.3.1.1. Identity. Across individual experiences, there was an exploration into a sense of self being entwined with their sibling's. This was illustrated both explicitly and subtly. For example, Lilly shared, "I couldn't really be my own self away from him...? It always felt like people would be like 'oh X's sister'". This hurt and left her feeling as if "I'm not really seen as a person, I'm kind of just seen as his carer or sister". Cassandra shared similar experiences of her identity being wrapped in her brother's and voiced that others at school "put us in the same boat". Because Cassandra felt that "they didn't see us as two separate people", when her brother

was laughed at, “it turned him into a laughingstock against me”. For Cassandra, it felt as if the humiliation her brother experienced was also then experienced by her.

Interspersed with these explicit acknowledgments of being seen as one by others, Lilly also shared her brother’s experiences when asked about her own, suggesting an automatic merging of their experiences and needs. Similarly to Lilly, Cassandra found it difficult to separate her own experiences from those of her brother and often mismatched pronouns when speaking – “I didn’t – he didn’t do something”, “he’d be like – I would be like...”. For Cassandra, separating out their experiences in school appeared more challenging when emotive experiences were being shared. This appeared to be an unconscious process for both participants.

Blue-Moon also shared frustrations around a loss of her individual identity—she often missed out in school as a result of this perception, and this was painful for her: “I used to do cooking there. But then I got told I wasn't allowed to go into the kitchen anymore because [...] of the way he acts, I might do the same sort of thing”. In contrast, for Lilly, being seen as one person became a comfort, and she shared feeling a loss of her identity when her brother was no longer in school. She shared her mind flooding with questions – “what do I talk about? Like, what do I do? I don’t know how to even go about this”. This speaks to a duality of experience and highlights how an enmeshed identity may provide both comfort and distress for different individuals.

Cassandra’s own identity also appeared wrapped up within labels given to her by her family and teachers in school. For example, she was labelled “the good sibling” by teachers and the “angel of the family”. For Cassandra, these roles showed up in school through helping teachers prepare for breakfast club and always “talking about something academic” with teachers. These roles also appeared present before the

interview started, with Cassandra sharing she had come prepared for the interview. At times, Cassandra shared feeling guilty about her labels, feeling she “didn’t deserve it because I didn’t do anything”. She also shared these labels were only given to her in comparison to her brother and this felt unfair as it “infers there’s something wrong with the other one [sibling]”. Cassandra shared a cognitive dissonance around both enjoying the labels and feeling worried for her brother’s feelings—this may further indicate the difficulty around extracting one’s identity from the other.

5.3.1.2. Roles. From all three older siblings, Rian, Cassandra, and Lilly, there was an exploration into the role as protector of their younger brothers. Rian shared this explicitly – “Obviously, he’s my younger brother. I’m very...quite protective over him.”, and later on explained that if others said the wrong thing “you might, it might make him sad or angry.” The use of ‘you’ here appeared to indicate a need for Rian to protect his brother against my own potential thoughts and actions also. Lilly shared how active her role as protector would be in school, with her going “behind the scenes trying to see what I could do out, so it wouldn’t fall back on him” when there was an incident in school. Lilly shared the purpose was to “make his school life a little bit easier” and this involved protecting him from bullying. Like Rian, Cassandra emphasised the role of protector being one an older sister – “trust me, you have an older sister I look mildly scary to them they won’t bother you”. While PETs from Blue-Moon are not included within this GET, statements from elsewhere in her interview strike a contrast to the role of protector as older sibling, with a role of being *protected* as a younger sibling. Blue-Moon shared “[when] he left, because he got kicked out, it felt like my courage went down [...] I was the baby and he’s just being pulled away.”

Throughout her interview, Lilly also appeared in role as protector for others around her, for example her teachers – “it’s going to make things worse for them [teachers]. so I tried my best to, like, de-escalate”, other students in school – “and if he’s screaming...it’s disturbing the lessons as well, so I’m trying my best to calm him down” and her friends - “then try and not put my bad mood into conversation with my friends or something, and make them feel bad, because it’s not their fault”. The role of protector appeared to have become such an integral part of her identity, it shows up across multiple relationships.

In addition to protecting their brothers, the role of responsibility for their siblings also came through during the interviews. Lilly spoke of turning down social plans in order to make sure her brother was cared for. She explained – “I can’t, because I’ve got to take my brother home, and then I’m going to get there late, [...] I’ve got to make sure if he’s had a bad day, he’ll be okay at home.” Rian also reflected on being taken out of class and made responsible for supporting his brother – “Well, just sort of go over there and see what’s wrong and if there was anything I could do to help him, like console him” Rian shared this was “not fair” and it felt as if this role of responsibility was out of his control.

Being responsible for their siblings also appeared to extend into parentification and adultification. Cassandra shared – “it’s always going to be on the older sis-or the older sibling or like older sister to be the parenting figure”. She appeared to grapple with the idea of being an extra parent, rejecting the label earlier on, because she felt this role is one any sister should take – “I don’t’ want to say extra parent because I feel like I was doing what any sister should”. Her role as parent however appeared so embedded she referred to her other brother as “my youngest”, much like a mother may refer to her

children. Similarly, Lilly shared “I didn’t live a lot when I was younger” and this was because “I was kind of in that, like, motherly role already”. For Lilly this increased in intensity during exam time when she would worry about his exam performance and would need to make sure he “had eaten and everything. He was cared for” before engaging with her own learning. For Lilly, parentification felt unavoidable and natural, although it was difficult to understand how she coped looking back – “I don’t know how (laughs), but I was very mature about the situation [...] I kind of easily like adapted to his needs.” Lilly shared it was not until her brother left school that this role changed, and she could “start to be more of a teenager”.

A role as educator also showed up across participant interviews. Cassandra shared educating her brother in order to support him in being safe in school – “I explain to him the consequences of what will happen...you just need to be quiet and get through the day”. Similarly, Lilly shared providing an education to her brother about how to navigate social situations – “And I had to go up to him and kind of describe certain people and say, ‘look not everyone has a bad intention, and they do want to help’” and “okay this is how you deal with this situation. This is the best thing you can do without causing a massive problem”. Rian also appeared in role as educator, but more in the form of an advocate for his brother’s needs, even with myself as interviewer – “because he doesn’t really know how to show his emotions sometimes. So, he might just start...getting angry at people for no reason or doing stuff he doesn’t actually mean to do”. Whenever Rian shared difficulties he personally expressed in relation to his brother, he followed it up immediately with an explanation, as if attempting to advocate for his brother in conversation with me.

From Rian there seemed to be a sense of role confusion, potentially as the youngest participant interviewed. He often reflected on not knowing what to do – “I felt bad 'cause I didn't want him to do something he didn't want to do. But I also thought like, I was a bit confused”. Rian also appeared to grapple with his role when his brother had meltdowns:

Sometimes quite difficult because he'll have a meltdown, or he'll try run away or something...you know? Sometimes he'll want to go out and then we'll say no, and he'll try, go out anyways. And then it's just a bit difficult (very quiet).

For Rian, his role feels somewhat unclear and more enmeshed with the role the rest of his family plays, demonstrated by the use of ‘we’ within his speech.

5.3.1.3. Gender. The roles and aspects of identity explored throughout this GET also appeared to be influenced by gender. Parenting, protection, and being seen as holding a shared identity were more commonly experienced by older sisters. This was echoed by Rian when he spoke about the role taken up by his younger sister (the middle sibling): “I'd say it was more my sister that had to go and sort him out than me, I—they called on her more.” When asked what may have protected him from his brother’s needs impacting his school experience, Rian explained he didn’t think about it too much because “obviously I know my sister's there or was there to help him.” For Rian, knowing his sister took on a caring role in school appeared to free him from the weight of responsibility.

Lilly and Cassandra also shared similar experiences of their other brothers expecting them to take on the caring roles as young women. When Lilly asked for support with their autistic brother, her other brother responded, “that’s your job.” The

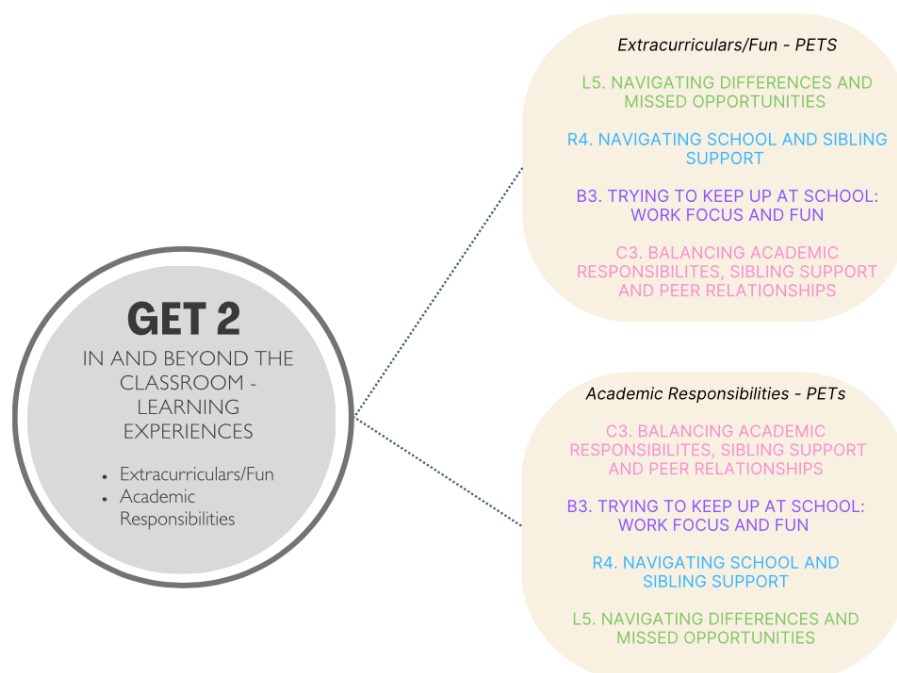
role of an older sister also appeared to be reinforced by teachers. Cassandra reflected on how the labels she received—such as being seen as the “good sibling” - were not applied to her other brother, even though “the youngest is a perfectly good like child, he doesn’t act out or anything, he just sits there in class and does work. I’m still labelled as the ‘good sibling.’” She also reflected that despite having another brother, “if anyone could calm him down, it would have been me.”

5.3.2. *GET 2: In and beyond the classroom – learning experiences*

This GET was reflected in the accounts of all four participants. As illustrated in Figure 14, this GET encompassed two subthemes: extracurricular activities and fun, and academic responsibilities. The individual subthemes within contributing PETs were split across the two GET subthemes – the specifics of which can be seen in Appendix L (Table L6).

Figure 14.

GET 2 – In and Beyond the Classroom – Learning Experiences



5.3.2.1. Extracurriculars activities and fun. When speaking about school-related extracurricular activities, participants shared a variety of experiences. Lilly reflected on the experience of missing out due to caregiving responsibilities related to her brother. She shared, “I didn’t really get the chance to join them [extracurricular activities] because obviously they were all after school, and my main focus was him [brother] getting home properly and safely.” This highlights a link between her roles as shared in GET 1 and the ripple effect across her school experience. This experience was shared somewhat by Cassandra, who reflected that she stopped an in-school cheerleading club due to providing in-school support for her brother. “I’d be in like I think it was a cheerleading club that I started and then he’d come in out of nowhere and be like ‘oh I need help with this.’” Cassandra shared it had been her teachers who had encouraged her brother to “seek [her] out,” and she remembered experiencing this as a “pressure to come together,” indicating that missing out was influenced by others around her rather than just an internal pressure. Similarly, Blue-Moon shared, “I wasn’t allowed to do any of the fun activities. I wasn’t allowed to use the climbing frames, play football, do dance, whatever it was going on out there.” For her, missing out on extracurricular activities was related to experiences where “school kind of sort of automatically started to assume the same sort of thing [behaviour that challenged them], like of me, like what as him I mean.” Through these assumptions, Blue-Moon missed out on fun throughout the school day, including her break times as well as lunch-based clubs. Blue-Moon also shared missing out on school trips was a common occurrence for her. She recalled watching her peers getting ready to leave school for the zoo: “She [a classmate] was like, ‘I got them [permission slips] last week, did you not get one?’ I was like, ‘no, they never got me one.’” Blue-Moon shared teachers assumed her parents would not be able to

attend the trip, and in order for her brother and her to go, parents would need to be in attendance to support their behaviour.

Cassandra also shared a sense that extracurricular activities after school could provide an escape and a break from her brother and from worrying about him. This was something she could choose to do once she was old enough to walk home from school alone.

“I’d take a few different clubs a week you know I’d like purposely loiter around outside of bus stops just with friends just like to make the journey home even a bit longer because once I made it through the front door it was all over again.”

When she was younger, Cassandra explained, “if an altercation happened with him, it’d be kind of like she [mum] had to pick him up early then wait around and then come get me rather than come get us both together.” She appeared worried about her mother’s experience here and instead took part in fewer clubs to avoid this inconvenience for her parents.

When reflecting on taking part in extracurricular activities with his brother, Rian shared being “confused” when his brother did not want to join in with sports day. Rian explained this “affected it [his experience] a bit.” For Rian, the effect on him was an emotional one, as he shared:

“...obviously I felt bad 'cause I didn't want him to do something he didn't want to do. But I also thought like, I was a bit confused 'cause I didn't really understand why he didn't, not why he didn't want to do it, but like why he didn't just do it.”

5.3.2.2. Academic responsibilities Participants discussed a range of academic experiences they felt were impacted by their brother's needs and teacher perceptions. One of the experiences shared was around missing out on education. Lilly recalled "being out of so many lessons, and then my grades were, like, really bad". For Lilly, this was related to being out of lessons for school-based counselling provided for her due to her asking for support while caring for her brother. Further to the experience of missing out on education, Blue-Moon shared following her brother's school exclusion and experiences of missing out due to assumptions about her own behaviour, she "learned absolutely nothing in Year 5 and not really that much in Year 6". She shared "I missed out on education, which then led to me in secondary school being behind everybody else". In contrast, Rian shared there are only "occasional disturbances", for him, but "sometimes I'd have to go and help him [brother]." Rian shared leaving lessons to support his brother was "not fair" but that "as long as nothing happens [with his brother]" school feels the same as his peers.

While in the classroom however, participants shared difficulties with focus and attention. Lilly's focus remained on her caregiving responsibilities and the guilt around not being able to fulfil them – "I'd be in class, and I'd feel, like... bad, and that I can't, first of all, be there to help him, and take away all the problems". Lilly also alluded to the difficulties with balancing their academic tasks with preoccupation around their brother's needs:

...it was difficult to try and do that and all the other stuff I was trying to do like reading the library when I knew that something's happened and I had to go check on him while I still could [...] before they took him into an office.

For Cassandra, her thoughts while trying to find a balance between supporting her brother and learning, appeared to race – “Do I work on this? Do I read my book? Or do I go to him?”. Her worries about how to balance her own learning, with supporting her brother influenced how fully she felt she could commit to her learning. This pressure seemed heightened in Year 6 when Cassandra was studying for her SATs exams. She explained she was “trying to be there for him while also trying to do my own thing so um...I’m terrible at maths so when I was in primary school I would try and do as much maths as possible”. It appeared that for Cassandra there was a dual pressure applied, one about her academic abilities and the other in regard to being there for her brother.

Similar experiences of struggling with focus were also shared by Blue-Moon, as she referred to her “mind going off the work” when she receives messages from home related to difficulties with her brother. For Blue-Moon this often resulted in her “worrying about the scenario going on at home or wherever he is”.

It makes me worried cause I don't concentrate or like I'll be in a zone where I'm wanting to work but then as soon as I get that message through, I'll be like, ah I wonder what's going on now.

There were also difficulties with completing homework and revision, due to their brothers’ needs. This seemed particularly prevalent around exam time. Lilly shared “during GCSE time, I struggled because I was thinking, like, erm I’ve got to navigate this, this and this [supporting her brother], and then I’ve got to also make sure that I’m getting all of this revision done”. Rian shared that homework may be affected by his brother as they share the same bedroom – “if just something's happening with him [brother] and I'm like...if he's with me, it might be a bit more difficult because we

share a room together, so it's...like sort of, he's there more". Rian explained this might have resulted in him doing his homework later than he'd have liked, but he guessed this "is the same as for everyone else".

Blue-Moon also expressed difficulties with completing her homework and coursework and shared this was because of conflict arising between her brother and parents. Blue-Moon felt this frustration would result in "he's [brother's] going to be in a mood too then that means my dad's going to be in a mood and I won't be able to ask him for help". This feeling of being on her own with homework was also experienced when she attempted to receive help from her mother:

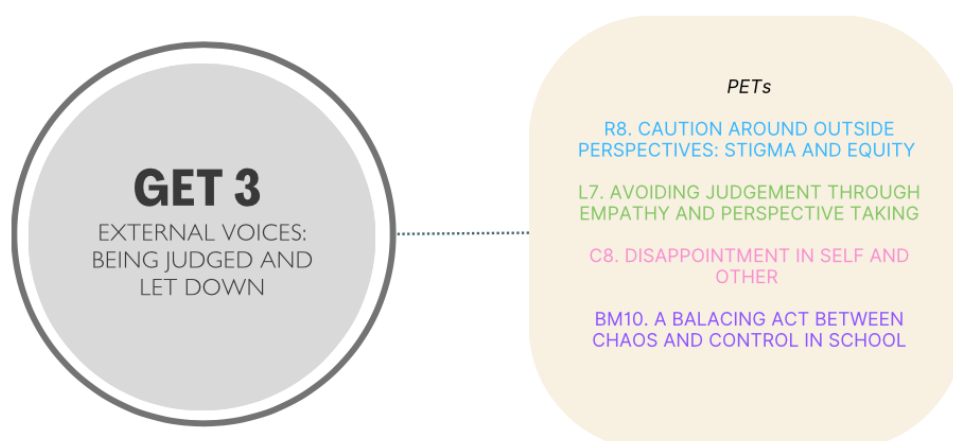
He'd [brother] appear out of thin air.... and he annoys her [mum] with a question and then she gets annoyed at me because, you know, I've then forgotten what she's explained to me, and she has to explain it all over again.

5.3.3. *GET 3: External voices: Being judged and let down*

This GET was reflected in one PET from each participant (Figure 15) This GET explores the experiences of judgement, actions taken to avoid judgement, and the emotional complexities around self-judgement and feelings of disappointment.

Figure 15.

GET 3 – External Voices: Being Judged and Let Down



Worries of being judged by others were reflected in the account from Rian, but his focus remained on the impact judgement might have on his family or brother, rather than himself. He shared, “I feel like they’re judging us for being like a bad family or something. I just don’t think it’s very fair that we should be judged for something that’s not in our control”. Rian also explained he wishes others would understand his brother because “I don’t want him to feel left out”. For Rian, the worry appears less related to how others may judge him, but the potential impact on his brother, illustrating an ingrained response to consider others before himself. Throughout participant interviews there also appeared to be an attempt to avoid any judgement from myself as interviewer. For example, when reflecting on how his school experience compared to peers without autistic siblings, Rian quickly stated that things were “similar to everyone else” and that he didn’t want “special treatment.” This was a pattern following a more emotive disclosure from Rian. A similar reflex to defend others or self in order to avoid interviewer judgement was also present for Lilly. When sharing her experiences with her parents, she shared that it was initially difficult for her to understand why her brother was receiving different treatment to her. Immediately after sharing things felt different with her parents, she said “I’ve noticed like the treatment I was getting which (higher pitch) is still like good, but like, and we’ve all got like a very healthy relationship with our parents”. Lilly appeared to stop herself sharing difficult feelings and instead shared a positive part of her relationship with her parents. Cassandra shared that others would “perceive [him] as quite a rude boy but i didn’t think he was rude I just thought there was something you know there that wasn’t there.....yeah”. Cassandra’s pauses and quick ends to sharing appeared to indicate a difficulty with sharing more difficult aspects of her

growing up with her brother – there appeared to be a worry around what I would think if she shared that he can be ‘rude’ or that she was sometimes frustrated.

Responses to judgement from teachers and peers varied across participants. For example, Lilly attempted to empathise and understand the perspectives of others, avoiding applying any judgement back regarding how she was treated. Lilly shared, “I don’t mind like some teachers asking [about her brother rather than her], obviously, because of how big (laughs) of a personality he was...but it kind of hurt sometimes”. Lilly also attempted to avoid judging peers who judged either her, or her brother “obviously, people who didn’t have erm siblings of Autism, they didn’t understand, which is fair enough”. For Lilly, any pain around not being understood was followed up with an understanding of the position of others. In contrast, Blue-Moon shared feelings of anger and frustration around teachers assuming she was the same as her brother. She explained that being left on her own during the day “obviously that then led to me on that day, creating chaos” and explained that “I made my headteacher’s life miserable on that day”. Blue-Moon articulated that she “misbehaved” because her teachers pre-judged her and that “it was their fault”. Blue-Moon’s anger and disappointment at the school-system was also echoed by Cassandra who expressed that her brother being “locked in a room led to a few disasters” and emphasised that “in my head I knew that could have been avoided if yeah someone had actually calmed him down”. She also explained that the pressure to be ‘his person’ could have been avoided and that “it [his person] could have been *any* of the teachers if they just wanted to”. The emphasis on “any” appeared to convey her feelings of disappointment at the school system and highlighted that both her and her brother were let down.

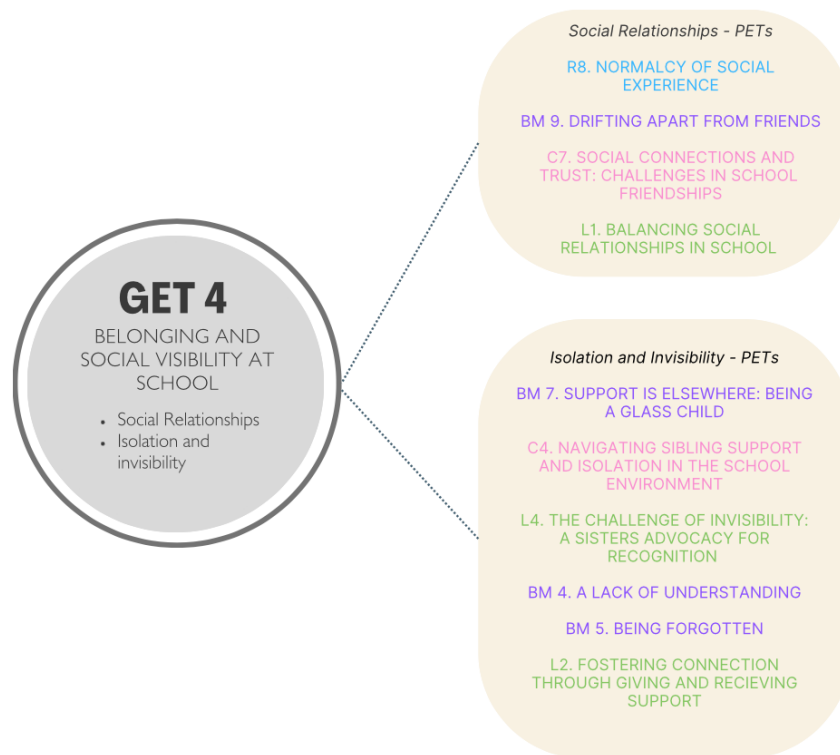
At times, for Cassandra, there appeared to be instances of judging herself and a sense that she had let her brother down through an earlier lack of understanding about his needs. When sharing arguments between herself and her brother, Cassandra explained “I didn't think I did anything wrong but you- there obviously something had happened for him to be able to understand that for him to be provoked”. Her use of “obviously” illustrated that for Cassandra, she felt that her brother’s needs should have been clear to her, and that she ‘should’ have been able to understand them. She often used “should” throughout her interview, explaining she ‘should’ have been able to calm him down, or prevent arguments between her brother and peers. Cassandra appeared to hold herself to high standards and judge herself if she felt she was unable to meet them.

5.3.4. GET 4: *Belonging and social visibility at school*

This GET explores participants' experiences of social relationships, including feelings of belonging, isolation, and invisibility, across two subthemes. The subthemes include six and four PETs respectively, with all participants contributing to the overall GET (see Figure 16).

Figure 16.

GET 4 – Belonging and Social Visibility at School



5.3.4.1. Social relationships Participants discussed the impact of their brothers' needs on their own friendships, extending across home and school. For example, Blue-Moon shared – “I tried bringing my girlfriend at the time over [home], but she said that she found it really uncomfortable here sort of thing because the way my brother was acting”. Blue-Moon also reflected that this was heightened due to feeling “embarrassed about some of the damage that was done in the house”. Lilly shared that she “missed out on a lot on friendship kind of things. I wouldn’t go out as much”, linking with her experience of being in role as a second parent as shared in GET 1. For Cassandra, this experience of missing out socially was described as putting her social life “on the backburner”, highlighting a feeling of her own social life being less important than supporting her brother. During adolescence when peers began to spend time together socially during school free periods, or during holidays, the contrast between being a young person with an autistic sibling, compared to those without, felt stark. Lilly shared that others “might have been stressed out, but they

didn't have loads of stress on them, and they were able to just go like, 'Oh, do you want to go out?'. Where her own social life had to be carefully considered, it felt that her friends could maintain a sense of spontaneity, something that made her jealous. In contrast, Rian shared that while his peers knew about his brother, there was not a negative impact on his social life. "When I was in primary school, people knew my brother [...] But I don't think it had any massive impact on it". For Rian, when he returned to class after supporting his brother, he felt that others' "didn't think much of it".

However, some participants highlighted that their brother's social interactions, affected their own friendships negatively, in addition to feelings of missing out. Cassandra reflected that she "realised that people can't always be trusted" following repeated experiences of others telling her about incidents related to her brother in an exaggerated manner. For Cassandra, she felt that this "breached her circle" of trust and that "picking which friends you can trust and which you can't while also trying to be there for your brother" was incredibly challenging. Friendships were also lost due to peers' perceptions of their brothers. For example, Lilly shared:

It was al-almost, like, kind of frustrating in the end because I'd lost so many friendships with certain people who many didn't want to speak to me or anything because of the way, like, the people he'd go for and all this kind of stuff (laughs)

This was also expressed by Cassandra who explained that when peers would see her brother outside the headteacher's office, they would laugh – "it was quite embarrassing for me because everyone was obviously judging me as well as him like 'oh that's your brother'". Lilly also shared that following attempts

to support and educate her brother, peers would “view me differently because it always looked as if I was defending him [...] this unintentionally worsened my relationship with a lot of people”.

At times frustration at peer responses resulted in conflict with peers. For example, with Cassandra shared, “I didn't want to like start shouting everyone because these are all my friends but at the same time i didn't want them to see him as like you know a nuisance because that's how they all perceived him”. At times, feeling that others did not understand them, or meet their own needs as siblings, also resulted in the breakdown of friendships – “I let it out on my friends around me. Which then leads to me losing friends, which isn't fun [...] Or hurting people who I don't want to hurt”. Blue-Moon also shared that when friends would ask for support with coursework she would “snap” at them because she hadn't been able to complete yet. She shared “I hate it, I hated it, but I'd yell at them sort of thing [...] I'm like, ‘no, I can't help you with it because I haven't done it yet’. Or I'd say it in a more snappier way”. For Blue-Moon it appeared that while her brother was not directly involved in this interaction, there were cascading social effects from not being able to complete her homework, as seen in GET 2. The impact on friendships was not a universal experience however, with Rian sharing that compared to peers without an autistic sibling, the social part of school “It doesn't really have too much of an effect on my social life”. For Rian this was partly because peers did not know about his brother as he was attending a different school.

Other school-based relationships discussed by participants were those with teachers. The quality of teacher relationships varied with Blue-Moon sharing, “[teachers] always try to make time for me” but often the amount of time they could provide for her was limited. Lilly also discussed disappointing experiences whereby

teachers would ask how her brother is, and neglect to ask about her, “I just think sometimes it’s a little frustrating, the fact that they can’t also ask me about myself or...not even have to ask me about myself, but just maybe just say hi (laughs)”. For Lilly, acknowledging these feelings felt difficult and uncomfortable, as indicated by her laugh as an attempt to lighten the load of acknowledging this pain. When outlining ‘good’ relationships with teachers, for Lilly these were related to those who could support her brother – “at-at secondary he had really good relationships with them [teachers], obviously because they looked after him and everything”. For Lilly, there is a conflict between what makes a good teacher, torn between one that supports her brother, and one that acknowledges her first and foremost.

5.3.4.2. Isolation and invisibility. Feelings of isolation and a lack of belonging in school were explored across participant accounts. Blue-Moon shared feeling like a “glass-child” – “you get seen straight through me through the glass and you just see my brother”. Even further to this, Blue-Moon shared that not only is she seen through, but that the glass also “reflects me off and it’s like, I’m not there. I get faded away” – highlighting a sense of being invisible, rather than just partially seen. Being seen through was also reflected by Lilly who shared she had to “chase for it [support in school]” and that “it wasn’t like they noticed it [she was struggling]”. For Lilly she felt as if she was “not seen as a person” and that “we [siblings] kind of get almost pushed to the side”. There was a sense that if school staff and peers looked closely enough, the feeling of being a glass child could have been avoided.

Being seen through and feeling invisible also extended to experiences for Blue-Moon where “...it seemed like my friends are ignoring me. [...] Whenever I’d say something, or it’d be like they wouldn’t acknowledge it” and where her parents focused more on her brother, leading to “being kind of swept under the rug”. For

Blue-Moon, it was shared that siblings “need some type of attention on them” and school would be the place to receive this attention. The juxtaposition between the hope and reality only heightened the feelings of being let down, explored in GET 3.

Isolation in school also came from experiences of not being believed and being the only one to truly understand their brothers. Blue-Moon shared her hypothesis that her teachers could not understand as “they haven’t ‘seen the damage or stuff that has happened [at home]”. There appeared to be a sense that although participants could empathise with why others may respond the way they did (see GET 3), the same empathy and understanding was not extended from others. Blue-Moon shared her teachers might “think that I was being lazy and kind of just wanting to slack off” if struggling during the school day. A sense of isolation was also communicated by comparing self to peers without autistic siblings. For Cassandra, she shared “they didn’t have to deal with everything that happened so they could just, I don’t know, do whatever they want” and that “they wouldn’t have to worry [...] they wouldn’t hear rumours”. To manage these feelings of isolation of experience, Cassandra responded by seeking out time on her own, leaning into the isolation as protection. She shared “I’d be like somewhere calm somewhere quiet somewhere like nothing can happen yeah so that’s where I’d spend all my time”.

Finding a community of people who truly understand what it is like to have an autistic sibling was important to combat feelings of isolation and loneliness. Lilly reflected on joining a support group in school for young carers.

That was the first time, probably two years ago now, that I found out that there were people like me, that had the same situation as me, kind of thing [...] and it was kind of a shock, but it also felt, like, really helpful, because I knew that I wasn’t alone.

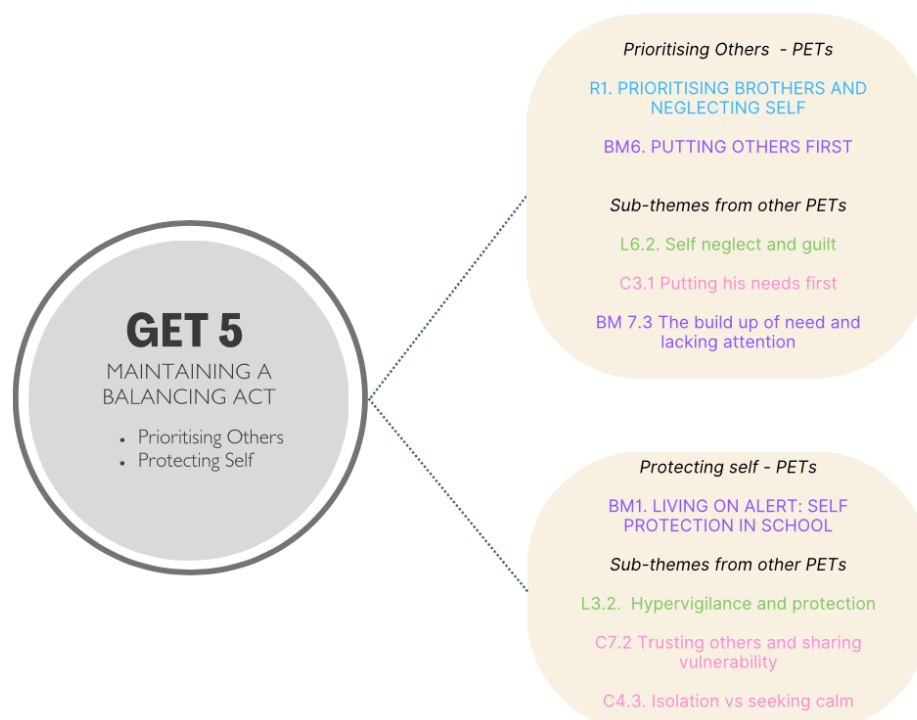
For Lilly, not only did this support her in feeling connected to others, but she also realised “maybe I do need to start putting myself first as well, which I still struggled with, but I feel like I was able to cope with more”.

5.3.5. GET 5: Maintaining a balancing act

This GET, reflected by all four participants to varying degrees, consisted of two subthemes: prioritising others and protecting self (see Figure 17). It included 3 PETs from Rian and Blue-Moon, with additional subthemes from Cassandra, Lilly, and Blue-Moon. This GET stands out as the only group theme with more subthemes than PETs, as the experience of balancing prioritising others and self-protection was woven throughout each interview in both speech and non-verbal cues. It was considered significant enough to be highlighted as a stand-alone GET to fully capture their stories.

Figure 17.

GET 5 – Maintaining a Balancing Act



5.3.5.1. Prioritising others This subtheme of the GET focuses on the experience of NTS neglecting their own needs in order to prioritise the experiences and emotions of their sibling, parents or others.

When speaking about her brother sitting with her and her friends at break times, Lilly shared “It was o...kay... like, I didn’t mind it, but I didn’t, like, love it”. Lilly went on to explain that although she “didn’t love it” she “felt guilty for fe-feeling like ‘I don’t really want you here’, so I never voiced it”. Despite break times being Lilly’s time to relax during the school day, she recognised her brother’s needs for connection and prioritised this over her own wishes for space. She explained:

It [sitting with her and her friends] meant that he could de-stress, and so he can go into his next lesson feeling okay. Erm, although it kind of put that stress on to me, it felt a lot better knowing that he was going to be okay.

Experiences of prioritising his brother’s social needs was also shared by Rian, who when asked what he wishes his peers would understand about having an autistic brother, he said “I’d hope that everyone could understand it because then I don’t want him to feel like left out or stuff like that”. For Rian it appeared his brother feeling supported and settled, was the main thing he could wish for, to feel comfortable and settled. The idea of balancing between meeting her own needs and being there for her brother was also echoed by Cassandra, who shared that the hardest part of being in the same school as her brother was “trying to be there for him while also trying to do my own thing”. Cassandra shared placing her brothers needs above her own and her label of “good sibling” that she had previously enjoyed by explaining how she would check on her brother throughout the school day – “then

I'd go over and check on him um I got in trouble quite a few times because I go and talk to him by the wall because you're not actually meant to speak when you're there". For Cassandra, her own discomfort, indicated also by a laugh, and role as a good student, was seen as less important to her than being there for her brother when he was isolated at break times.

The experience of putting others' needs ahead of their own, also expanded outside of their siblings. For example, Lilly shared prioritising her friends needs also.

[...] and I would ask my friends, like, 'Is it okay if he comes and sits with us?' And they were always understanding anyway, and they said, 'Yeah, it's completely fine', but I always made sure that they were okay with it, if not I was going to go sit somewhere differently with him, so he still had me.

Blue-Moon shared similar experiences of prioritising others – this time her parents. Despite sharing her own fear and worry about her brother's physical behaviours which she referred to as "scary" earlier in the interview, Blue-Moon's focus remained on her parent's safety. "Obviously I'm worried about him, hurting mum and dad, because, you know, I mean, they're getting older". Blue-Moon also voiced prioritising her parents over her learning from home during the COVID-19 pandemic. She explained a sense of vigilance towards her dad's needs during this time.

I'd have to kind of take my headphones out sort of thing, or put my headphones in, try to listen. But then I'd have to keep one out in case if I needed to go help my dad or something.

Considering the needs of others in a way that interrupted learning and revision was also shared by Cassandra. She explained that during the school day, she

would often have to leave her work in order to support her brother. Cassandra's use of the words 'had to' also signalled for her, placing her brother's needs above her own felt non-negotiable. Lilly explained a similar situation whereby her own revision schedule was dependent on her brother and her prioritising his needs.

Obviously, I'd deal with him, make sure he's eating and everything. He's cared for. Try and get him to revise. Wouldn't work. And then in the evening, I'd start revising, and then I'd end up staying up late revising. And then I'd get up early to put more revision in, and I was barely sleeping.

The experience of prioritising sibling needs also presented more subtly, presenting as difficulty in identifying their own needs. Participants often defaulted to explaining their siblings needs – a response that seemed automatic. For example, when asked what he may need from school staff, Rian said “what, what my brother needs?”. When this was followed up with clarification around what Rian may need he said, “I'm not really sure. Like...I'm more worried about if they understand him instead of me.” Lilly also reflected on the distress she would feel in relation to even considering her own needs, ahead of her brother's. She explained when she considered asking her brother to give her and her friends space at lunch time, “I kind of got that feeling in my stomach, like, and I felt, like I said, guilty about it, because I didn't want him to think that he's a burden or anything”. Lilly also shared that she felt school was ‘refreshing’ after her brother left, and that she could “walk freely in school” – she quickly voiced her guilt around sharing her own authentic experience “[that] kind of sounds not the best (laughs)”. In contrast to Lilly's feelings of guilt around her own needs being voiced or met, Blue-Moon shared the painful experience of having her

needs “build up” when others continue to prioritise her brother’s needs above her own.

I get seen straight through and they have to worry about him more sort of thing, which isn't fun. But then obviously my needs kind of start to get kind of built up and I can't really do anything about that.

For Blue-Moon, there appeared to be a learned neglect of her own needs as she voiced “I can’t really do anything about that [being seen through]”.

5.3.5.2. Protecting self. In contrast to the more conscious prioritisation of others’ needs, the young people also shared automatic fight-or-flight responses aimed at protecting themselves throughout the school day. These reactions persisted even after their siblings were no longer at school. Blue-Moon described avoiding being hurt at lunchtime by standing at the back of the queue: “I learned it’s better just to get a skip-the-queue pass.” She believed this was linked to her brother’s physical outbursts at home and her fear of being “crushed” during these altercations. Waiting at the back of the line was Blue-Moon’s form of self-protection.

I feel like you always got the pressure kind of pushing down on you. Cause then when I was standing at the back of the line, I felt like I had that pressure sort of thing taken off of me and I could relax sort of thing. I wouldn't have to worry.

Cassandra also shared ways she would protect herself socially in school at break times. She shared, “I didn't like going outside it wasn't...it didn't appeal to me because it was just too loud [...] I'd be like somewhere calm somewhere

quiet somewhere like nothing can happen yeah so that's where I'd spend all my time".

A sense of hypervigilance was also shared by Lilly who reflected on walking through school when her brother was no longer there. She shared feelings of anticipation and worry about if her brother was being laughed at, and what others would think of her.

[...] Because if there was another, like, erm kid of special needs that was having a meltdown, I kind of got that pit in my stomach, thinking, 'Oh, God, where is he?' And then I realised it's not him.

For Blue-Moon, the experience of being hypervigilant extended to worries she held about being restrained by staff in school at a time where assumptions were made that her behaviour was similar to her brother's.

I felt like...although people weren't actually hurting me, it felt like they were. It felt like as soon as they grabbed hold of me, like that's it, you're out sort of thing. So, I'd be trying to run away from them.

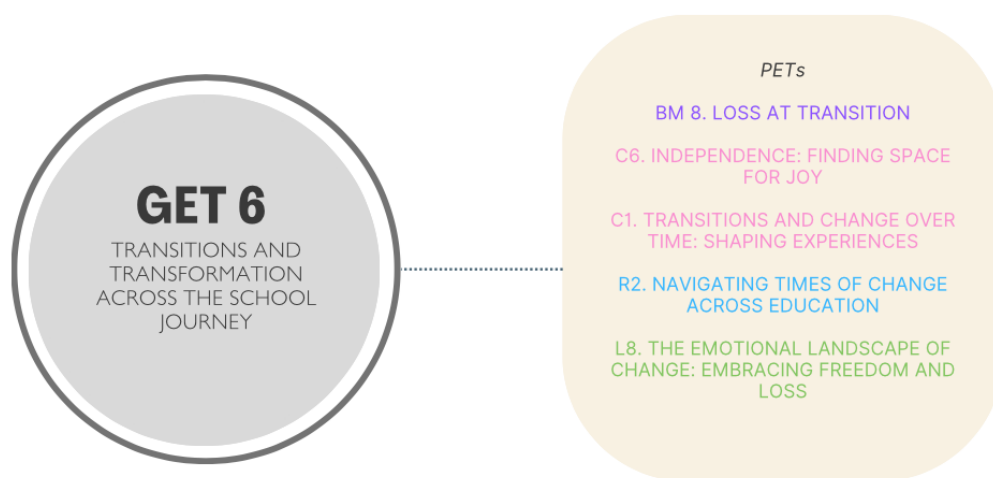
In addition to remaining alert to physical ways to keep themselves safe, such as running away, Cassandra shared a sense of hypervigilance within friendships and reflected on measures she had taken to protect herself in friendships moving forward. Cassandra said she "realised people can't always be trusted" and that it is important to "listen with caution" to those outside of the "one person" she can truly rely on.

5.3.6. GET 6: Transitions and transformations across the school journey

This GET captures the experiences shared by participants in regard to transitioning away from their siblings at school and highlights the transient nature of experiences in school over time. The overall GET comprises of 5 PETs from across all participant accounts (see Figure 18).

Figure 18

GET 6 – Transitions and Transformations Across the School Journey



When discussing a transition away from their sibling at school, for example when moving to a new school, complex and conflicting emotions were shared. Cassandra shared while “most people’s anxiety would be like starting a new school [...] mine was leaving”. She shared this was due to worries her brother would need her and “I wouldn’t be there to help out and it would just...blow up worse”. For Cassandra there appeared to be a worry that her role and identity as protector, educator and advocate for her brother (see GET 1) would be needed, but she would not be there to fulfil it. In contrast Cassandra appeared to grapple with feelings of freedom but also guilt when she moved to a new school, sharing “I’ve had fu- quite a lot of fun”, appearing to monitor through her self-correction, how much fun she may be ‘allowed’ to have.

Feelings of preoccupation with whether their siblings' needs could be met without them was also shared by Rian – “I was thinking I wouldn't be there if he did need me or something [...] if something happened to me-him, I was a bit worried that if I wasn't there, something bad could go wrong”. This worry when transitioning away from their brother's appeared related to a deeper feeling no one else could meet their siblings needs as they could.

There were also feelings of sadness around the loss of role as protector and carer, along with a query around who they would be without their brothers. For example, Lilly shared, “it was really hard to come to terms with for a while [...] I literally was very confused, and I felt kind of lost almost, because it was just all I knew, and it was *gone*”. The sense of loss also extended towards a feeling of abandonment, with Blue-Moon sharing “it felt like there was a piece missing from me. Because obviously he wasn't there anymore”. She shared if this transition apart had been expected and planned for, it might have felt easier. However, because he was excluded suddenly, she shared feeling like an animal losing its parent, of being vulnerable and exposed – “I was the kind of, I was like the baby sort of thing, and then I was like, yeah, and he's just being pulled away sort of thing”. Blue-Moon also appeared to be contemplating a duality of this experience and one where her brother may also be the one feeling vulnerable without her, “I- It felt like, in a way, you know when an animal gets its baby taken away from it sort of thing, that's what it felt like”.

Being without their sibling in school was also described as a transition that needed time to adjust to. With role being wrapped up in supporting their sibling for much of their educational lives, the difference felt challenging to navigate. For example, Lilly shared:

I can just walk freely in school without having to erm deal with...something, or I'm not getting pulled out of lesson for something, I'm able to be in all my lessons willingly, I'm able to, like, get on with what I want to do, I can kind of start to be more of a teenager now.

A sense of being uncertain was also shared by Rian, although for him it was related to being away from both of his siblings – “it was a bit weird not having my brother or sister in my school, but I got used to it, I suppose, after time”.

Changes over time were also described by Lilly as changes to her personality when discovering her new role and place socially, a difference that was visible to others – “I think it's a massive shock to everyone, and everyone's just, like, 'oh my God, I never would expect this [being more confident socially]!'”. Lilly also reflected not being able to “deal with” all of the free time because “she was so used to being occupied with something”. For her, finding a new role felt paramount to her sense of belonging. Having more free time was also shared by Cassandra although she highlighted, “I still get the occasional message like say something's happened at his school like I'll talk to you later by my mum or something”. Cassandra shared this can still cause distraction during her lessons even though she's not “a constant presence in his school life”.

Participants reflected on how their school experiences changed over time, particularly during transitions between year groups or in response to academic pressures. Exam periods often intensified difficulties, both due to their own stress and that of their autistic siblings. Rian explained, “if he [brother] gets more stressed out like if he's got exams or something, then it will make me more stressed out” and “if there's something stressful going on for him, then it will affect me.” Similarly, Cassandra found Year 6 challenging as she tried to balance preparing for SATs

while supporting her brother, saying she would “pick up where I can but then also, I had SATS to practice for.” Lilly described her own struggles in primary school, feeling jealous when teachers would “take him completely out of class, and you’d see out the window that he was in the playground playing with all the toys.” Yet she also reflected that primary school was “a lot easier” because she was “too young to fully get it” but also likely because she was too young to be placed in the same caregiving role as she was at secondary school.

In contrast, Cassandra shared secondary school feeling easier to navigate, due to increasing independence. When Cassandra was able to, she shared leaving home earlier “so I can meet up with my mates because I wanted to go to school by myself”. For her, this contrasted with the frustration of needing to wait with her mum to collect her brother and juggle both siblings together. During adolescence, Cassandra was able to explore greater levels of independence which helped her to feel more in control and settled – “I’d like purposely loiter around outside of bus stops just with friends just like to make the journey home even a bit longer”.

There was also an exploration of what a change or transformation would look like at school if they had never experienced school with their sibling. This was hypothesised to hold both positive and negatives. For example, Cassandra shared “I would have more of a like a life in that school I wouldn’t have to worry about people”. For Cassandra there was an alternative world where she would be able to concentrate on both her learning and her social life. This experience was slightly different for Blue-Moon who shared feeling her “courage went down” without her brother in school. She hypothesised that without her brother at all:

It might have been easier but then sometimes slightly harder [...] I wouldn't have so many like stones in my bag. It would feel like I only had maybe two instead of 170 or something like that weighing me down.

5.4. Chapter Summary

The GETs illustrated within this chapter highlight the complex and varied nature of the school experiences of adolescents with autistic siblings. The young people involved in the research shared a multitude of experiences, from missing out on social experiences and academic learning to the conflicting experiences during times of transition. In addition to this, the young people grappled with aspects of role, identity and personal construct, exploring who they are, both with and beyond their sibling relationships, and did so in the context of external viewpoints and pressures of the school system. These findings will be discussed in depth in the following chapter, with reference to the wider literature, theoretical frameworks and implications for practice.

6. Discussion

6.1. Chapter Overview

This chapter reflects on the school experiences of adolescents with an autistic sibling in the context of both the existing literature, and relevant psychological theories (SRM, SESF and Attachment Theory). To do this, this chapter will provide insights related to the GETs shared within the previous chapter and in keeping with IPA, will focus on wider implications of individual experiences, rather than making broad generalisations based on the data (Smith et al., 2022). This chapter will also highlight limitations, areas for future research, a dissemination strategy and personal reflections as the researcher. Finally, this chapter will conclude with school-based recommendations from the voices of the individual participants.

6.2. Commentary on Findings

A commentary of findings will proceed which seeks to answer the research question – ‘what are the school experiences of CYP with an autistic sibling?’. This commentary will do so by exploring each GET in the order they were introduced in Chapter 5. A focus within this commentary will remain on what this research adds to the field, and what sense can continue to be made of the information provided by each participant. Although the focus here will be on both convergence and divergence of participant accounts, it is recognised that each individual participant has shared their unique experiences, and this nuance is not to be lost or overlooked.

6.2.1. *Playing a part and being in role*

Particularly for the young women interviewed as part of this research, the idea of a sense of self enmeshed with that of their sibling, was something explored at length.

This was experienced as both an internal grappling with identity illustrated by the switching of pronouns when talking about self and sibling, and an external view of being '*in the same boat*' and being '*seen as his sister*'. The idea of being 'one' with their autistic siblings is something that has not been explored explicitly within the literature thus far, especially in relation to teacher perceptions in school. In terms of the wider sibling literature in this area, Buhrmester and Furman (1990) suggested that typical sibling relationships tend to decrease in intensity with age and become more egalitarian, particularly beyond early adolescence. However, as illustrated, the participants within this research displayed a contrasting pattern where sibling relationships remained enmeshed and unequal over time. Older siblings frequently assumed caregiving roles regardless of their age or age order, indicating a divergence from normative sibling developmental trajectories. This ongoing enmeshment and responsibility challenge typical expectations of sibling roles relaxing during adolescence, underscoring the unique impact of having an autistic sibling on sibling relationship dynamics.

The hurt and frustration experienced by NTS when sharing being viewed as one with their sibling can be framed within the SRM of Disability (Connors & Stalker, 2007) and related to ideas of disability by association (Burke, 2010). It is important to note here that NTS are not being seen as disabled, but as experiencing some barriers to being based on an association with their sibling. These 'barriers to being' are illustrated here as the behaviours of others which affect their own emotional experience and self-esteem. This can be extended further when thinking about how the NTS enacted being 'one' throughout the interviews, through the switching pronouns, and repeated attempts to share their siblings' experiences, rather than their own. This is being understood through the lens of psychosocial disablism – an

experience where people are left feeling psychologically and emotionally undermined by the behaviours and comments of others (Reeve, 2019). For example, where Lilly shared teachers asking how her brother was rather than asking about her, or where Blue-Moon shared that teachers expressed she may do the same things as her brother and so excluded her from activities. This psychosocial disablism also appeared to present as internalised oppression for the female participants. It appeared through repeated exposure in school to being viewed as one person, this narrative was internalised, affecting their own identity and resulting in confusion when without their siblings.

Further to an exploration of identity, the experience of explicit labels was raised by Cassandra. Particular labels used were ‘the good sibling’ and the ‘angel of the family’. Although not explored in research related to siblings of autistic children, research with siblings of children with disability highlighted being seen as the ‘shining stars’ of the family (Pavlopoulou & Dimitriou, 2020). This previous research explored these roles as they presented within the home environment while the current research explored how these presented in school also. This can be explored in relation to concepts from personal construct psychology (Kelly, 1991) which posits individuals interpret their experiences through frameworks shaped by past experiences and relationships. In this case, the idea of being the perfect child at home, appeared to present in the ‘perfect’ student in school. Important to note here is this was not the case for all participants due to the varying other systems and frameworks the young person was embedded within, as in the SESF. For Blue-Moon for example, an experience of being a ‘glass child’ (see GET 4), was present across home and school and this resulted an increase in externalising behaviours which are explored later within this chapter.

When reflecting on the roles taken up in school, participants shared being protectors, extra parents, advocates, and shared the additional responsibilities they shouldered for their siblings. This was also highlighted in the literature where family members labelled NTS as 'protectors', 'bodyguards' and 'mother hens' (Cridland et al., 2016). In contrast to the previous research (Cridland et al., 2016) it appears these labels transcend system boundaries and are present across contexts, rather than being solely located in one system. Being a protector appeared to be part of the NTS identity such that they had been internalised and showed up within other relationships, not just with their autistic siblings. This is something also illustrated by Nuttall et al. (2018) and Tsai et al. (2018) where NTS attempted to protect their parents from the potential stresses of caring for their autistic sibling. CYP in this research shared protecting their peers' learning experiences, protecting their teachers from blame and shielding their friends from their 'bad moods'.

While previous research shared some of the emotional experiences of taking on these roles (Cridland et al., 2016), this research highlights the emotional pressure of taking on the role of protector and responsibility in school, and how looking back, this felt like a loss of childhood. A loss of childhood and parentification was raised explicitly by Lilly and Cassandra who highlighted feeling like an additional parent and more mature than their age, and more implicitly by others through the sharing of being protective and advocating for their sibling needs. Childhood parentification has been linked with the concept of 'compulsive caretaking' which often encompasses a belief that one knows what is best for someone else and attempts to control social interactions as a protective mechanism (Nuttall et al., 2018; Hennon., 2013). Compulsive caretaking presented for Cassandra for example when she explored feeling frustrated that teachers would not allow her to support her brother, despite

her feelings that she knew what he needed the best. This highlights a complex emotional experience whereby being asked to support an autistic sibling can result in a combination of resentment and exhaustion, but these feelings can also be present if not allowed to help.

While the roles of protector and advocate, for example, were highlighted within the previous literature (Cridland et al., 2016; Pavlopoulou et al., 2022), what is evident within this research is the active nature of taking up these roles, even within the interview itself. For example, after explaining difficult experiences with their siblings, participants followed up with explanations, rationalisation, and empathy for their sibling. The role of protector taken up by Cassandra, Rian and Lilly contradicts previous research into the roles taken up by TD siblings whereby ‘protection’ was typically a role taken by older brothers of sisters (Davies, 2019). For the participants in this research, having an autistic sibling appeared to negate this typical dynamic, with females taking this role also. What is common across this previous literature and the current research, however, is the experience of protection being a role taken up by older siblings primarily. This may explain why for Blue-Moon, she felt her courage drop in the absence of her brother. Despite the level of support her brother needed when he was in school, he still provided a level of protection as an older sibling.

It is important to recognise that some protective and guiding roles are common to all siblings, including TD dyads. As Kramer and Conger (2009) observed, older siblings often teach younger siblings how to socialise, while younger siblings introduce new interests and perspectives. Similarly, Kluger et al. (2006) highlight that siblings shape one another’s identity and social learning in powerful ways. However, what distinguishes the experiences described by participants in this study is

the intensity, constancy, and systemic expectation of these roles. Rather than being occasional or reciprocal, these responsibilities became central to their identity, maintained by social attitudes and institutional dynamics, and rarely balanced by opportunities for their own needs to be prioritised.

The roles of responsibility and experiences of parentification for NTS can be understood within the Siblings Embedded Systems Framework (SESF) (see Figure 1). This framework highlights that it is not simply the event of having an autistic sibling that impacts NTS, but rather the ongoing feedback and interactions across multiple systems. In the school setting, NTS often find themselves advocating for their sibling and educating both peers and teachers about their sibling's needs. In doing so, they are frequently placed in the position of navigating ableist views of Autism within their school and wider society, often without external support. This relates to the idea that any disability by association is maintained by outside perspectives, rather than inherent to the individual sibling (Connors & Stalker, 2007). For many NTS, the repeated experience of being left alone in the role of supporting their sibling may lead them to internalise this as their personal responsibility. Within the SESF, this dynamic then feeds back into the system, reinforcing expectations that NTS should continue in this role across different contexts.

In further considering how wider societal perspectives may have influenced the roles and experiences of NTS, consideration will now be given to the role of gender. Although previous quantitative research from Mates (1990) suggested no significant difference between males and females in relation to their psychological adjustment and academic performance, this research illustrates a different picture. Within this research, Lilly and Cassandra shared caring for their brother in school was their responsibility, despite having other brothers, and school-based staff who could have

stepped in to provide support. Rian also shared staff called on his younger sister to support their autistic brother, rather than him, reinforcing a gender-based pattern in caregiving at school. This was not highlighted by Blue-Moon who was the only younger sibling within the research and so it may be that the intersection between being female, and being an older sibling, increases the vulnerability to taking on these roles (Cleveland & Miller, 1977). Women being more likely to take on caregiving responsibilities is also highlighted within a review that illustrated adult sisters of disabled siblings are more likely to co-reside later in life (Davys et al., 2011). It is likely social norms around gender and caregiving influences the roles taken up in schools, by the adolescents within this research. An unconscious and often internalised bias from teaching staff may be resulting in teachers seeking out female sibling support with autistic CYP, rather than support from brothers. This may also be reinforced at home based on familial beliefs about caregiving, roles, and expectations (SESF), and then may feed back into the behaviours of sisters themselves in school – for example actively mediating between peers, isolating themselves from friends, and being positioned as an expert about their siblings needs (Herman, 2013).

General attempts to interpret their individual roles and sense of identity emerged across all interviews, despite this not being an explicit focus of the questions. This preoccupation with identity and role within school is likely influenced by the participants' developmental stage. According to Erikson (1968), CYP between the ages of 12–18 are in the fifth stage of psychosocial development: identity versus role confusion. At this stage, CYP are actively exploring their sense of self and how they fit among peers and in wider society. Applying this perspective to the current research may explain Rian's greater uncertainty, as the youngest participant in the

study. At his age, he has had less opportunity to explore his identity outside of his family, which may have contributed to his difficulty in articulating his own experiences. In contrast, the older participants (aged 16+) appeared more consciously aware of their enmeshment with their autistic siblings. While some degree of role confusion remained, their reflections suggested this had become more integrated into their sense of self, rather than being experienced solely as a source of uncertainty.

6.2.2. *In and beyond the classroom – learning experiences*

Previous, quantitative research in the area demonstrated NTS of autistic children were spending less time engaged in extracurricular activities, however due to the methodology utilised, did not explore the reasons why or the lived experiences of siblings (Barak-Levy et al., 2010; Herman, 2013). Within this research, similar themes were illustrated, and this time with an explanation in the words of the CYP. For Lilly, ‘barriers to doing’ (Connors & Stalker, 2007) (as per the SRM) presented as getting her brother home from school safely, and for Cassandra, these barriers enforced externally were in the form of a pressure from teachers for her brother to seek her out while in cheerleading club. The barriers to doing illustrated by Blue-Moon highlight increasingly overt discrimination from school staff, and the concept of disability by association for NTS was clear when she was not asked to attend a school trip. Blue-Moon was seen as ‘one’ with her brother to the point where she was ‘*not allowed*’ to take part in some activities and may have experienced being ‘treated as a lower-class citizen’ much like the young person who shared in research from Herman (2013). For Rian, rather than barriers to doing, he appeared to experience barriers to being – the more emotive experience as outlined by the SRM. For example, although Rian did not recall attending less clubs, he shared the experience

of worrying about his brother during sports day. The divergence of accounts is likely due to a multitude of differing variables, include the intersection of age, gender, previous lived experiences in school and at home, and the combination of how these intersecting experiences/parts of identity are likely to have influenced their interpretations.

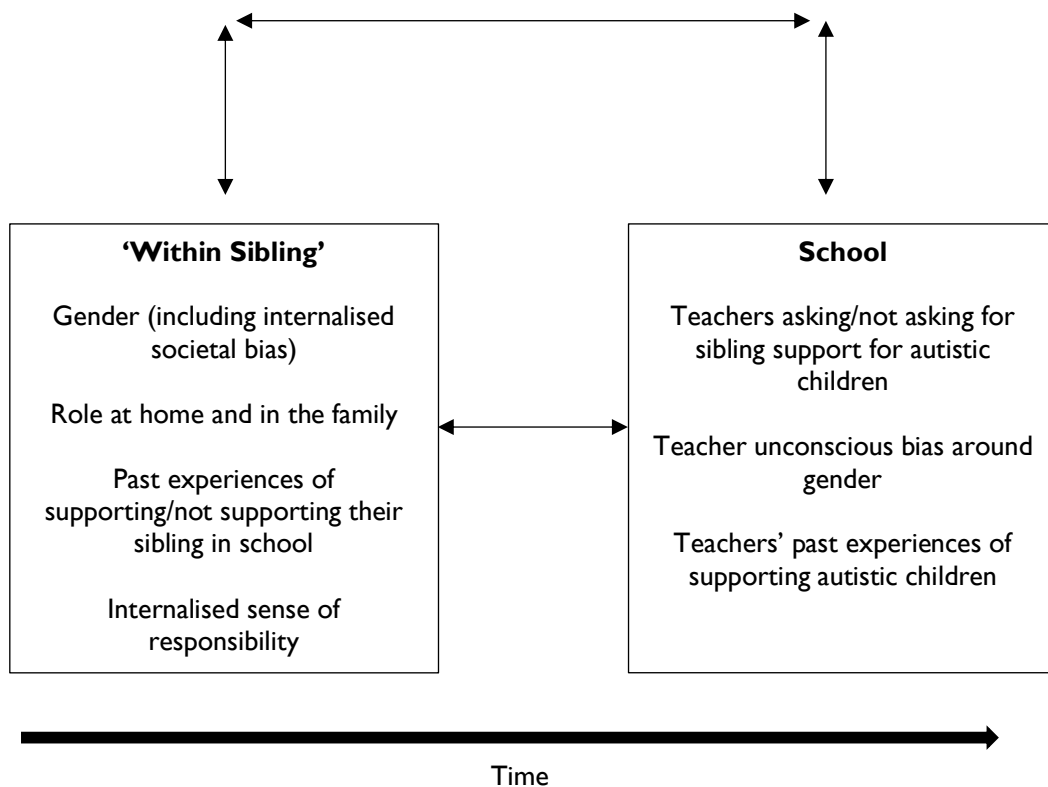
Within previous qualitative literature (Pavlopoulou et al., 2022), only one participant shared feeling there were barriers to accessing extracurriculars as related to their sibling. The participant sample was younger than that of the current research, and it may be that with adolescence and a greater importance on peer relationships (Dumontheil, 2016), comparisons become more common, and differences become more evident to the young people themselves.

In relation to the school day and academic experiences in general, participants shared the sentiment that their school days could be quickly influenced by those of their siblings, much like research from Herman (2013) and Pavlopoulou et al. (2022). Participants in the current research also shared experiences of being asked to leave lessons to support their siblings but also reflected a level of preoccupation in their lessons even if this was not the case. Participants may have been highlighting an internalised sense of responsibility, whereby their roles of compulsive caretaking surfaced again. Previous experiences of being asked to support their autistic siblings may also play a role here. If teachers previously asked NTS to support their siblings, and leave lessons to do so, over time this experience would feedback into the system (SESF) and likely become part of an internalised role for NTS. This appeared to create both internally and externally reinforced 'barriers to doing' – being asked to leave lessons by teachers and struggling to

concentrate when in lessons. Figure 19 shows an expanded subsection of the SESF and has been created to illustrate this 'loop' within a part of the wider framework.

Figure 19

An expanded section of the SESF.



Note. This expanded section of the SESF illustrates the interaction between 'within sibling' factors and the school system feedback as part of the wider 'microsystem'.

Arrows are reciprocal to illustrate the bi-directional flow between different parts of the system.

A potential loop through Figure 19 may be that teachers in schools are not relying on internal school-based systems for supporting autistic CYP. They may have also had past experiences of the support they provided feeling not good enough, or ineffective, for example. This may then result in them asking for sibling support, which may lead to a feeling of internalised responsibility *over time* for NTS. This will

likely be interpreted differently by individual CYP based on 'within' child factors such as gender, their roles at home and in the family, and their past experiences of supporting their siblings in school.

Regarding academic outcomes, previous literature has highlighted academic difficulties in NTS of autistic children (Barak-Levy et al., 2010; Herman, 2013) and that this may be related to symptoms of inattention and related to subclinical presentations of autistic symptoms in NTS (Chien et al., 2017; Ben-Yizhak et al., 2011). Although quantitative measures of academic outcomes were not explored within the current research, Lilly and Cassandra shared anecdotal information about struggling with certain subjects, and shared their grades were "really bad". This feeling of struggling with learning may also be related to the idea of low academic self concept (Gregory, 2020). Particular pressure points over their time in education were also pointed out by all of the young women, for example during Year 6 SATS and GCSEs in secondary school. It might be that during times of increased academic pressure, the participants' own needs required more attention and focus and this influenced their levels of guilt and confusion around their roles.

Lower academic self confidence, difficulties with focus and struggling in lessons may also be related to the experiences of interrupted homework and studying at home. For Blue-Moon and Rian, this looked like less or interrupted parental support for homework and coursework similar to that reported by Herman (2013) and Pavlopoulou et al. (2022), and for Lilly was experienced as putting her brothers revision schedule above her own. Rian shared a slightly alternative perspective as although his homework was interrupted, he felt it did not impact him and his grades in the longer term. This difference from the other participants may be related to his age and the fact he has not yet started revising for his GCSEs.

6.2.3. External voices: *Being judged and let down*

Participants shared their experiences of wanting to avoid judgement from peers and teachers, mirroring the experiences of hoping to avoid judgement within the wider community (Hwang, 2009; Keirse, 2016; Mascha & Boucher, 2006; Tsai et al., 2018). Rian also shared hoping others in school would understand his brother, but rather than this being around his own emotional experience (Petalas et al., 2012), his concern was for his brother's wellbeing and sense of being included. Potentially as a way to reject the notion of disability by association, Rian also voiced not wanting any "special treatment" himself. This may have also impacted how defensive he felt within the interview. Participating in this research may, in itself, have constituted as "special treatment" and may explain some of his quick and short answers around everything feeling 'fine'. Similar requests for understanding autistic siblings needs before their own, was also highlighted by younger children (Pavlopoulou et al., 2022) who felt teachers understanding and empathy would also help themselves as NTS to navigate the school environment. This is an experience which appears to extend past the primary school years and into adolescence.

Participants also showed increased levels of empathy and reduced levels of judgement towards others, even if that experience was not interpreted as reciprocal (Cridland et al., 2016; Herman, 2013). Within this research, this appeared to extend a step further with participants appearing to explicitly empathise with others (parents, teachers, and peers) as if they did not want themselves or others to be judged by myself as interviewer. For example, after sharing differing treatment from her parents towards herself and her brother, Lilly quickly reassured me that her treatment and parenting was "still very good". Similarly, when Cassandra shared some of her brother's challenging behaviour, she followed it up with an explanation of why he

may react in that way. Blue-Moon also shared teachers were busy, and this may be why they could not provide her with the attention she needed. This role of empathising with others appeared to be automatic and could be seen as a real strength for CYP with autistic siblings. It must also be considered however, how this could lead to 'compassion/empathy fatigue' (Maslach et al., 1997), particularly in relation to oneself. The idea of empathy fatigue may be seen for Cassandra for example, and the language she uses to explain her experience in school when supporting her brother. She regularly expressed she 'should' understand her brother and be able to help him, and that his needs were 'obvious'. Here, she is able to express empathy for her brother and has previously explained why teachers may not understand his needs but does not extend this compassion to herself as this may be a role less practiced for her. Despite empathising and compassion for school staff and peers, participants shared feelings of being let down by the school system. For example, Blue-Moon shared feelings of anger at staff assumptions and how this impacted her own behaviour, while Cassandra shared the experience of knowing her brother was locked in a room without support.

6.2.4. *Belonging and social visibility at school*

An exploration of friendships featured throughout all participants within this research, despite it never being an explicit topic within the semi-structured interview schedule. This is likely because during adolescence, friendships become increasingly important, with this stage of life characterised by an increase in peer influence (Youniss & Haynie, 1992). Friendships during adolescence are critical for understanding and exploring one's own thoughts and feelings and this became evident as participants reflected on their friendships, peer responses to them, and

interpreted their own roles in relation to how peers saw them (Youniss & Haynie, 1992).

Similarly to previous literature (Pavlopoulou et al., 2022), there was a mixed picture in terms of missing out on social experiences and feeling isolated from friends. Participants in the current study shared feeling their social life was on the “back burner” and that bringing friends and/or partners home from school was a challenge due to fear around their siblings’ behaviour, similar to research from Stampoltzis et al. (2014). At the same time, Rian shared feeling like the impact on his friendships was minimal. It appears this mixed picture in terms of social experiences persists from childhood (Pavlopoulou et al., 2022), and into late adolescence. For those in the current research who shared challenges within their social lives, their isolation appeared to be related to disability by association (Burke, 2010).

Particularly for the young women interviewed here, there was a fear around being judged, viewed differently and an explicit sharing of how others would view them differently because of their brother’s behaviour. Within Herman (2013)’s research, NTS showed signs of heightened self-reliance, and this is understandable when participants are experiencing judgement and isolation. Within this research, self-reliance was explored in more depth, with Cassandra sharing her view that trust could easily be broken and that “one friend is enough”.

As mentioned, this pattern of self-reliance and loss within friendships was not experienced across all participants, namely not experienced by Rian with the same intensity. This difference is being thought about in relation to gender differences within friendships that have been explored during adolescence. It has been highlighted that during adolescence, girls tend to spend more time in unstructured social situations, whereas boys spend more time in structured social activities (e.g.,

clubs) (Youniss & Haynie, 1992). It may be that attendance at structured activities for boys is easier to maintain than more casual social interactions experienced by adolescent girls. The latter have also been said to experience more peer pressure socially so be more aware of the difference between themselves and peers (Youniss & Haynie, 1992). I acknowledge this takes a somewhat binary view of gender and it is much more nuanced than this. However, differences based on these binary societal expectations may form a basis for the differences in CYP experiences within this research and so it is pertinent to explore it. Further to an exploration of gender and friendships for NTS, male friendships are said to be characterised by less self-disclosure during adolescence (Youniss & Haynie, 1992). This may be why for Rian, he may feel less worried when returning to class after supporting his brother – he shared many of his peers did not know much about his brother and therefore experiences of disability by association may be less prevalent.

Regarding feelings of belonging, and in contrast, isolation, participants spoke of being seen through and the idea of being “a glass child”. This concept was eloquently explained by Blue-Moon who shared “you get seen straight through [...] you just see my brother [...] it’s like I’m not there.” The experience of being a glass child is also explored in research where siblings spoke of self-censoring their own needs in order to make life easier for their parents (Hanvey et al., 2022). The current research suggests the feeling of being seen through spans across contexts and can be experienced in relation to parents, and teachers in school. Previously Kovshoff et al. (2017) shared that the interplay between home and school as illustrated in the SESF was an area where research was lacking – this lived experience of being seen through across contexts begins to explore this gap in the literature. The overlap of experiences is being understood here by exploring the idea of an ‘internal working

model' of relationships (Bowlby, 1969). For siblings of autistic children, their early experiences of being perceived through the lens of their sibling - often feeling unseen or treated as "glass children"- may have shaped their expectations of relationships beyond the home. This pattern of relating appears to be mapped onto other interactions, such as those with teachers, reinforcing an expectation that their individual needs and identities will be overlooked. These internalised constructs of relationships are influenced by both home and school environments, shaping how siblings interpret social interactions more broadly. Notably, the extent to which this pattern develops may be influenced by factors such as sibling age gaps. For example, in Rian's case, the impact appears to be less pronounced, possibly because the wider age difference meant by the time his autistic sibling was born, his internal working model of attachments had already been established.

6.2.5. *Maintaining a balancing act*

This group theme highlighted multiple layers of balance that NTS expressed, experienced, and were attempting to navigate at school. One key area of balance was between conflicting constructs - participants' own individual needs and desires, and the needs of their autistic siblings. For participants, this looked like prioritising siblings' revision schedules over their own, supporting their sibling in social interactions, and missing out on their own regulating breaks during the school day to provide their brother with support. Any thoughts around meeting their own needs instead were characterised by feelings of guilt and discomfort and were often then ignored or avoided.

Experiences of guilt around increasing personal independence is something characteristic of young carers (Chikhradze et al., 2017) and appears to also be experienced when attempting to get an education - aside from engaging in more

typically 'fun' activities. Much like young carers supporting their parents (Chikhradze et al., 2017), self-neglect of needs in order to meet the needs of others also showed up for siblings, and in this case, within multiple school-based relationships. This suggests previous research around self-neglect in NTS at home (Papacek, 2012) extends to school also. It remains unclear whether this prioritisation of others' needs would persist if siblings had never attended the same school, and further research is needed to explore this fully.

In relation to prioritising their siblings' needs over their own, there appeared to be a level of automaticity in this position. During interviews, participants often required regular reminders to share their own experiences, thoughts, and needs, rather than those of their siblings'. An emerging hypothesis here may be around the core beliefs that NTS in this research held about their own needs, compared to those of their siblings. For the young women in particular, potential core beliefs appeared to be around their needs being less important, and/or others being less able to meet them. Understanding and prioritising others' needs cannot be seen as a solely negative experience, however, and can instead be framed as a selfless and desirable trait linked to increased levels of perspective-taking (Shivers, 2019). This will likely differ based on the cultural background of NTS and the value placed on meeting others' needs within their family.

NTS also appeared to be balancing prioritising others with a need to protect themselves at a more fundamental level. They described self-protective behaviours such as running away, "causing chaos", seeking out quieter spaces, and being hypervigilant to spaces where they might become physically hurt. It seemed that the moments in which NTS were able to put their own needs first were often when they felt physically at risk - this frequently presented as a fight-or-flight type response,

indicating the level of distress they were experiencing in school. Within the literature, Chien et al. (2017) and Barak Levy et al. (2010) explored higher levels of externalising behaviours in NTS at school. This research highlights that this may be related to a build-up of unmet needs, a lack of attention, and difficulty in knowing how and where to access school-based support.

6.2.6. *Transitions and transformations across the school journey*

All participants discussed their experiences around transition points within education, for example moving to secondary school and away from their sibling, or in relation to their sibling's exclusion from school. Transitions across the school journey have not been explicitly explored in the previous literature and were also not something explicitly asked about within this research. According to Baxter (2011, p.94), even within typically developing sibling dyads, transitions are turning points and are 'occasions of major identity shift in which the relationship identity is upended in some significant way'. Within this research it therefore makes sense participants would share their experiences of transitions, as they grappled with sharing information around their sense of identity and place within peer groups and school.

Similarly to the younger children interviewed by Pavlopoulou et al. (2022), participants in the current research shared feelings of anxiety around leaving their brother in school while they moved on. The anxiety appeared two-fold, both in relation to feeling a loss of identity and role, and in relation to worrying about who would support their sibling in school without them. For NTS dyads the transition from primary to secondary school has been identified as a significant stressor for young adolescents (Mackenzie et al., 2012), and one that has been associated with increased mental health concerns. The literature presented in the scoping review (Chapter 2), highlighted the increased internalising difficulties in children with

disabled siblings and therefore it is likely there is a compounding effect whereby transitions are already challenging, but adding in the dynamic of caring for an autistic sibling, emphasises the emotional response.

When thinking of what a school transition looks like for siblings specifically, research has highlighted considerations at transition points are usually only in relation to the parent experiences (Davies, 2019). Research has explored how challenging school transitions are for TD siblings as their sense of self within education is often embedded with one another (Davies, 2019). It has been said that 'it is hard to shake free from them [sibling relationships] at an emotional level', even after transition (Smart, 2007, p.45). This experience was shared by Lilly when she expressed hearing another autistic young person in the halls of school after her brother was no longer there, and her immediate reaction was 'a feeling' in her stomach and a worry of him needing her help.

In further considering the wider sibling literature around transitions, there is limited research focused on sibling dyads separating across primary and secondary schools. However, research exploring the experience of an older sibling transitioning to college highlights that these relational changes can result in disappointment and longing, and for some, excitement and a welcome change (Halliwell, 2016), a mix of emotions also represented in the current research. It is suggested that transitions can prompt a process of identity renegotiation, often producing mixed emotions rooted in the disruption of an established sibling identity. The 'identity shift' that many participants experienced was marked by a struggle between certainty and uncertainty, whereby it was not necessarily the physical separation itself that was most challenging, but the uncertainty and loss of shared relational roles introduced by separation (Baxter, 2011).

The current research builds on this literature by showing how, for CYP with autistic siblings, these feelings of identity disruption and loss are closely tied to concerns about their sibling's well-being, learning, and social belonging in school. Cassandra, Lilly and Ryan all described their worries not just as a loss of daily contact, but as a loss of their established roles as protectors, advocates and co-regulators within the school context. This suggests that, in school settings, identity loss for NTS siblings of autistic children may be particularly pronounced because their sibling role is so embedded in everyday routines, peer interactions and even their own sense of belonging in school. This finding adds to the existing literature by highlighting the unique emotional and relational complexities of transitioning away from a sibling with additional needs in the school environment - a context in which their relational identity has been continually performed, reinforced and made visible.

Similarly to sibling research highlighting mixed emotional responses at transition (Halliwell, 2016), participants in the current research also shared feelings of confusion and guilt around having fun and their feelings of freedom once apart from their siblings in school. Younger children (Pavlopoulou et al., 2022) shared feelings of looking forward to a transition away from their sibling and hypothesised they might make more of their own friends in secondary school. While this was shared as an outcome of the transition in the current study, the reality was more complex for participants, as their freedom was laced with guilt and confusion around their roles. It may be that without preparation for the emotional nuance around transitions, NTS find it challenging to process and anticipate the emotional experience of separation.

The experience shared by Blue-Moon around feeling a loss of courage when her brother was excluded from school, has also not been well researched in the literature. Without knowing the separation was going to happen, it was likely even

more challenging for Blue-Moon to process her experience of being apart from him. Research has explored the idea of being labelled by association in school, based on their sibling's behaviour (Wenham, 2020) and this is something which may have compounded with the idea of disability by association for Blue-Moon.

Finally, in relation to transitions within a school year, participants highlighted increased levels of stress around exam periods. This stress around Year 6 and GCSE revision appeared related to the higher stakes associated with their own academic lives and the difficulties with balancing this with their responsibilities for their siblings. In relation to the SESF, this highlights the change over time, within even just one microsystem.

6.2.7. *Commentary Summary*

This part of the discussion chapter has focused on exploring the current findings in relation to the previous literature, and wider theoretical concepts and frameworks. The main and overarching addition to the current research base is a qualitative exploration into the lived experiences in school, for NT adolescents with an autistic sibling in the UK. However, this research has also added and explored the following:

- The depth of an enmeshed identity with an autistic sibling, including being seen through and seen as one.
- The variety of labels and roles assigned to NTS in school – the protector, educator, and advocate.
- An exploration into the role of compulsive caretaking and how this interacts with societal views of gender and sibling age.
- An exploration into 'barriers to being' and 'barriers to doing' in relation to academic learning, homework support and engagement in extracurricular activities.

- The experiences of peer relationships including the presence and absence of difficulty in friendships throughout school.
- The experience of external judgement from others.
- The balancing act between protecting oneself as a NTS and meeting the needs of their siblings.
- An exploration into the emotional complexity at school transition points, including the challenges experienced by NTS during periods of heightened academic pressure.

In order to explain these experiences, I have drawn on attachment theory, the SRM of Disability, and the SESF. In further conceptualising and illustrating these findings, I have created a reworked version of the SESF for application in schools to illustrate the intricacies *within* the school micro/mesosystem (see Figures 20 and 21).

Figure 20

Focus area of SESF

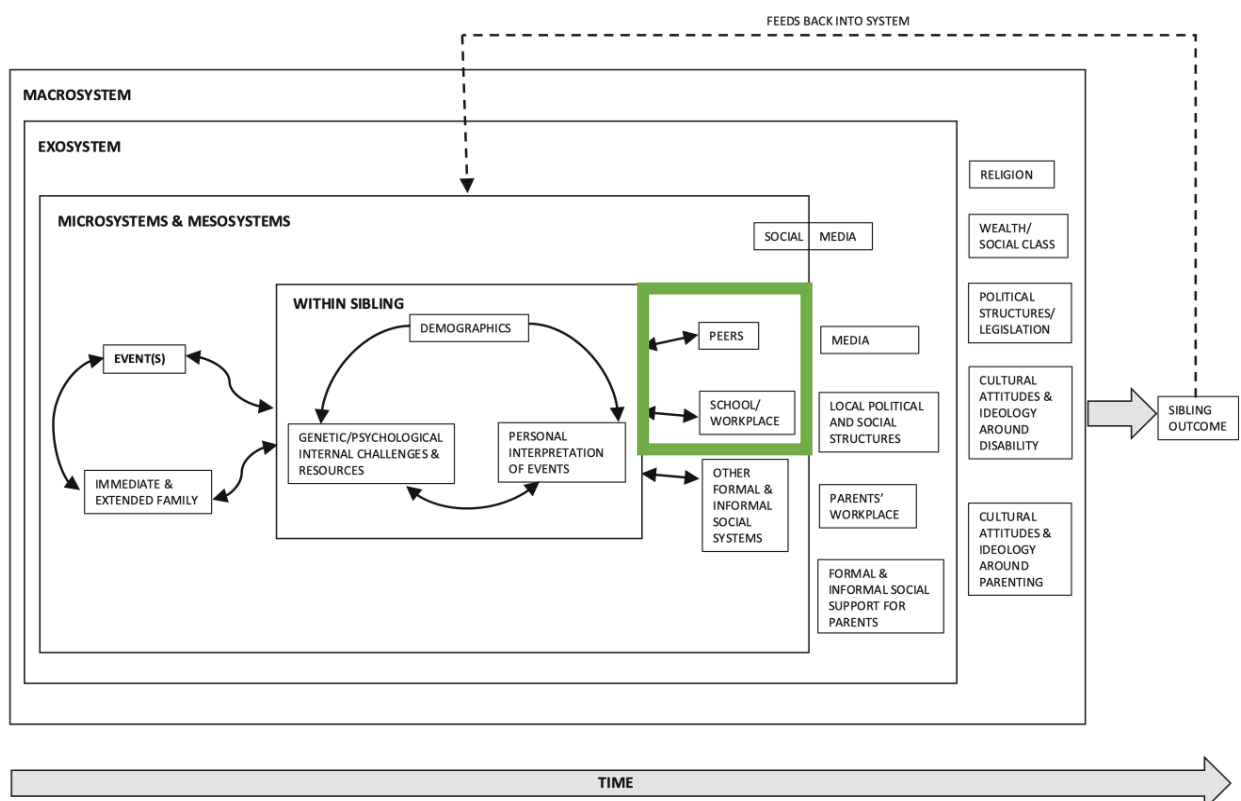
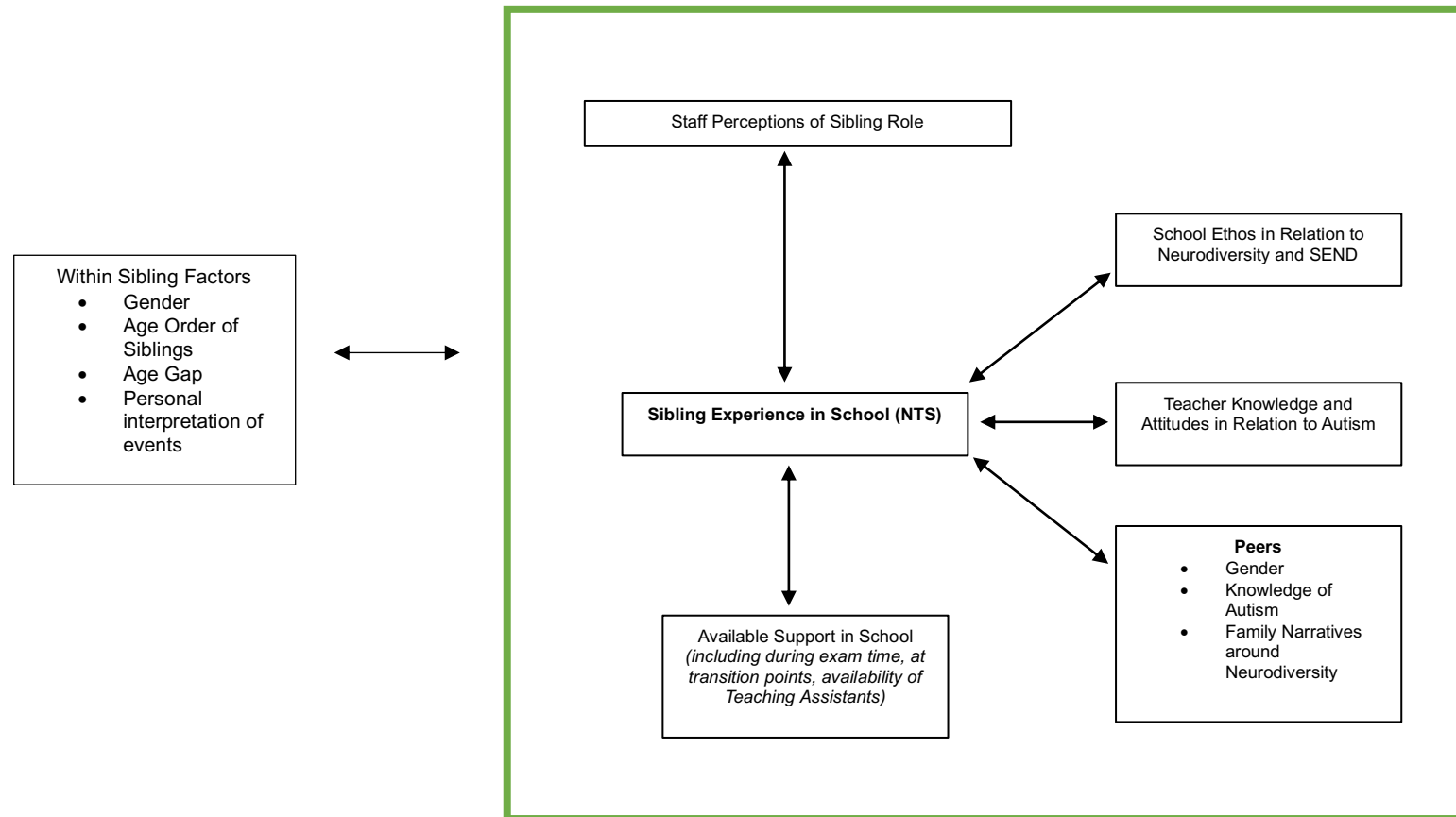


Figure 21

SESF Reworked for Application in Schools



Note. The figure shows the complexities within the school microsystem of the SESF. It highlights that sibling experience is impacted by within sibling factors, the support available in school, teacher and peer knowledge and attitudes towards Autism, the school ethos and staff perceptions of sibling role.

This reworked version of the SESF for application in schools offers a lens through which to understand the complex, multifaceted experiences of NTS of autistic children within school. At its core, it recognises that sibling experiences in school are not formed in isolation but shaped through dynamic interactions between individual sibling factors and the wider school and social environment. Within-sibling factors such as gender, age gap, birth order, and personal interpretations of events influence how young people make sense of their roles and responsibilities. These individual experiences are further mediated by systemic influences including teacher attitudes, peer dynamics, school ethos, and the availability of support. Notably, the framework highlights how societal narratives around neurodiversity, as well as the perceptions held by school staff, can reinforce or challenge the caregiving roles that NTS often adopt. By integrating these layers, this reworked model offers a holistic representation of the factors that shape NTS experiences shared within this research. The ways in which this model can be used by EPs to support NTS in schools, is explored within the implications section (6.5.2).

The following sections of the discussion chapter will share personal reflections, research limitations, implications of this research, plans for dissemination, and suggested avenues of further research.

6.3. Self-Reflection

Quality qualitative research includes the consideration of one's own role as researcher, including our potential biases, and influence on the research process (Critical Appraisal Skills Programme, 2018). This level of reflexivity is important within IPA as even within a hermeneutic cycle involving the researchers' own interpretations, the goal is still to ensure the interpretations arise from, and are

inspired by, the participants words' (Smith et al., 2022). Researcher reflexivity is marked by a consideration of (Haynes, 2012):

- 1) The researcher's motivation for conducting the research.
- 2) The underlying assumptions and biases the researcher brings to the research.
- 3) The researcher's connection to the researcher, theoretically, and the effect points 1 and 2 may have had on the researcher's approach.

My motivation for undertaking the research was introduced during Chapter 1, but the following reflects on Haynes (2012) three points together.

Of particular importance here is consideration of my own experience as a younger sibling with an older sister diagnosed with ADHD. There are of course stark differences between my own lived experiences as not only is the diagnosed neurodiversity different, but all of my participants spoke about their brothers. However, throughout the process I felt a strong sense of identification with certain parts of the participants' lived experiences – their roles as protectors and advocates and their sense of worry about their brothers' experiences in school. This level of personal identification may have resulted in the idea of sibling role becoming elevated within this research and may have been seen within interviews with more follow up questions and a push for a deeper exploration in relation to this area. I found the sense of identification particularly strong when participants shared more aspects of identity with myself and I spent time in supervision ensuring this internal sense of becoming enmeshed with certain participants at different points, was explored. This has been thought of as part of a parallel process – an unconscious re-enactment of a relationship within a therapeutic setting. Although the interviews were not designed to be a therapeutic space, it makes sense that with my lived

experiences and role as TEP, they occasionally became such. This feeling of becoming enmeshed with participants may have reflected their roles with their own siblings, a position I may have unconsciously taken up because of my own lived experiences.

Another aspect of my own experience which added a layer to the interpretation is my past experience as a teacher. When participants shared feelings of being let down by their teachers, their switching language to share '*you* should have' or '*you* could have', felt like it took additional effort to stay in role as researcher. My instinct was to reassure, share in their frustrations and apologise. Initially, I resisted this sense of being pulled into many differing roles and found myself wanting to remain as an 'independent' researcher. However, I am not only a researcher, but a sister, TEP and teacher. Through supervision and personal reflexivity, I found these roles combined to enrich the research, rather than impede it. When I stepped into my role as TEP, I was guiding participants to ensure their own wellbeing and provide containment for their experiences. When I named their own bravery and resilience I spoke as a sister. And when I felt apologetic and frustrated, I spoke as a teacher. On reflection, this added a depth to my research whereby I was able to explore their painful and/or joyful experiences by coming alongside their experiences with true empathy. My roles as sister, TEP, researcher and teacher did not have to be separate within this research, nor should they have been.

Further reflections on the research process have been around the difference felt in interview with Rian. As the youngest participant, and also the only male, I spent time exploring what this may have meant for the interview, the data subsequently analysed, and the power dynamics present in the room. Within all interviews, the relationship between researcher and participant can become blurred as there is an

attempt to control the conversation by both parties. During the interview with Rian, answers were often quite short and brief and at times it felt challenging to keep the conversation flowing. According to Schwalbe and Wolkomir (2001), in the case of female interviewing a male, some men tend to keep their answers to a minimum as a defence against vulnerability and as an attempt to rebalance the power differential. I wondered whether both his age, and gender played a part in potentially heightened defences when it came to sharing vulnerabilities, and what my role was in strengthening this power difference. In supervision, I explored how this may have both influenced my questioning in the moment, and any subsequent analyses.

Further to gender, I also wondered about the influence of other aspects of my identity may have been on the research, namely being a white British woman. For example, my own assumptions are that individuality is something to be explored, expressed, and celebrated, whereas I feel concerned about the idea of being so closely enmeshed with another. I am aware of my own bias here from being raised in an individualist society, but throughout the process of analysis and write up, have regularly prompted myself to seek out other ways of interpreting these experiences.

Finally, it is important for me to acknowledge the emotional experience of researching in this area, both in terms of the weight of some of the experiences participants shared with me, and due to the personal insight into what was shared. This combination has been marked by distinct drive to share the voices of participants who feel invisible and ensure others can listen.

6.4. Research Limitations

As an important part of ensuring credibility and trustworthiness of this qualitative research, a number of limitations are recognised (Noble & Smith, 2015)

In relation to participant recruitment, there were a number of challenges. For example, three out of four participants were aged 16 and over, and recruitment for young people between 14-15 presented with additional barriers. Three additional participants of this younger age were identified during the recruitment stage of this research but in all cases, the parents shared their autistic child was experiencing heightened levels of emotional dysregulation which was making home life challenging. In these cases, parents shared they could not support their NT child to attend a research interview and felt they could not commit to the process. In these cases, as the potential participants were under 16, I could not reach out to them directly and therefore I was not able to explore flexible ways for them to participate or hear their views. This may be a contributing reason why this field of research is under explored, for access to children's voices, there is a pathway of gatekeepers which means the child is the last person to be reached, despite being the focus of the research (Coyne, 2010). The idea that it is more important that children are able to have an opportunity to decide their research involvement (Coyne, 2010) needs to continue being balanced with the ethics around keeping children safe within research.

On reflection around the deep exploration into the roles of responsibility that siblings within this research took on, it is possible that research in this field will be skewed to explore the views of siblings who are more likely to fall into the role of educator and advocate. For example, these roles are ingrained to the extent where taking part in research, without obvious gain, may have been a further enactment of the positions they take within relationships. Therefore, hearing an alternative experience from NTS may be less likely.

It is also possible siblings in this research may have undiagnosed needs themselves. Three of four participants included in this research were female, a group underdiagnosed and overlooked for referrals (UCLA Health, 2023).

A homogenous participant sample is also recommended for IPA. Although every effort was made to ensure this was the case (see Chapter 4, Section 4.5.1.1), there were some variations within the sample. For example, participants varied in the number of siblings they had, some had multiple autistic siblings, or siblings with other diagnosed needs (e.g., Dyspraxia). These differences may have impacted how siblings interpreted and shared their experiences.

Finally, in line with the idiographic nature of IPA, it must be recognised that findings illustrated within this research are not generalisable to the wider population, nor are they intended to be so. Instead, this paper focuses on the individual lived experiences and highlights areas of potential transferability.

6.5. Implications

Although the findings of IPA based research are not intended to be generalisable, there is an acknowledgment of the potential transferability of findings to other, similar contexts. In this case, based on the lived experiences shared by the participants in the current study, several wider implications will be shared. Implications will be discussed as they relate to school staff, EPs and the wider government system.

6.5.1. Teachers and School Staff

Recognising and identifying children with autistic siblings within the school setting is an important first step for teachers and school-based support staff. Siblings in this research shared the difficulty of being invisible and having to advocate for their own support – if school staff take the initiative to recognise and engage siblings in

conversations about their lived experiences, this could create a significant shift in their school experience. This may look like teachers gathering information about sibling needs when meeting their new classes and then having open conversations with the siblings about their experiences and needs. An important part of this work will be taking a non-judgemental and open-minded approach, not assuming what the experience may be like. For example, many children in this research shared their complex emotional responses when transitioning away from their siblings to a new school. Being mindful at transition points, but not assuming transitioning away from a sibling will feel like a relief is an important step in challenging an ableist narrative. In line with the SMD (Shakespeare, 2006), siblings are not viewed as burdens, and they should not be assumed as such. However, school staff will need to explore what the *lived reality* is for the sibling, in order to meet their needs too.

ELSA (Emotional Literacy Support Assistant)-led 1:1 sessions may also provide siblings with a space to process their complex experiences at home, school, and during transitions. This may serve as an early intervention to support siblings in having a safe space for their emotional experience to be contained (Bion, 1985), as well as meet the need for 1:1 connection that may be more challenging to experience at home. ELSA work may look at exploring sibling roles, setting boundaries and exploring their own, individual sense of self. Where needed, school staff will be aware of the boundaries of their expertise and refer siblings for counselling where this is viewed as appropriate. This will always be coupled with discussions with the young person around how they can be supported to attend, and how demands can be reduced across the rest of their timetable.

In regard to academic support, teachers and school staff need to be aware of the potential additional emotional and cognitive load associated that siblings may be

experiencing and will adjust expectations and support in response. This is especially necessary where siblings take on a role of caregiving at home and may look like providing homework and coursework extensions and allowing classroom breaks to both respond to and prevent burn out. Teachers and school staff should provide appropriate support to autistic students without relying on their siblings for assistance during the school day. Conversations with individual siblings will be important in order to understand how the NTS wish to be alerted of any challenges their sibling faces during the school day, if at all.

At the heart of effective school-based support is open, collaborative dialogue with siblings to understand their needs and how best to support them.

6.5.2. Educational Psychologists

EPs are well placed to advocate for the often-overlooked needs of CYP who have autistic siblings. One meaningful contribution is through systemic consultation, where EPs can raise awareness of sibling experiences and ensure they are considered in planning and support. For example, when working with autistic CYP, EPs might use Bronfenbrenner's Ecological Systems Theory (1979) to understand the sibling relationship as a significant influence, using reflective questioning to explore how typically developing (TD) siblings are impacted and supported.

Beyond casework, EPs can support staff to reflect on how they work with CYP who may take on caring roles or hold complex emotions related to their siblings. Drawing on Bion's (1985) idea of 'containing the containers', EPs might offer supervision or consultation to help staff process and respond thoughtfully to these dynamics. This supports a whole-school approach to emotional wellbeing that includes sibling experiences.

Participants in the current research highlighted the value of community spaces where siblings can share experiences and feel understood. EPs could play a key role in initiating and facilitating such groups, helping to foster connection and reduce isolation beyond the school setting.

Additionally, the reworked SESF for application in schools (Figure 21) offers EPs a practical, systemic tool to map and reflect on the multiple, interacting influences shaping the experiences of NTS. It can be used as a visual to guide an exploration of what the child's day-to-day experience may look like across areas such as school ethos, teacher confidence and attitudes, peer relationships, and within-sibling factors. By mapping out experiences across these interconnected areas with pupils, school staff and families, EPs can help schools identify where support could be most meaningfully targeted - whether through staff development, peer awareness work, or creating spaces for siblings to express and process their experiences.

Finally, EPs can contribute to wider advocacy. The absence of sibling recognition in statutory frameworks, such as the SEND Code of Practice (DfE, 2015), highlights a need for policy change. EPs are well positioned to promote this, encouraging the routine identification of siblings, gathering their views, and ensuring these perspectives inform planning and support at home and school. By keeping siblings visible within both direct and systemic work, EPs can support more inclusive and relational approaches to the needs of families of autistic children.

6.6. Dissemination Strategy

This research will be shared with all participants who took part and shared their lived experiences. All participants will be sent an email sharing the research and will be offered time to speak with me virtually if they wish. The research will also be shared via a presentation within the Educational Psychology Team in the LA in which

this research took place and will also be shared via presentation to the senior leaders within Children's Services. A request has also been made to share this research at a conference for ELSAs within a different LA. There are also hopes to publish in a relevant peer reviewed journal in order to share this research more widely.

6.7. Future Research

Considering the findings of the current research, a number of avenues for further exploration are recommended:

- An exploration into school-staff perspectives of NTS in school. Of particular interest may be an open exploration into they view NTS, as well as a focus on their own experience of teaching them in school.
- All of the participants in this research spoke of their experiences with autistic brothers. It may be beneficial to explore the convergence and/or divergence in the school experiences of adolescents with autistic sisters.
- Further related to gender, research exploring the school-based roles taken up by NTS of different genders is important. Three out of four participants in this research were cisgender females and expanding out this perspective will be important next step.
- A qualitative exploration of the school experiences of siblings where the age difference, number of siblings, and order of birth are explored in more depth.
- This research highlighted salient, emotional experiences during school transition points, particularly those which resulted in them moving away from their sibling. It is recommended that research focuses on transition points in more detail, as well as examining the experience of NTS when their siblings were excluded from school.

- An exploration into the roles taken up by NTS when they have never attended the same school as their autistic sibling. This may allow an exploration into if the roles illustrated within this research (advocate, protector, parent), show up in school-based relationships where their sibling is not present.
- Research into the school experiences of NTS of young people from different racial, linguistic and ethnic backgrounds.

6.8. Recommendations from Participants

During the course of the interviews, participants shared information around what might have supported them during their time at school, or what they wished others had known. These recommendations from participants are shared here with the aim of bringing this research back to the individual lived experiences and providing a platform for their voices to be heard. The participants shared the following:

- A wish for a level of attunement and ‘noticing’ from school-based staff.
 - “I think people should also just focus on the people around them [their autistic sibling] that have to deal with it, because it is like, we kind of get almost pushed to the side”
 - “Like if they look burnt out in class, maybe give them a little bit more extra support”
 - “Ask them in the morning how they’re feeling.” – the focus here was on asking sibling consent to share information with other members of staff – “write it in an email.... but then also ask the student themselves as well.”

- Hopes that school staff would understand and notice if extra learning help was needed.
 - “People just need to be more understanding that homework might take more time to be handed in, or they need a bit more extra help in lesson because they’ve got either stuff going on at home, or they’ve got to just deal with their sibling and just be a bit more understanding when it comes to it”
- Wishes for a deeper level of understanding, both about their siblings and themselves.
 - “Maybe for them [teachers] to not assume straight away that because one person has got, like one sibling has got Autism, that it means that the other will kind of have that or act the same way.”
 - “They need attention. They don’t have that much attention at home, and they need it.”
- Wishes for support in school, both for themselves and their sibling, without having to ask.
 - “I was always just more of a confident person.... whereas not a lot of people are.... give extra support or something because I didn’t have that. I know I had to chase for it.”
 - “It [his person] could have been any of the teachers if they just wanted to... I would have had more of a life in that school, and I wouldn’t have to worry about people...or like checking up on him constantly.”

7. Conclusion

This research presents the first known small-scale, qualitative, UK-based exploration into the school experiences of adolescents with an autistic sibling, offering insight into their lived realities and providing a platform for their voices to be heard.

Four young people, aged 14–17, took part in semi-structured interviews. These were analysed using Interpretative Phenomenological Analysis (IPA), which generated six GETs: (1) Playing a Part and Being in Role; (2) In and Beyond the Classroom – Learning Experiences; (3) External Voices – Being Judged and Let Down; (4) Belonging and Social Visibility in School; (5) Maintaining a Balancing Act; and (6) Transitions and Transformations Across the School Journey. Together, these themes highlight new insights into the experiences of NTS in schools. Key insights include experiences of Disability by Association (Burke, 2010), a sense of self deeply entwined with caregiving and sibling identity, and the emotional burden of care - particularly for the young women in this study. The emotional complexity of transitioning away from an autistic sibling also surfaced as a new area of understanding. In contexts where participants consistently felt responsible for their siblings, such transitions evoked feelings of both freedom and loss. The challenge of maintaining a social life, especially for the girls, was also strongly felt, coming at a developmental stage where peer connections become increasingly important and influential.

To conceptualise these contributions, a reworked version of the SESF for application in schools was developed. This model situates school experiences within a bidirectional loop, capturing the influence of gender, age gap, societal constructs, and the interpretations of NTS themselves, and how these interact with the school

microsystem. The model brings together the dynamic and evolving nature of the school experience for this group and is offered as a tool for better understanding and supporting NTS in education.

These findings highlight a responsibility for both school staff and EPs to actively listen to NTS, to truly hear their stories, and to avoid assumptions about their needs. For EPs, this includes raising awareness in consultation, training, and therapeutic work and, at its heart, the role of the EP must include being a voice for NTS who may feel they have lost theirs. Both teachers and EPs are uniquely placed to challenge the implicit narrative that NTS are responsible for their siblings, and to offer support that recognises their individual needs.

To build on this research, future work will need to explore teachers' perspectives on NTS and the roles they perceive these children to take up in schools. This will help to provide essential insight into the external factors shaping the reworked and applied SESF and enrich the conversation about systemic change.

In summary, while there is still much to learn about the lived experiences of CYP with autistic siblings, it is hoped this research supports those who feel invisible to become visible, and that all glass children in schools can feel a little more seen.

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Appendices

Appendix A: Autism Description (DSM)

Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history: stereotyped or repetitive motor movements, use of objects, or speech, insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour, highly restricted, fixated interests that are abnormal in intensity or focus, and lastly, hyper- or hyperreactivity to sensory input or unusual interest in sensory aspects of the environment (APA 2022).

Appendix B: Literature Review – Rationale for Inclusion/Exclusion

Table B1. Title Search

Papers are presented in the order they were presented on the database search.

Number	Article	Meets Criteria	Rationale
1	Measuring social-communication difficulties in school-age siblings of children with autism spectrum condition (Gangi, 2021)	No	Paper looking at if siblings experience social communication needs. Children are school age but it doesn't look at their school experiences or measures of academic attainment.
2	Academic self-concept and sense of school belonging of adolescent siblings of autistic children (Gregory, 2020)	Yes	N/A – Meets criteria
3	Predictors of pragmatic communication of school-age siblings of children with ASD and low risk controls (Greenslade, 2019)	No	Research looks at if siblings experience social communication needs. Children are school age, but it doesn't look at their school experiences or measures of academic attainment.
4	School Functions in Unaffected Siblings of Youths with Autism Spectrum Disorders (Chien et al., 2017)	Yes	N/A – Meets criteria
5	Language related abilities in unaffected school-aged siblings of children with ASD (Drumm, 2015)	No	Research looks at school-age siblings of those with Autism but does not look at school experiences or measures of academic attainment.
6	Is it in the family? The importance of siblings and peers of theory of mind and school readiness in children with and without autism spectrum disorder (Matthews, n.d)	?	Access to paper requested but not received
7	Diagnostic outcomes in school age siblings of children with autism (Seidman, 2013)	No	Not an empirical research paper – this is a book.
8	Pragmatic language and school related linguistic abilities in siblings of children with autism (Ben Yizhak, 2011)	Yes	N/A – Meets criteria

9	Siblings of autistic children: their adjustment and performance at home and in school (Mates, 1990)	Yes	N/A – Meets criteria
10	Siblings of autistic children: their adjustment and performance at home and in school as a function of sex and family size (Mates, n.d)	?	This is the thesis version of the Mates (1990) paper (see above). The thesis was not accessible although requested but the above paper was included.

Table B2. Abstract Search

Papers are presented in the order they were presented on the database search.

Number	Article	Meets Criteria	Rationale
1	Characteristics and correlates of aggressive behaviour in autistic youths (Brown et al., 2024)	No	The focus of this paper is on the autistic children rather than their siblings.
2	Mid-childhood autism sibling recurrence in infants with a family history of autism (Bazelmans et al., 2024)	No	The paper does not include a focus on the school experiences of NTS.
3	Do school and equality education characteristics influence young children's understanding of sex/gender constancy (Alcock et al, 2024)	No	The paper does not include a focus on the school experiences of NTS.
4	Sibling experience of autism: through a family systems lens (Fontes, 2023)	No	The paper does not include a focus on the school experiences of NTS
5	Co-morbidity between neurodevelopmental disorders and childhood-onset type 1 diabetes	No	The paper does not include a focus on the school experiences of NTS.
6	Complex autism spectrum disorder: Structural Determinants of health and their impact on their diagnosis (Canale et al., 2023)	No	The paper does not include a focus on the school experiences of NTS.
7	Adaptive behaviours and related factors in children and adolescents with autism spectrum disorder: Report from the ELENA cohort (Miniarikova et al., 2023)	No	The focus of this paper is on the autistic children rather than their siblings.

8	Determinants of inclusion in mainstream school for children with autism spectrum disorders from the EpiTED study: A 10 year follow up cohort (Lafont et al., 2023)	No	The paper does not include a focus on the school experiences of NTS.
9	A phenomenological study of the lived experiences of siblings of individuals with autism spectrum disorder (Benini, 2022)	No	The paper does not include a focus on the school experiences of NTS.
10	A meta-analysis of sibling mediated interventions for youth with autism (Brown, 2023)	No	The paper does not include a focus on the school experiences of NTS.
11	The lived experiences of parents raising a child with autism spectrum disorder (DeGeorge, 2018)	No	The focus is on parental perspectives rather than NTS.
12	A multiple case study to capture and support the engineering design thinking of children with mild autism (Ehsan, 2020)	No	The paper does not include a focus on the school experiences of NTS.
13	Perceived support needs of families of children with autism: a qualitative descriptive study (Onwukwe et al., 2022)	No	The paper does not include a focus on the school experiences of NTS.
14	Feelings of loneliness and social dissatisfaction in siblings of children with autism spectrum disorders: the role of birth order and perceived social support (Koukouriki et al., 2022)	No	The paper does not include a focus on the school experiences of NTS.
15	Increased IgG-4 levels in patients with autism spectrum disorder complicated by autoimmune pancreatitis (Tsou et al., 2022)	No	The paper does not include a focus on the school experiences of NTS.
16	Diagnostic stability and phenotypic differences among school-aged children diagnosed with ASD before age 2 (Landa et al., 2022)	No	The paper does not include a focus on the school experiences of NTS.
17	The value of telehealth and a team-based approach in improving developmental and behavioural care during COVID-19 pandemic (Barnhardt et al., 2021)	No	The paper does not include a focus on the school experiences of NTS.
18	Measuring social communication difficulties in school-aged siblings of children with autism spectrum disorder: standardised vs naturalistic assessment (Gangi et al., 2021)	No	The paper does not include a focus on the school experiences of NTS.

19	Beyond the toddler years: a meta-analysis of communicative abilities in siblings of children with autism spectrum disorder (Roemer, 2021)	No	The paper does not include a focus on the school experiences of NTS.
20	Depressive symptoms of autism spectrum disorder children's siblings in Greece: associations with parental anxiety and social support (Koukouriki et al., 2021)	No	The paper does not include a focus on the school experiences of NTS.
21	Autism and access to care during the COVID-19 crisis (Nadler et al., 2021)	No	The paper does not include a focus on the school experiences of NTS.
22	Teaching texting on a smart phone to children and adolescents with autism spectrum disorder (Gilder, 2020)	No	The focus of this paper is on the autistic children rather than their siblings.
23	Adaptive skill benefits of peer exposure for children with autism spectrum disorder (Peterson, 2020)	No	The focus of this paper is on the autistic children rather than their siblings.
24	Emotion regulation, self-concept and quality of life of siblings of children with autism and related disorders (Slass, 2016)	No	The paper does not include a focus on the school experiences of NTS.
25	An examination of parent-reported facilitators and barriers to organised physical activity engagement for youth with neurodevelopmental disorders, physical and medical conditions (Papadopoulos et al., 2020)	No	The focus is on parental perspectives rather than NTS.
26	'No one could calm him down': Mothers experience of autism diagnosis and obtainment of resources in an urban public school district (Johnson et al., 2020)	No	The focus is on parental perspectives rather than NTS.
27	Listening to parents to understand their priorities for autism research (Clark et al., 2020)	No	The focus is on parental perspectives rather than NTS.
28	Self-reported Health-related quality of life and anxiety among Greek school-aged siblings of individuals with autism spectrum disorders (ASD) in relation to parental mental health and social support (Koukouriki et al., 2020)	No	The paper does not include a focus on the school experiences of NTS.
29	Neural and behavioural indices of face processing in siblings of children with autism spectrum disorder (ASD): A longitudinal study	No	The paper does not include a focus on the school experiences of NTS.

	from infancy to mid-childhood (Shephard et al., 2020)		
30	Siblings of children with autism spectrum disorders: social support and family quality of life (Garrido et al., 2020)	No	The paper does not include a focus on the school experiences of NTS.
31	Parent and teacher ratings of social skills, peer play and problem behaviours in children with autism spectrum disorder (Clark et al., 2020)	No	The focus of this paper is on the autistic children rather than their siblings.
32	Training siblings in pivotal response treatment: Impact on sibling interactions and psychosocial wellbeing (Allclair et al., 2020)	No	The paper does not include a focus on the school experiences of NTS.
33	Academic self-concept and sense of school belonging of adolescent siblings of autistic children (Gregory et al., 2020)	Yes	Already found from title search
34	Prevalence and correlates of autism spectrum disorder in Qatar: A national study (Alshaban et al., 2019)	No	The paper does not include a focus on the school experiences of NTS.
35	Parent perceptions of barriers to friendship development for children with autism spectrum disorders (Daughrity, 2019)	No	The focus is on parental perspectives rather than NTS.
36	Script fading for children with autism: generalisation of social initiation skills from home to school (Wichnick-Gills et al., 2019)	No	The focus of this paper is on the autistic children rather than their siblings.
37	Physical and psychosocial impact of university-based, volunteer student led running program for children with autism spectrum disorder (Marggraff et al., 2018)	No	The paper does not include a focus on the school experiences of NTS.
38	Autism spectrum disorder and mental health co-morbidity leading to prolonged inpatient admission (Gupta et al., 2019)	No	The paper does not include a focus on the school experiences of NTS.
39	The joint impact of cognitive performance in adolescence and familial cognitive aptitude on risk for major psychiatric disorders: A delineation of four potential pathways to illness (Kendler et al., 2018)	No	The paper does not include a focus on the school experiences of NTS.
40	Family characteristics and children's receipt of autism services in low resourced families (Karp et al., 2018)	No	The paper does not include a focus on the school experiences of NTS.

41	Broad autism phenotype: theory of mind and empathy skills in unaffected siblings of children with autism spectrum disorder (Eyuboglu et al., 2018)	No	The paper does not include a focus on the school experiences of NTS.
42	School functions in unaffected siblings of youths with autism spectrum disorders (Chien et al., 2017)	-	Already found from title search
43	Mid-childhood outcomes of infant siblings of familial high-risk of autism spectrum disorder (Shephard et al., 2017)	No	The paper does not include a focus on the school experiences of NTS.
44	Development of two-dimensional measures of restricted and repetitive behaviour in parents and children (Evans et al., 2017)	No	The paper does not include a focus on the school experiences of NTS.
45	A phenomenological study of single fathers of children with autism in Trinidad (Seepersad, 2016)	No	The focus is on parental perspectives rather than NTS.
46	Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters (Cridland et al., 2016)	Yes	N/A – Meets criteria for inclusion
47	Minimal risk of internalising problems in typically developing siblings of children with high-functioning autism spectrum disorder (Rodgers et al., 2016)	No	The paper does not include a focus on the school experiences of NTS.
48	School-age outcomes of infants at risk of autism spectrum disorder (Miller et al., 2016)	No	The paper is not about NT siblings, the focus is on children who are likely to develop autism.
49	Proximity as a barrier to friendship development for children with autism (Williams, 2015)	No	The focus of this paper is on the autistic children rather than their siblings.
50	Language related abilities in unaffected school-aged siblings of children with ASD (Drumm et al., 2015)	No	The paper does not include a focus on the school experiences of NTS.
51	Is early joint attention associated with school-age pragmatic language (Gillespie-Lynch et al., 2015)	No	The focus of this paper is on the autistic children rather than their siblings.
52	Psycho-social characteristics of children and adolescents with siblings on the autistic spectrum (Stampoltzis et al., 2014)	Borderline (not included)	This paper focuses on the 'psychological adjustment' of NTS with an acknowledgement of how emotional responses and behaviours may impact peer relationships and school experiences. This was a small section of the research and school experiences were not an explicit research aim/question, so the paper was not included in a full review.

53	Review of with the light: Raising an autistic child (VanBergeijk, 2014)	No	Book rather than empirical paper.
54	A new methodology of viewing extra-axial fluid and cortical abnormalities in children with autism via transcranial ultrasonography (Bradstreet et al., 2014)	No	The focus is on parental perspectives rather than NTS.
55	Growing up with autism: The educational impact on neurotypical siblings (Herman, 2013)	Yes	N/A – Meets criteria for inclusion.
56	Is it all in the family? The importance of siblings and peers for theory of mind and school readiness in children with and without autism spectrum disorder (Matthews, n.d)	?	Requested but no access given.
57	Script fading for children with autism: Generalisation of social initiation skills from school to home (Wichnick, 2013)	No	The focus of this paper is on the autistic children rather than their siblings.
58	The effects of high and low functioning autism on siblings: A booklet for mental health professionals (Arli, 2013)	No	The paper does not include a focus on the school experiences of NTS.
59	Developmental co-ordination disorder plus: A diagnosis by exclusion (Santosuosso et al., 2012)	No	The paper does not include a focus on the school experiences of NTS.
60	A comparison of urinary mercury between children with autism spectrum disorders and control children (Wright et al., 2012)	No	The paper does not include a focus on the school experiences of NTS.
61	Pragmatic language and school related linguistic abilities in siblings of children with autism (Ben-Yizhak et al., 2011)	Yes	Already found from title search
62	Language performance in siblings of non-verbal children with autism (Levy et al., 2011)	Yes	N/A – Meets criteria for inclusion
63	A meta-analysis of peer-mediated interventions for young children with autism spectrum disorders (Zhang et al., 2011)	No	The paper does not include a focus on the school experiences of NTS.
64	Review of in his shoes: a short journey through autism (Shtayermman, 2011)	No	The focus of this paper is on the autistic children rather than their siblings.
65	The lived experiences of parenting a preschool age, moderately retarded autistic child (Lendenmann, 2010)	No	The focus is on parental perspectives rather than NTS.
66	The effects on siblings of children with autism (Farber, 2010)	No	The paper does not include a focus on the school experiences of NTS.

67	Siblings of those with developmental disorders: Career exploration and likelihood of choosing a helping profession (Eget, 2009)	No	The paper does not include a focus on the school experiences of NTS.
68	It looks like autism: caution in diagnosis (Snyder et al, 2008)	No	The focus of this paper is on the autistic children rather than their siblings.
69	The efficacy of peer-mediated interventions for promoting social interactions among young children with autism spectrum disorders: A meta-analysis (Zhang, 2008)	No	The focus of this paper is on the autistic children rather than their siblings.
70	An ethnography of invisibility: Education and special needs children in Japan (Maret, 2008)	No	The focus of this paper is on the autistic children rather than their siblings.
71	Advanced paediatric psychopharmacology: Loxapine treatment in an autistic child with aggressive behaviour: Therapeutic challenges (Reinblatt et al., 2006)	No	The focus of this paper is on the autistic children rather than their siblings.
72	Collaboration among parents and professionals with discrete trial training in the treatment for autism (Devlin et al., 2004)	No	The focus of this paper is on the autistic children rather than their siblings.
73	Childhood autism spectrum disorder in the Barwon region: A community-based study (Icasiano et al., 2004)	No	The focus of this paper is on the autistic children rather than their siblings.
74	Supporting children on the autism spectrum in peer play at home and school: Piloting the integrated play groups model in Taiwan (Yang et al., 2003)	No	The focus of this paper is on the autistic children rather than their siblings.
75	Language abilities of siblings of children with autism (Pilowsky et al., 2003)	No	The paper does not include a focus on the school experiences of NTS.
76	Increasing joint attention, play and language through peer supported play (Zercher et al., 2001)	No	The focus of this paper is on the autistic children rather than their siblings.
77	Incorporating children with autism's thematic ritualistic behaviours into games to increase social play interactions with siblings (Baker, 1999)	No	The focus of this paper is on the autistic children rather than their siblings.
78	Applied behavioural analysis: Astonishing results – reply (Perry et al., 1995)	No	The focus of this paper is on the autistic children rather than their siblings.
79	Teaching preschoolers with autism to self-monitor their social interactions: An analysis of	No	The focus of this paper is on the autistic children rather than their siblings.

	results in home and school settings (Strain et al., 1994)		
80	Siblings of autistic children: their adjustment and performance at home and in school (Mates, 1990)	N/A	Already found from title search
81	The later creation of a transitional object (Resch et al., 1988)	No	The paper does not include a focus on the school experiences of NTS.

Table B3. Scoping Search

Number	Article	Meets Criteria	Rationale
1	A multi-rater study on being teased among children/adolescents with autism spectrum disorder (ASD) and their typically developing siblings: Associations with ASD symptoms (Nowell, 2014)	Borderline (not included)	Paper looks at the experiences of bullying in autistic children compared to their TD siblings, but this is a small section of a paper which does not explicitly address school-based experiences. The main focus of the paper is looking at correlates of bullying.
2	I often have to explain to school staff what she needs: school experiences of non-autistic siblings growing up with an autistic brother or sister (Pavlopoulou, 2022)	Yes	N/A – Meeting criteria for inclusion

Appendix C: Data Extraction Table

Article	Aims	Location of Research	Population (age, ethnicity)	School Overlap with autistic sibling	School Attending (mainstream secondary, primary)	Method (data collection and data analysis)	Findings	Critique
Siblings of autistic children: their adjustment and performance at home and in school (Mates, 1990)	The broad aim was 'to examine the adjustment of siblings of autistic children across home and school'. They aimed to look at self-concept, academic achievement, home adjustment and school adjustment. In particular this paper aimed to look at if gender and family size played a role in sibling outcomes.	North Carolina, America	33 children. 18 boys and 15 girls. 18 of these were from two child families and 15 were from families with multiple children. 24 were the oldest sibling, 8 were younger than the sibling with ASD but older than other children in the family and 1 was a twin. All children were therefore the oldest neurotypical children in the family. Children were aged between 8 and 17 years old. 8 of the children	Not mentioned	School age in America but the paper does not specify what type of schools were attended	Quantitative: The measures used were the Piers Harris Self Concept Scale, The Wide Range Achievement Test, The Rutter Questionnaire for Parents (and one for teachers). Information was analysed using statistical tests (ANOVAs)	Results revealed no significant difference on measures of sibling adjustment between females and males or between siblings from two child or multi child families. None of the groups had scores significantly different from the normative samples on any of the measures. Any impact of having an autistic sibling that has been previously reported is said by these authors to not have an impact on school attainment or behaviour in school or home.	Strengths: Triangulation of information from children, parents and teachers. Limitations: Bias in recruitment and also measures used e.g, psychometric test bias. All children had received sport via a TEACCH programme which is designed to help those families with an autistic child and therefore no significant difference for the siblings may be a result of support they are receiving through the program. No

			were 'non white'.				Although not significant, there was a higher mean self-concept score in this study compared to the normative sample, it may be that having an autistic sibling is related to positive self-concept, interpersonal and caretaking skills.	qualitative information gathered from any participants in the research. Regarding the normative samples, are the normative samples excluding children with autistic siblings? If not, this may need to be considered when comparing to the normative sample.
Adjustment characteristics of healthy siblings of children with autism (Barak-Levy, 2010)	The aim of this research was to look at child and parent reports related to behaviour, social and emotional adjustment. This paper aimed to add qualitative information to previous quantitative accounts of sibling experiences	Israel	27 children with autistic siblings between the ages of 6-18 years old. 12 siblings were male and 15 were female. All autistic children attended specialist educational settings, and all children lived with their siblings at home. All families were middle class and living in	Not mentioned	Autistic children in specialist school - no mention of schools that the neurotypical siblings were attending.	Mixed Methods Child behaviour check list includes both open ended questions and information gathered along a Likert scale. The first part assesses behavioural and emotional adjustment as well as school performance, social relations and child activities. The second part	Parental Reports: show that siblings have lower participation in social activities (e.g, youth club, hobbies and extracurriculars). Over half of the siblings reportedly have more academic difficulties than the norms that results were compared against. Social relationships were in the typical range for 77% of the siblings but for	Strengths: Inclusion of qualitative and quantitative information allowed a deeper exploration than quantitative alone might have. Triangulation of child and parent perspectives. Limitations: The paper states school difficulties but does not go into any more detail which makes future

	at home and school.		Israel. This included a control group who completed the same measures (qual and quant).			assesses anxiety, depression, cognition, rule breaking, aggressive behaviour, social problems. This was completed by parents. The Weinberger Adjustment Inventory was then used with the children themselves. This assessed self-control and emotional distress. Measures were translated into Hebrew where needed.	the rest there were difficulties here too. Qualitative themes were pulled - 59.2% of parents said their children were helpful/responsible and nice. These were lower for control group parents. Parents cited difficulties in behaviour at school. Sibling reports - also found themes of helping others, taking on more chores within the house	recommendations difficult to discern. Richness of qualitative data lost when quotes were reduced to themes and then descriptive statistics were used. Small sample size. Teacher perspectives on school behaviour and difficulties may have made the perspectives richer.
Pragmatic language and school related linguistic abilities in siblings of children with autism (Ben Yizhak, 2011)	This was part of a longitudinal study. The aim of the original study was to identify markers for Broad Autism Phenotype (symptoms that look like Autism in unaffected siblings), and	Israel	35 children with autistic siblings (11 girls and 24 boys) aged between 9-12 years old. The typically developing group was 42 siblings (21 girls and 21 boys, also aged between 9-12. All participants had an older	Not mentioned	School types of either unaffected siblings of those with ASD, or siblings of typically developing children, or the autistic siblings themselves,	Quantitative: Parents completed the Social and Communication Questionnaire, children complete the WRAT-III test of school achievement, Diagnostic Battery for Reading processes in	Children with autistic siblings with BAP themselves, presented with poorer performance on pragmatic language compared to siblings of TD children and siblings of those with Autism without BAP	Strengths: diagnosis confirmed, transparent and stringent inclusion criteria. If siblings were later diagnosed with Autism, they weren't included for analysis. Authors used diagnostic criteria from the Baby Siblings

	to look at the trajectory of this development from birth into childhood. This study is a follow up of the children between ages 9-12 - focusing on language, reading and school achievement at follow up. <i>Note.</i> BAP may include social difficulties, internalising and externalising behaviours, executive dysfunctions). It is not an Autism diagnosis, merely identification of similar traits.		sibling, across both groups. The paper states that demographic information was collected but it is not reported. Participants were screened for BAP so there ended up being three groups - unaffected sibs with BAP, unaffected typically developing siblings and those who were typically developing and had typically developing siblings.	was not mentioned	Hebrew, the WISC assessment the CELF to assess language abilities. Measures were administered at home for three videotaped sessions. The same experimenter conducted the first two sessions (120 minutes), and another experimenter administered the ADOS on the third visit. Experimenters were blind to previous performance	themselves. School achievement and reading processes were not affected in any group with autistic siblings. Severity of autistic symptoms was associated with full scale/verbal IQ scores. No associations were found between high vs low functioning and siblings linguistic functioning.	Research Consortium to identify unaffected siblings that developed BAP. Used ADOS and ADI-R to verify Autism diagnoses. Limitations: bias in the standardised assessment scoring, lack of transparency around ethical considerations taken.	
Growing up with autism: The Educational Impact on	The aim of this paper was to look at the academic impact that	New Jersey (America)	14 high school students who have a sibling with ASD, and a control group of	Almost none of the participant s attended	Siblings were recruited from mainstream	Mixed Methods - Participants completed a survey about their academic	Participants with autistic siblings reported participating in less extra-	Limitations: Sample size - the necessary power needed for statistical

Neurotypical Siblings (Herman, 2013)	having a sibling with Autism has on the neurotypical sibling. This was named a 'pilot study'.	25 students who have a sibling without Autism. Students aged between 14-18 (siblings with ASD) and controls were between 13-18 years old. Autistic siblings were between 9-19 years old, 7-23 for control sibs. 6 males and 8 females were in the ASD sibling group. 4 males and 21 females in the control group. Majority (all but 1 White British).	the same school as their sibling	high schools, private schools supporting those with ASD and outpatient clinics that support those with Autism.	experiences. This included brief open-ended questions and items that needed a response along a Likert scale. The Likert scale came from a subscale of the Motivation and Engagement Scale. This data was analysed via t-tests and correlations, MANCOVA, ANCOVA and a Mult regression analysis. Three open ended questions were included at the end of the survey to allow descriptions. This qualitative data wasn't analysed formally but was included descriptively.	curricular activities that those with typically developing siblings. They believed school was less important than the control group (the authors wondered if there was a link between the two points. The greater number of extracurricular activities that the participants were in, the greater likelihood they had to wish for more time in school, the same was true for homework. The more extracurricular activities also correlated with more time spent on homework (the authors wondered if both groups had a mindset of overachieving). No matter which group participants were in, parents placed the same level of emphasis	analyses was compromised. Group sizes between the experimental and control groups were not even. Sample is likely not representative of the whole population; all students were high achievers for example. 'Severity' of Autism not considered, and some siblings had more than their ASD diagnosis. Closed questions sometimes mean that an exploration into 'why' is lost. Strengths: Inclusion of qualitative information within the survey to allow views to be heard. Comparison group.
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							on the importance of school. Those with autistic siblings felt they had less support from parents to complete homework, but also reported needing less help, potentially indicating a level of learned self-sufficiency. No GPA/academic performance impact. Siblings cited being less judgemental of others in school. There was no difference between siblings of ASD and the controls in terms of if they felt they had to do better academically.	
Families living with ASD: roles and responsibilities of adolescent sisters (Cridland, 2016)	The aim of this research was to explore the experiences of neurotypical girls with younger adolescent brothers with	Australia	Aged 12-17 years old, all females and older than their autistic brother. Included 11 participants from 3 families. As the parents were spoken to as well as the	Not mentioned	Mainstream Secondary School	Qualitative - using an interview schedule. Questions were asked of the parents and children. Analysed using Thematic Analysis.	School: Sisters advocated for their brothers, being the big sister, mother hen, bodyguard were some of the terms used. Sisters would take up roles of liaising with their teachers	Limitations: Small sample, lack of generalisability as a result, social desirability of participant answers (named here as 'faking good'). The study does not just

ASD. It is stated that there was particular attention paid to the roles and responsibilities taken up at home and school.	siblings. This therefore involved 3 girls with autistic brothers who took part in the interviews.	about issues concerning their sibling. Sisters spoke of needing to protect their brothers from bullying, as well as educating their brothers about how to manage incidents in future. Sisters shared positive impacts e.g., feeling good about themselves, being able to help and understand their brother but also negatives around when their brothers didn't listen. Home: Tension between wanting to distance self and also engage with the family system. Wanting quality 1:1 time with their parents but sharing that opportunities were limited. General: Resilience, reduction in attention from parents and other, parents were unaware of their	explore the voices of sibling so some of the depth and breadth is not addressed fully. Strengths: exploration across a family system, allows an insight into the roles taken and what support siblings may need. Triangulation. Data on shared time in school not mentioned.
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							sibling desire for parental support.	
School Functions in Unfasted Siblings of Youths with Autism Spectrum Disorders (Chien et al, 2017)	The aim of this study was to compare several domains of school functioning in unaffected siblings of those with Autism, compared to siblings of typically developing children. Authors also hoped to identify possible correlates for any impaired school functioning in the unaffected siblings (e.g., IQ, any autistic traits, ADHD symptoms). Authors hypothesised that unaffected siblings demonstrate better school	Taiwan	Three groups of children were recruited. 66 young people with Autism, 66 unaffected siblings and 132 typically developing controls. All were aged between 8-19. Half of the unaffected sibling group were male, 63 out of 66 of the Autistic group were male and 98 in the TD group were male. ASD and sibling groups were recruited through Department of Psychiatry in Taiwan University Hospital. All participants are Chinese.	Information not collected	Aged 9-19 - school type not mentioned	Quantitative: ADI-R was used to validate diagnoses of ASD (translated into Chinese and accepted by World Psychological Association), Social Adjustment Inventory for Children and Adolescents - A semi structured interview tool that uses Likert ratings. The authors used four areas from this measure - academic performance, attitude towards schoolwork, school social interactions and school behaviour problems subscale. Parental reports were also gathered on the domains of school functioning and	The results showed that unaffected siblings of ASD youths do not have more severe impairments in academic performance and social interaction at school as compared to typically developing siblings. However, they demonstrated more negative attitudes toward schoolwork and more severe school behavioural problems. Unaffected siblings also have more comorbid symptoms of ADHD and oppositional defiant disorder, and this is suggested to be related to more behavioural difficulties and negative attitudes	Limitations: Recruitment was from one hospital, information around academic performance came from parental reports which may have been less accurate than looking at school data, and that the male dominance in the typically developing control group meant that there could not be statistical analysis around gender differences. Information around school settings was lacking - e.g., if siblings attended the same school. The data from the semi-structured interview tool are not analysed so qualitative

functions than their siblings with ASD, but worse than the typically developing controls. They hypothesised that school functions would be predicted by their own autistic traits, ADHD symptoms, sibling relationship, parenting style and autistic severity.

peer relations sections of the tool. Social Communication Questionnaire - 40 item parent rating scale to assess the characteristics of autistic behaviour. This was used to assess 'severity' of ASD. SNAP - IV scale which looks at core symptoms of ADHD. This was used with unaffected siblings. Social Responsiveness Scale - parent report scale using likers. Again, this measures ASD symptoms and was used to assess autistic traits in unaffected siblings. Parental bonding instrument - measures parenting style in the first 16 years.

towards school. These ADHD symptoms predicted academic underachievement, negative social interaction and behavioural problems in school. Specifically, it was inattentive symptoms rather than hyperactive-impulsive types which were related to school performance. Autistic traits in unaffected siblings were also related to school behaviour problems. They also found that communication difficulties in ASD siblings predicted lower school social interaction in unaffected peers. Parenting style was not related to school functioning in unaffected siblings.

information is lost. **Strengths** are related to investigating the unaffected siblings in a non-western country and using several reliable and validated measures. ASD sibling diagnoses were also validated by researchers.

Academic self-concept and sense of school belonging of adolescent siblings of autistic children (Gregory, 2020)	The aims of the study were to: (1) to explore group differences in academic self-concept and school belonging in those with autistic siblings compared to those with neurotypical siblings (2) To explore differences in self and parent reported psychological and behavioural measures across both groups and explore if any differences were related to differences in school outcomes.	UK	Aged between 11-16 years old. Used a control group who had siblings without ASD, and an experimental group with autistic siblings. 93% of the experimental group spoke English as a first language, and the same was true for the control group. Neighbourhood deprivation was between 1-10.	Information not collected	Secondary School in the UK	Quantitative: Scales = I as a learner, Psychological Sense of School Membership, Strengths and Difficulties Questionnaire (parent, self and teacher reported). Data analysed using t-tests, descriptive statistics, chi-squared, and regression. A group of 65 Autism siblings and 57 control siblings completed measures of school belonging, academic self-concept and behaviour problems. Parents and teachers also completed the SDQ for both groups.	Siblings of those with Autism reported significantly lower school belonging and academic self-concept. They also had significantly poorer self-reported behaviour problems, and this was also mirrored in their parents reports, Even when demographic variables were controlled for, these differences remained. Self and parent reports showed higher externalising difficulties (and parent reports also showed higher internalising difficulties).	Strengths: Triangulation of Information from self-reports, teachers and parents. Quantitative measures used mean that findings are clear and the impact of having an autistic sibling can be illustrated clearly. When analysing the data, demographic variables were controlled for and the link between having an autistic sibling and lower school belonging was still seen. Limitation: No qualitative information means we do not hear from the individual siblings and what contributed to the answers they gave on standardised questionnaires. There is also no information collected around
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								how long these children spent at school with their siblings, if at all.
I often have to explain to school staff what she needs: school experiences of non-autistic siblings growing up with an autistic brother or sister (Pavlopoulou, 2022)	Overarching goal: To stimulate the interest of educational psychology scholars in siblings by portraying their perspectives. The aims of the study more specifically were 1) to look at the nature and impact of siblings shared time at home during school term time, 2) explore the nature and impact of siblings shared time in school and 3) look at the levels of support that non-autistic siblings	UK, Southeast and the Midlands.	28 children between ages 6-14. 8 were boys and 20 girls. All autistic siblings had a formal diagnosis and 25 of them were boys. Most families were White British, some were Eastern European, Chinese, British Indian and Black. Some siblings had additional diagnoses > ADHD and Down Syndrome. All neurotypical siblings had no diagnoses of neurodevelopmental and mental health conditions. All families within socioeconomic groups 1-3.	Some participants attended the same schools as their siblings	Most attending a Primary School (19 of the participants)	Qualitative - using Reflexive Thematic Analysis. The data was collected via photo-elicitation interviews. In this method photos were used to prompt conversations around participant experiences. Participants all generated their own photos, drawings or brought their own objects to support the interview. Interviews were completed with a semi-structured interview schedule.	Findings indicate that there is impact of home experiences on schoolwork, homework, sleep disruptions, interactions in school impact on overall school experience, sense of connectedness with others with an autistic sibling/autistic teacher, teachers attitudes impact siblings experiences and wellbeing. Siblings shared a number of positives of having an autistic brother or sister, for example feeling they had learned to self-regulate, perspective take and share. Social time in school is said to be important as well as parents playing a key role in	Strengths: First qualitative exploration using participatory methods. Allowing participant voices to be heard. Sensitivity to participant autonomy. Limitations: Small sample size, only representative of those already seeking help via social media support groups, sample not homogenous in terms of sibling birth order or number of sibs in a family. Study lacks insight into researcher reflexivity and ideas around bias.

receive at school.	sibling support. Siblings also noted managing their brother/sisters' behaviours of concern.
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Appendix D: Critical Appraisal Tables

Table D1. Critical Appraisal Skills Programme (CASP) – Qualitative Research

Critical Appraisal Question	Article	
	Families living with ASD: roles and responsibilities of adolescent sisters (Cridland et al., 2016)	I often have to explain to school staff what she needs: school experiences of non-autistic siblings growing up with an autistic brother or sister (Pavlopoulou et al., 2022)
1. Was there a clear statement of the aims of the research?	Yes - the aim of this research was to explore the experiences of neurotypical girls with younger adolescent brothers with ASD. It is stated that there is particular attention paid to the roles and responsibilities taken up at home and school. There is a hypothesis stated: 'it is anticipated that there be an element of parentification' and that this will extend across both home and school. The author states that it is unclear how the two interact.	Yes - 3 aims 1) to look at the nature and impact of siblings shared time at home during school term time, 2) explore the nature and impact of siblings shared time in school and 3) look at the levels of support that non-autistic siblings receive at school.
2. Is the qualitative methodology appropriate?	Yes - the use of interviews allowed an exploration into participant experiences in line with the research aims	Yes - the study is clear that it is aiming to explore perspectives and experiences
3. Was the research design appropriate to address the aims of the research?	Authors outline how the research was conducted but not why interviews were selected to address the research questions	Yes - The authors use a participatory approach and explain clearly that this was to take an emancipatory approach to the research. Researchers explained that this would likely help keep the focus on topics that the siblings wanted to explore. They used a 'Sibling Advisory Group' who were involved in recruitment, creating information sheets and designing the methodological procedures. It is stated that the study adopts an 'Experience based collaborative and flexible approach to understanding sibling experiences rooted in the lifeworld theoretical model'. The framework is clearly outlined. However, it is not clear how and why the interview questions were selected or how the tasks were presented to either the advisory group or participants
4. Was the recruitment strategy appropriate to	Clear eligibility criteria are stated. Recruitment took place via local secondary schools and community groups, although the exact community groups and how this recruitment took place is unclear. Following interest, the author met with participants for an	The recruitment of the advisory group is unclear. It is also unclear how schools were approached as part of recruitment. Authors state that recruitment took place through advertisements on school and Autism social network sites in the UK but it is not

the aims of the research?	introductory meeting and to explain the information sheet. It is not stated if a number of participants opted out at this point or if all introductory meetings resulted in participation	stated which platforms were used and how many schools were approached. Authors state a snowballing approach within a Primary school but again it is unclear how this primary school became involved. It's not clear what the inclusion and exclusion criteria were.
5. Was the data collected in a way that addressed the research issue?	Yes. Data was collected using interviews which were created through 'multiple discussions with the authors'. This was piloted and adjustments were made - including wording changes to questions (although it is not stated what these adjustments looked like). There are appropriate considerations around the inclusion of 'warm up' questions to relax the participant. The interview had scope for flexibility allowing the exploration of participant experiences.	Yes. The data was collected via photo-elicitation interviews. In this method photos were used to prompt conversations around participant experiences. Participants all generated their own photos, drawings or brought their own objects to support the interview. Interviews were completed with a semi-structured interview schedule.
6. Has the relationship between researcher and participants been adequately considered?	No - not mentioned	No mention of the relationship or the potential relationship between the author and the school/social media channels used.
7. Have ethical issues been taken into consideration?	Ethical approval gained from university's human research ethics committee. Author states that ethical standards for researching with children were upheld and this included written consent from participants and parents. Interviews were conducted at a time appropriate for the participants and were conducted at an appropriate pace (although there is no explanation of what this looked like). Names were removed from all data presented in the paper.	Authors state they gained ethical approval and that pseudonyms were to anonymise participant identity.
8. Was the data analysis sufficiently rigorous?	Data analysed with the support of NVivo and used inductive coding outlined by Braun and Clarke, (2006). The authors outline the steps taken within thematic analysis but have not explicitly named that this is the approach used. The results section includes	Author uses Reflexive Thematic Analysis to look at themes. Themes and subthemes are shown as well as excerpts from the individual interviews to show where the themes came from. There

	named themes and uses excerpts of the transcripts to illustrate the themes.	is no outline of the process of thematic analysis, steps taken, and no mention of potential researcher bias.
9. Is there a clear statement of findings?	Yes. Findings indicated that sisters undertook various responsibilities for their brothers in school. Sisters reported that these became more prominent as they became older. There were mixed feelings around these roles (positive and negatives) but some reported burn out. Sisters shared that they also took on caregiving responsibilities at home. Sisters reported understanding and acceptance of their brothers and that this increased over time.	Very clear in the abstract: findings indicate that there is impact of home experiences on schoolwork, sleep disruptions, interactions in school impact on overall school experience, sense of connectedness with others with an autistic sibling/autistic teacher, teachers attitudes impact siblings experiences and wellbeing. Authors outline the strengths and limitations of the research and steps taken to ensure reliability and credibility (e.g., checking themes, intercoder reliability exercises).
10. How valuable is the research?	Authors outline additional support siblings may need and highlight the benefits of formal support services, for example family systems therapy. They discuss the need for sibling social support groups while also recognising that adolescents may resist formal support services. Authors highlight that it is critical for professionals to be aware of sibling needs and support this conversation and sharing of their views with parents and school staff. Authors suggest the need to look at a range of factors such as family size and culture and how these impact sister experiences in school and home.	Authors clearly state recommendations around training for staff, EP consultations in multiagency meetings, need for intervention at a whole school level and the need for follow up research. Follow up research is said to be needed in more diverse samples, looking at siblings in the adolescent age range, and exploring what siblings themselves may feel would increase inclusion.

Table D2. Holland and Rees Framework - Quantitative Research

Critical Appraisal Question	Article			
	Siblings of autistic children: their adjustment and performance at home and in school (Mates, 1990)	Pragmatic language and school related linguistic abilities in siblings of children with Autism (Ben Yizhak, 2011)	School Functions in Unaffected Siblings of Youths with Autism Spectrum Disorders (Chien et al., 2017)	Academic self-concept and sense of school belonging of adolescent siblings of autistic children (Gregory, 2020)
1. Focus - What is the topic of concern?	The 'adjustment' of children with autistic siblings, across the home and school contexts.	The linguistic abilities (pragmatic language, school achievements and reading processes) of children with an Autistic sibling, compared to those with a typically developing sibling.	School functioning amongst unaffected siblings or children with Autism.	School belonging, academic self-concept and behaviour difficulties in children with autistic siblings, compared to those with neurotypical siblings
2. Background - How does the researcher argue that the topic is worthwhile?	Yes - the paper explores the previous literature around the impact of neurotypical children when they have an autistic sibling. The paper clearly explains the mixed research in the idea and the idea that some children perform more highly on measures of self-concept when they have an autistic sibling. The paper outlines that the purpose of this paper is to extend and clarify the previous research by also looking at if gender and family size impact on the adjustment of siblings. The paper outlines similar research when a child has a sibling identified as 'disabled' but not Autism specifically. No clear explanation of what 'adjustment' refers to.	Yes somewhat - the authors explore the prevalence of increased risk of Broad Autism Phenotype in siblings of those with Autism and explain what difficulties this may be associated with. The authors outline the rationale for a longitudinal study to look at how this BAP develops over time and how it affects different areas of functioning in the siblings. They clearly state a summary of findings from the same group of children from when they were 4 months to 7 years old. Authors clearly outline the impact on academic abilities seen in unaffected siblings. There is no clear statement or argument as to why this research is worthwhile or why this understanding around linguistic	The introduction follows a clear structure to outline why this topic is important to research. It does this by first explaining the importance of education (as related to later life and health prospects), then the paper outlines school functioning in those with Autism and shares research around why this may be (related to executive function challenges for example). The paper then outlines that siblings have not been given as much attention within the research so far and that exploring their school functioning is important in	The paper clearly explains the national context regarding Autism and uses family systems theory to outline the importance of the sibling relationship. The authors outline previous literature into the outcomes for children with autistic sibling and outlines the need for this understanding across different contexts (e.g, school in this case)

		and school abilities is needed for this age group.	order to provide any support needed.	
3. Aim - What is the stated aim of the data collection?	The purpose is to 'assess whether gender of the sibling or family size played a significant role in the adjustment of siblings of autistic children'. This is clearly stated alongside 2 hypotheses. 1) female siblings will show poorer adjustment than males, and 2) siblings from two-children's families will show poorer adjustment than multi-child families. However, there are only very brief rationale for making these hypotheses.	This was part of a longitudinal study. The aim of the original study was to identify markers for Broad Autism Phenotype (symptoms that look like Autism in unaffected siblings), and to look at the trajectory of this development from birth into childhood. This study is a follow up of the children between ages 9-12. It is not clearly stated in the aims, but based on the methodology, appears that the specific focus is on linguistic abilities, pragmatic language, school achievements and reading processes)	The aims of this study are clearly stated at the end of the introduction: the aim was to compare several domains of school functioning in unaffected siblings of those with Autism, compared to siblings of typically developing children. Authors also hoped to identify possible correlates for any impaired school functioning in the unaffected siblings (e.g., IQ, any autistic traits, ADHD symptoms).	The aims are clear - they are focused on looking at group differences in school belonging, academic self-concept and behaviour in children with autistic siblings, compared to those with neurotypical siblings, as part of a control group.
4. Methodology - Does the approach taken seem suitable given the study aim?	The approach seems suitable - children were administer measures to assess self-concept and academic achievement was assessed. Teachers and parents given measures to report home and school adjustment. There are no specific details of how the academic achievement test was administered or how the teacher was selected to obtain school-based information. The use of the same measure to assess self-concept as previous research feels suitable in order to make comparisons around gender and family size, in the context of previous research.	Yes - this is an appropriate approach. Measures of school achievement as explored at home may be a different picture to in school, however.	The methods appear appropriate given the study aims however there are no details around how different measures were administered (e.g., online or in person).	The authors use an experimental and control group and administer 3 different standardised questionnaires to all children. Parents also completed one measure looking at behaviours. The methods appear appropriate, although there are no details around how they were administered (online, in person, private and confidential space etc)

5. Tool of data collection - What was the method used, is it reliable and accurate?	The Piers-Harris Self Concept Scale was used, along with Wide Range Achievement Test, Rutter Questionnaire for parents and Rutter Questionnaire for teachers. There are no comments around reliability of measures or rationale for why measures were selected (aside from the Piers-Harris scale being used in previous sibling research). Authors also compare children to the normative sample, rather than using a control group living in the same area/in the same schools.	Participants completed the Social and Communication Questionnaire, WRAT-III test of school achievement, Diagnostic Battery for Reading processes in Hebrew, the WISC assessment the CELF to assess language abilities. Any measures that needed to be, were translated into Hebrew. There are no comments around the reliability or validity of any measures used and no acknowledgment of any issues related to the translations/how culturally responsive standardised assessments may be.	ADI-R, Social Adjustment Inventory for Children and Adolescents, Social Communication Questionnaire, SNAP-IV and Parental Bonding Instruments were used. For each instrument used authors clearly state statistics of reliability and validity (for example, internal validity, test-re-test reliability, concurrent validity, discriminant validity and internal consistency). Where measures were translated into Chinese, this is transparently stated, along with clear indications of if this was the first time this translation had been done.	Strengths and Difficulties questionnaire, I as a Learner and the Psychological Sense of School Development tools were used. Data was also collected regarding demographics. Authors do not supply a copy of the demographic questionnaire created and there are no mentions of the accuracy or reliability of the standardised questionnaires. For example, no mentions of adjustment based on individual child needs (EAL).
6. Method of data analysis - Is the process described? Are the results clearly presented?	Authors present a very short results section. They outline that six, two-factor analyses of variance were used and that there were no differences on any measures as a function of gender or family size. The results are not outlined in any additional detail, for example p values are not reported and there are no explanations to accompany the table about what SSII, do and f, represent. It is therefore challenging to critique and interpret the data	Somewhat - The results are explored in terms of the significant differences on each measure, across the three groups (those with an autistic sibling with BAP themselves, those with an autistic sibling without BAP themselves and those with typically developing siblings. There is no exploration of software used to run the analyses.	There is a clear statement of the statistical tests used and that multiple comparisons were adjusted using Bonferroni corrections. Effect sizes are presented with Cohen's d. The statistical software used to run all tests is stated. Univariate and multi-variate analyses are used to examine determinants (e.g, ADHD traits) as related to school functioning. Information is	Clear statement that all data was screened and checked for any missing items. There is transparency around how many items were missing and that due to a low number, no participants were excluded from analysis. It is clear what statistical tests were used to analyse the data (t-tests, chi squared, regressions) and that guidance has been followed regarding interpreting data from varying effect sizes. There is no information supplied about the software used to analyse the

	independently from the authors discussion section.		outlined in a table but not presented clearly in a graph or chart. The Social Adjustment Inventory is used and said to be a semi-structured interview. However, analysis seems to only be taken from the Likert ratings - any qualitative information has been lost.	data. Information is outlined within a table but not presented clearly within a graph/chart.
7. Sample - how many people are the results based on?	33 children (18 boys and 15 girls). 18 of these were from two child families and 15 were from families with multiple children. 24 were the oldest sibling, 8 were younger than the sibling with ASD but older than other children in the family and 1 was a twin. All children were therefore the oldest neurotypical children in the family. Children were aged between 8 and 17 years old. 8 of the children were 'non white'. There are a clear statement of the number of teachers, parents and young people who did not complete certain sections of the study (e.g, 90% of teachers completed the teacher Rutter Questionnaire)	35 children with autistic siblings (11 girls and 24 boys) aged between 9-12 years old. The typically developing group was 42 siblings (21 girls and 21 boys, also aged between 9-12. All participants had an older sibling, across both groups.	The results are based on 66 Autistic young people, 66 unaffected siblings and 132 typically developing controls without Autistic siblings	The results are based on 65 Autism siblings and 57 control siblings. 73 parents completed the SDQ for the Autism group and 67 for the control group.
8. Ethical considerations - Did an ethics board approve? Is the whole study ethically rigorous?	There is no statement around ethical approval, and no exploration of measures taken to protect the wellbeing of participants (e.g., through debriefing) and no discussion of how participant data was stored safely. There is no exploration into the dynamics of conducting this	No statement around ethical approval gained, or any discussion around ethical issues pertaining to requiring children to complete a significant number of standardised assessments, or how data was stored securely/participants rights were respected. No information	There is a clear statement that the Research Ethics Committee of Taiwan University Hospital approved the study prior to recruitment. It is stated that written, informed consent was gathered from parents, but it is not	Information is supplied around ethical approval for the research. There is also clear mention of an 'opt in consent procedure' although this is not outlined in depth. There is transparency around offering participants a £5 voucher as payment for their time. There is a clear statement that all

	research with families who were part of the Chapel Hill TEACCH Centre - it is unclear if this was a centre that the researcher was personally affiliated with and therefore how this may have resulted in biased results or methods - equally this gives no room to explain how this bias was mitigated, if it was considered. Ethical considerations lack transparency.	around how consent or assent was sought from participants.	clear if written consent was also gathered from those over 16, and assent for those under 16. There is no mention of how data was stored securely or how it was anonymised. Authors do not mention how culturally responsive the standardised measures used were and if this was considered when interpreting results.	raw data was kept confidentially although it is not clear how this was done. No mention of standardised questionnaire bias or issues around equality, diversity and inclusion when using these measurements.
9. Main findings - Are these clear?	There is a clear statement of findings at the beginning of the discussion. Authors state that there was no significant difference across measures of adjustment between males and females, or between multi-child vs two child households. They also state that there are no differences between the siblings of those with Autism, and the normative samples on any measures. However, due to the limited results section, it is not possible to independently evaluate if these findings are coherent with the raw results.	Somewhat - the findings are identifiable but as the paper does not have a conclusion, the general summary/main findings can be somewhat difficult to follow.	Findings are clearly stated within the discussion. Unaffected siblings had more negative attitudes to schoolwork and more behavioural problems, but did not have significant impairments in academic performance and social interaction. As hypothesised, unaffected siblings ASD and ADHD traits were predictive of this, as were communication difficulties in their ASD siblings and difficulties in sibling relationship. Parenting style was not related. It not explored in depth how the unaffected siblings compared to their Autistic siblings as all findings are presented as the unaffected siblings compare to typically	Findings are clear as outlined in the abstract. Siblings of children with Autism reported significantly lower school belonging, academic self-concept and also reported externalising behaviours. Parents reported internalising behaviours also. When demographic variables were controlled for, group differences remained.

			developing controls - the information around ASD siblings is stated within the tables but not explored explicitly.	
10. Conclusion and recommendations - If they had a hypothesis is it stated if this was supported or rejected? Are clear recommendations made?	Hypotheses are rejection by the statement of findings. There are limited statements around further research and recommendations are unclear. For example, there is a statement around siblings not needing therapeutic intervention but that educational materials may serve as sibling interventions instead, but it is unclear that these materials refer to and why these may be needed, as the hypotheses around poorer sibling adjustment were rejected.	Authors state a hypothesis that siblings with BAP will show lower language related abilities - there is no clear statement later accepting or rejecting this. There are no recommendations made.	There is a clear statement within the conclusion about the findings of the paper. It is not explicitly stated which hypotheses are rejected or accepted but based on clear findings it is mostly clear. It is less clear as to if the hypothesis around unaffected siblings showing higher school adjustment than ASD siblings but lower than typically developing controls, is rejected or accepted. There are clear recommendations around the role of health and educational professionals, as well as recommendations for further research which is longitudinal.	There is no hypothesis stated. There is a clear conclusion about the differences between groups and clear suggestions for future research into younger children, children's qualitative experiences, longitudinal research into reasons for poorer outcomes, and exploring impact on academic attainment. There are recommendations made around practitioner awareness of sibling need so they can be supported within school-based consultations, assessment, intervention and training sessions, as well as exploring whole school approaches for this at-risk group.
11. Overall strengths and limitations - What are they? Did they acknowledge?	Strengths: Triangulation of information from children, parents and teachers. Authors explore the high response rate of gathering this information from the necessary individuals. Limitations: Bias in recruitment and also measures used e.g, psychometric test bias. All children had received support via a	Yes - somewhat although the exploration of strengths and limitations is limited. They note a small sample size as a limitation but that using a comparison group was a strength.	Yes - these are transparent and stated clearly within the discussion. Limitations are discussed to be that recruitment was from one hospital, information around academic performance came from parental reports which	Yes - these are transparent and clearly acknowledged. Strengths include the sample size, a focus on a narrow age range and triangulation of information. Limitations include the method of recruitment which may have led to bias in sampling, social desirability when answering questionnaires and a lack of

	TEACCH programme which is designed to help those families with an autistic child and therefore no significant difference for the siblings may be a result of support they are receiving through the programme. No qualitative information gathered from any participants in the research. Regarding the normative samples, are the normative samples excluding children with autistic siblings? If not, this may need to be considered when comparing to the normative sample. Authors acknowledge that many variables were also not controlled for (e.g., age range of siblings).		may have been less accurate than looking at school data, and that the male dominance in the typically developing control group meant that there could not be statistical analysis around gender differences. Information around school settings was lacking - e.g., if siblings attended the same school. Strengths are related to investigating the unaffected siblings in a non-western country and using several reliable and validated measures. ASD sibling diagnoses were also validated by researchers.	measuring 'prosocial' behaviours as the SDQ does not measure this - there may have therefore been a loss of information about the positive of having an autistic sibling.
12. Application to practice - How do the results relate to practice?	Results are not directly linked to EP, teacher or parent practices. There are no statements around further intervention other than the comment around needing educational materials rather than therapeutic intervention for siblings. There is no explanation around what this may mean or look like.	Results are not clearly linked to practice. There are no statements around follow up research or support that any individuals within the study may need.	The paper broadly states that a number of professionals should monitor unaffected siblings, but it is not clear what this might look like, and does not explore the EP role in being part of this supportive picture,	These results are related clearly to EP practice in supporting schools. The paper may have benefited from acknowledgement of how teachers may play a role in supporting siblings of those with Autism, as well as what a whole school approach may look like, based on findings.

D3. Mixed Methods Appraisal Tool (MMAT) -Mixed Methods Research

Barak-Levy et al, (2010)		
Category of Study Designs	Methodological Quality Criteria	Response
Screening Questions	Are there clear research questions?	No - there is an explanation of the purpose, but this is not framed as research questions. The purpose is said to be a mixed methods exploration into the social and emotional adjustment of children with an autistic sibling
	Do the collected data allow to address the research questions?	Yes - the data collected allow an insight into the area being explored. Due to there not being clear research questions, it is not possible to say if they are 'answered' however.
Qualitative Component	Is the qualitative approach appropriate to answer the research question?	Somewhat. There are two questions asked of parents 'what troubles you most about your child' and 'describe the good qualities of your child'. These questions allow deeper insight into parent views, but they do not directly address social, emotional and school adjustment and are leading questions.
	Are the qualitative data collection methods adequate to address the research question?	Somewhat - use of two open ended questions. It is not clear if follow up prompts were used as part of a semi structured interview or otherwise.
	Are the findings adequately derived from the data?	There is no explanation of how themes were derived from the answers given. Authors state that answers were themed and then statistical analyses using Mann Whitney-U was used to compare percentages of theme occurrence between test and control groups.

	Is the interpretation of results sufficiently substantiated by data?	Somewhat - quotes are presented to illustrate the themes but it is less clear which quotes formed each theme.
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes - authors draw on various sources during the discussion/findings sections to both interpret and analyse data and draw conclusions.
Quantitative Component	Is the sampling strategy relevant to address the research question?	Yes, somewhat - purposive sampling used to find families that fit within the target population. Teachers were also involved in recruiting families, but it is not clear how this took place
	Is the sample representative of the target population?	Yes - inclusion criteria are that children live at home with their autistic sibling and that their autistic sibling is in specialist school. 27 families took part and there is a relatively even split between males and females (all aged 6-18). A well-matched comparison group was also recruited. Unclear if this number and gender split is representative of those generally with autistic siblings.
	Are the measurements appropriate?	Yes. Child Behaviour Checklist used by parents and Weinberger Adjustment Inventory used with children. These were Hebrew translations which were reported to have good reliability and validity measures.
	Is the risk of nonresponse bias low?	Unsure - this is not discussed.
	Is the statistical analysis appropriate to answer the research question?	Yes, in the form of descriptive information and Mann Whitney U tests to compare groups.
Mixed Methods Component	Is there an adequate rationale for using a mixed methods design to address the research question?	Somewhat - it is stated in the discussion as allowing a more comprehensive picture of siblings, but this is not stated at the outset as a

	rationale for using mixed methods - this is more of a reflection in retrospect.
Are the different components of the study effectively integrated to answer the research question?	Yes, the two strands are integrated. There is more focus on the quantitative information, but this is proportional to the amount of quantitative vs qualitative data gathered.
Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	As Above
Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	N/A
Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	To some extent - this is not transparently discussed within the research. Specifically, there are no comments around credibility and trustworthiness for the qualitative information gathered.

Table D4. Thesis Appraisal Tool

Herman, (2013)	
Critical Appraisal Questions	Methodological Quality Criteria
Study aims Is there a clear statement of the aims of the research? Is the aim / goal important and relevant?	Yes. The aim of this paper was to look at the academic impact of having a sibling with Autism. The author explains why it is important (e.g., because most previous papers have looked at psychological outcomes, rather than school experiences).
Participants Was the recruitment strategy appropriate for the aims of the study?	Detailed explanations around how recruitment took place. Information sheets and study materials passed out by class teachers/appropriate school-based adults. There is a clear explanation about why and how recruitment from specialist schools was different.
Method / design / analysis Is the methodology appropriate for the research aims? Does the researcher justify their choice of method / design / analysis? For Mixed Methods - are the two strands integrated well? Are the methods used clear e.g., if interviews used, is there indication of how they were conducted?	Clear and transparent information around the methods used. For example, surveys shared via Survey Monkey and guidance around how long surveys took to complete. Explanation of the qualitative questions included at the end of the survey, and these are shared descriptively within the paper. MANCOVA tests run on the data. Effect sizes reported.
Worldview / paradigm / ontology and epistemology? Is this clearly stated? Is it appropriate? Any tensions?	Not stated
Findings / knowledge generated Is this transparent and coherent? Is there impact and importance of the knowledge generated? The 'so what?' of the study. What are the implications of the study? Are they stated?	Findings are stated in detail and are split into themes of academic performance, sibling relationship related to academic experiences, parent relationships as related to academic experiences and general time for school-related activities. Implications around professional awareness was explored.
Ethical considerations Have ethical considerations been taken into consideration and if so, how? E.g., ethical issues discussed, ethical approval sought, EDI considerations more generally e.g., re reflexivity, researcher impact?	Authors share considerations around protecting participant anonymity and confidentiality, as well as sharing both consent and assent forms for children who were under 16 but over 13. Clear explanation of how data was secure when collected via survey monkey (including an upgrade to ensure data was encrypted).

Is there **compatibility and alignment** between the assumptions, position, design and critique of the study?

Researcher reflexivity

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

Not addressed in the paper

Has the researcher examined their role and influence in the study?

Is there sensitivity to context regarding previous literature, the perspective and sociocultural context of ppts, and in data analysis?

Data analysis

Is there sufficient depth of analysis and inclusion of all data to generate new insights?

Is there an in-depth description of the data-analysis process?

If other researchers coded the data, why was this and was it appropriate?

How were disconfirming cases explored?

Paper trail / audit?

Qualitative information gathered is not analysed using a formal method which may mean that some data is lost or not given the depth of analysis is requires to show insights about experience. No mention of a second data coder for reliability.

Appendix E: Ethical Approval

E1: Tavistock and Portman NHS Trust Research Committee Approval

The Tavistock and Portman 
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699

<https://tavistockandportman.nhs.uk/>

Maisie Thurman

By Email

26 March 2024

Dear Maisie,

Re: Trust Research Ethics Application

Title: *'An exploration into the school experiences of children and young people who have a sibling with Autism Spectrum Disorder (ASD).'*

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please be advised that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

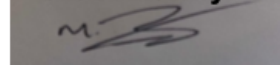
If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Michael Franklyn



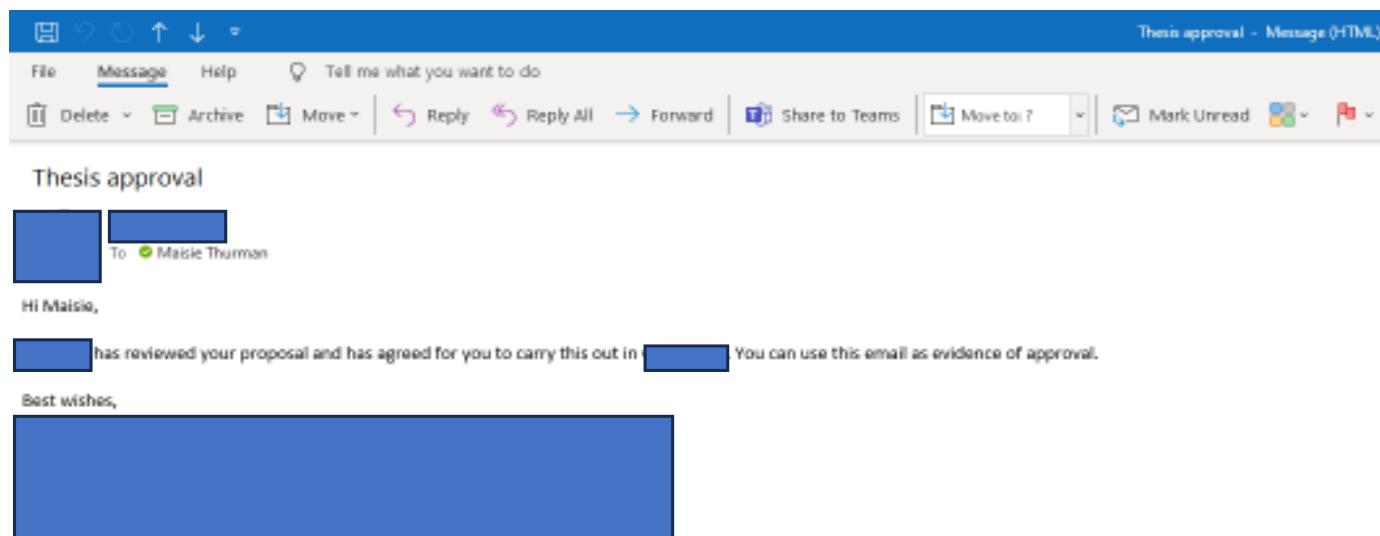
Academic Governance and Quality Officer

T: 020 938 2699

E: academicquality@tavi-port.nhs.uk

cc. Course Lead, Supervisor, Research Lead

E2: Approval from LA Principal Educational Psychologist



Appendix F: Research Flyer for Recruitment

The Tavistock and Portman **NHS**
NHS Foundation Trust



CALL FOR PARTICIPANTS

"An exploration into the school experiences of children and young people who have a sibling with Autism Spectrum Disorder (ASD)."



My name is Maisie

Im a Trainee Educational Psychologist and I'm currently studying at the Tavistock and Portman NHS Trust.



My Research

As part of my research, I would like to speak with young people (aged 14-18) who have a sibling with Autism Spectrum Disorder* and who are currently attending a school or college. I would like to hear about your experiences in education.



Taking Part

If you take part in this study, it will involve a 1:1 interview with me where we explore your experiences in school. You can choose for this to me in school/college or at home.



Extra Information

The interview will last around an hour and will be voice recorded so that I can listen back to it.



More Information

For more information, please email me, or if you are under 16, ask your parent/carer to email me. My email is **mthurman@tavi-port.nhs.uk**

THANK YOU!

Participant Information Sheet: Parents and Carers

Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

The purpose of this information sheet is to provide the necessary background information about this research project. This information will need to be thoroughly read and considered in order to give informed consent for participation.

Who is doing the research?

My name is Maisie Thurman, and I am a Trainee Educational Psychologist. This piece of research is part of my course and will be supervised by Dr Lisa Bostock.

What is the aim of the research?

The aim of this research is to understand how young people who have a sibling with ASD experience education. While children and young people who are diagnosed with ASD have been involved in research to understand their own experiences, their siblings have rarely been involved in sharing their own experiences. Some research has looked into how having a sibling with ASD influences experiences at home, but so far, understanding how this may influence educational experiences hasn't been explored in much depth. It is hoped that by understanding the experiences of siblings more, those who work with them may be better able to provide support if needed or be more equipped to celebrate their strengths.

Who has given permission for this research?

X Educational Psychology Service has given permission for this research to take part in schools within the local authority. In addition to this, the Ethical Review Board of the Department of Education and training at Tavistock and Portman NHS Foundation Trust, with whom I am completing my training, have also provided ethical approval for this research to proceed. With this approval, my full research proposal has been considered and it has been decided that this research project meets the necessary ethical standards to protect the safety and wellbeing of all participants who are involved.

Who can take part in this research?

I am looking for young people between the ages of 14-18 who have a sibling diagnosed with ASD, and who are happy to talk both about this experience, as well as their experiences with school or college. It is really important that your child is aware of their sibling's diagnosis.

What will be involved in taking part?

If your child takes part, the steps will be as follows:

- Your child will be asked a few questions about their experiences of having a sibling with Autism, both at home and school, and how the two may impact on each other.
- Your child will be offered the chance to draw to gather their thoughts about the questions presented to them.
- This conversation will be audio recorded and transcribed (written up), and I will keep their drawing so that I can refer to it when looking at their answers.

As the conversation will be led by what your child chooses to share, there is a potential that they may share things that have been difficult for them, and that the conversation could feel challenging. If this is the case, they can choose to end the interview, or I will stop it if necessary. In the event of them becoming distressed, you will be informed, as will a nominated adult within school. The named adult in school will then check in with your child before the end of the day, and then a week later.

What are the possible benefits of taking part?

It is hoped that your child will feel empowered by sharing their own experiences in education, and that they will benefit from a space to feel listened to and heard. In providing important information about their lived experiences, they are also adding to a so far limited research base that people who support them can use to help others with similar experiences, as well as themselves.

Where will this research take place?

The interview will last for approximately an hour and will either take place in your child's school or college, at your house, or at XXX, depending on what you and your child prefer. If at your house, the interview can take place in person or online using Zoom. If online, it will be conducted using a laptop, rather than a phone to ensure a secure connection. The interview will take place in a quiet space so that the conversation can be recorded. Your child does not need to bring anything with them for the interview, unless they wish to complete a drawing from home, in which case they will need some paper and pencils.

What will happen to the interview recording and drawing?

When the interview ends, your child will be asked to choose a pseudonym (an alternative name) that they wish to be used instead of their real name, to protect their anonymity. This pseudonym will be used when reflecting on their interview when writing up the paper and will be used instead of their own name on all other stored information (for example the name used when saving the audio recording).

Any drawing or writing your child has done will be scanned and saved in a password protected folder, the original copy will then be destroyed securely. Only I will have access to the password for all files saved on a computer.

The audio recording and drawing will be retained in a password protected location and after the audio recording has been transcribed, the recording will be deleted. The transcript and any drawing completed will be included in the write up of the research.

Any records related to your child taking part will be stored and handled appropriately for 6 - 10 years in line with the Tavistock and Portman NHS Trust Data Protection Policy [Trusts' s Data Protection and handling Policies](#).

Will taking part be kept confidential?

If your child takes part in the research, their involvement will not be shared with anyone, other than a named adult who will be nominated to check on them afterwards, and a member of school staff if your child wishes to have the interview

conducted there. If they choose to have the interview conducted in school, all that will be known by the SENCo or Headteacher, is that your child is involved in research, and what the nature of the research is - they will not be informed of the content of the interview, unless there are any concerns about a risk to your child, or others, raised in the duration of our conversation. If this is the case, yourself and your child will be informed who will be told, and the nature of the disclosure.

Disclaimer

Your child does not have to take part in this study, and if they do take part, they are free to withdraw at any time during the interview. If they choose to end the interview, they don't have to give any reason.

Further information and contact details:

If you have any questions about any part of the research, please get in contact with me and let me know.

Email: mthurman@tavi-port.nhs.uk

Phone Number: 07864685487

Supervising Educational Psychologist email: lbostock@tavi-port.nhs.uk

Tavistock and Portman Trust Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Paru Jeram, Trust Quality Assurance Officer pjeram@tavi-port.nhs.uk

G2 – Young Person/Participant

Participant Information Sheet

Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

Who is doing the research?

My name is Maisie Thurman, and I am a Trainee Educational Psychologist. This piece of research is part of my course and will be supervised by Dr Lisa Bostock.



Would you like to part in this research?

- Before you decide if you would like to take part, it is really important for you to understand why this research is being done, and what it would involve for you.
- Take some time to read through this information sheet so you can decide if you want to take part or not. You don't have to take part if you don't want to, it is up to you.
- If you are under 16, we will also need to get permission from your parent/guardians.

What is the aim of the research?



- The aim of this study is to understand more about the school experiences of young people who have a sibling with Autism Spectrum Disorder (ASD).
- At the minute, there isn't much research into ASD where the siblings are asked about their experiences and opinions – I would really like to hear this from you.
- My hope is that in understanding these experiences better, young people who have a sibling with ASD can access support if they need it or can feel empowered to share their experiences with other people in their lives.

Who has given permission for this research?

- X Educational Psychology Service (where I work) and the Ethics Board at the Tavistock and Portman NHS trust (where I study) have given me permission to do this research.
- A committee of people at the Tavistock have checked my research plans to make sure that your rights will be protected if you take part, and that the research will be carried out safely.



Who can take part in this research?

- I am looking for young people who have sibling with ASD, who feel comfortable to talk to me about their experiences in education.
- You do not have to take part in this research, it is completely up to you.
- You are free to withdraw (stop taking part) at any time up until 2 weeks after your interview and you don't need to tell me why. If you decide to withdraw, that is absolutely fine, and your choice will be respected without question.

What will I have to do?



- You can choose to meet me at your home (in person or on Zoom, using a laptop), in school/college or at XXX – wherever you feel more comfortable to speak to me.
- If we meet at school, someone in school will tell you where to meet me. It will be during the school day, and we can make sure it isn't during a time where you are having a break or lunch.
- Wherever we meet, we will be in a quiet room, and we can put a sign on the door to tell people not to enter during our conversation.
- I will ask you some questions about your experiences in school and at home, and you may also do some drawing if this helps you to think of what you want to share with me. This will last for around 1 hour.
- Our conversation will be audio recorded, but there will be no video recording. This is so that I can listen back and make sure I don't miss any parts of what you share.
- Only I will have access to the audio recording, and it will password protected on a computer to make sure it is safe.
- The recording will be deleted once I have typed it up, and your drawing will be shredded after I have scanned it onto a computer and password protected it.
- You will have the chance to choose a pseudonym (pretend name) so that your interview can be kept confidential and won't be identifiable as yours. Your school's name and any other names you share will be removed when I write up your interview.



What are the possible benefits of taking part?

- There isn't much research that looks at the experiences of siblings at the minute – sharing your thoughts increases the knowledge of people who help young people in schools.
- In sharing your experiences, you have the opportunity to reflect on how things have been for you. I think this would be really helpful for those who currently support you in school and at home, in case you feel you need more support, a chance to share your successes, or a bit of both.



Will taking part be kept confidential?



- Yes. If you take part, I follow all the ethical and legal practice guidelines for carrying out research. All information you share will be stored securely and password protected.
- Your identity on all records will be protected with the pretend name that you choose, rather than your own name.
- The audio recording will be written up, and then I will delete the recording.
- Any records related to you taking part will be stored for 6 - 10 years and then destroyed in line with the Tavistock and Portman NHS Trust Data Protection Policy [Trusts' s Data Protection and handling Policies.](#)
- When the research is written up, it will be accessible to the public on the internet. Because I am only speaking to a small number of young people (around 4-6), it is possible that people who know you well, will be able to tell which answers are yours, even though your name, your siblings name, or the name of your school will not be included.
- **However**, if you tell me something that makes me concerned about your safety or the safety of others, I might have to share that information with someone who can help to keep you safe. I would always discuss this with you first, and we can discuss who will need to be informed.



What will happen to the findings of the research?

- The findings of my research will be typed up and will be my thesis which is a part of my Educational Psychology Qualification.
- After my thesis is completed, it will be accessible to the public on the internet.

Disclaimer

You don't have to take part in this research, and you are free to withdraw (stop) from the interview at any time. You don't have to give me a reason for withdrawing and no one will mind at all. If you decide to stop the interview, I will delete your audio recording and any other information that I have from you.

Further information and contact details:

If you have any questions about any part of the research, please get in contact with me and let me know. If you are under 16, please ask your parents/carers to reach out to me.

Email: mthurman@tavi-port.nhs.uk

Phone Number: 07864685487

Supervising Educational Psychologist email: lbostock@tavi-port.nhs.uk

Tavistock and Portman Trust Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Paru Jeram, Trust Quality Assurance Officer pjeram@tavi-port.nhs.uk

Participant Information Sheet: Parents and Carers (Pilot Study)**Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)**

The purpose of this information sheet is to provide the necessary background information about this research project. This information will need to be thoroughly read and considered in order to give informed consent for participation in a pilot study.

Who is doing the research?

My name is Maisie Thurman, and I am a Trainee Educational Psychologist. This piece of research is part of my course and will be supervised by Educational Psychologist Dr Nikki Collingwood.

What is the aim of the overall research?

The aim of this research is to understand how young people who have a sibling with ASD experience education. While children and young people who are diagnosed with ASD have been involved in research to understand their own experiences, their siblings have rarely been involved in sharing their own experiences. Some research has looked into how having a sibling with ASD influences experiences at home, but so far, understanding how this may influence educational experiences hasn't been explored in much depth. It is hoped that by understanding the experiences of siblings more, those who work with them may be better able to provide support if needed or be more equipped to celebrate their strengths.

What is a 'pilot study'?

Your child is being invited to take part in the first step of this research project, which is called a pilot study. A pilot study helps a researcher to know how much time subsequent interviews will take, if any additional questions need to be asked of other children who take part and helps to make any adjustments to the research if needed based on their feedback of taking part. Your child's participation in the pilot will be included in the write up of this research, but their full interview will not be analysed along with the rest of the children and young people who take part.

Who has given permission for this research?

X Educational Psychology Service has given permission for this research to take part in schools within the local authority. In addition to this, the Ethical Review Board of the Department of Education and training at Tavistock and Portman NHS Foundation Trust, with whom I am completing my training, have also provided ethical approval for this research to proceed. With this approval, my full research proposal has been considered and it has been decided that this research project meets the necessary ethical standards to protect the safety and wellbeing of all participants who are involved.

What will be involved in taking part?

If your child takes part, the steps will be as follows:

- Your child will be asked a few questions about their experiences of having a sibling with additional needs, both at home and school, and how the two may impact on each other.
- Your child will be offered the chance to draw to gather their thoughts about the questions presented to them.
- This conversation will be audio recorded and transcribed (written up), and I will keep their drawing so that I can refer to it when looking at their answers.

As the conversation will be led by what your child chooses to share, there is a potential that they may share things that have been difficult for them, and that the conversation could feel challenging. If this is the case, they can choose to end the interview, or I will stop it if necessary. In the event of them becoming distressed, you will be informed, as will a nominated adult within school. The named adult in school will then check in with your child before the end of the day, and then a week later.

What are the possible benefits of taking part?

It is hoped that your child will feel empowered by sharing their own experiences in education, and that they will benefit from a space to feel listened to and heard. In providing important information about their lived experiences, they are also adding to a so far limited research base that people who support them can use to help others with similar experiences, as well as themselves.

Where will this research take place?

If at your house, the interview can take place in person or online using Zoom. If online, it will be conducted using a laptop, rather than a phone to ensure a secure connection. The interview will take place in a quiet space so that the conversation can be recorded. Your child does not need to bring anything with them for the interview, unless they wish to complete a drawing from home, in which case they will need some paper and pencils.

What will happen to the interview recording and drawing?

When the interview ends, your child will be asked to choose a pseudonym (an alternative name) that they wish to be used instead of their real name, to protect their anonymity. This pseudonym will be used when reflecting on their interview when writing up the paper and will be used instead of their own name on all other stored information (for example the name used when saving the audio recording).

Any drawing or writing your child has done will be scanned and saved in a password protected folder, the original copy will then be destroyed securely. Only I will have access to the password for all files saved on a computer.

The audio recording and drawing will be retained in a password protected location and after the audio recording has been transcribed, the recording will be deleted.

Any records related to your child taking part will be stored and handled appropriately for 6 - 10 years in line with the Tavistock and Portman NHS Trust Data Protection Policy [Trusts 's Data Protection and handling Policies](#).

Will taking part be kept confidential?

If your child takes part in the research, their involvement will not be shared with anyone, other than a named adult who will be nominated to check on them afterwards, and a member of school staff if your child wishes to have the interview conducted there. If they choose to have the interview conducted in school, all that will be known by the SENCo or Headteacher, is that your child is involved in research, and what the nature of the research is - they will not be informed of the content of the interview, unless there are any concerns about a risk to your child, or others, raised in the duration of our conversation. If this is the case, yourself and your child will be informed who will be told, and the nature of the disclosure.

Disclaimer

Your child does not have to take part in this study, and if they do take part, they are free to withdraw at any time during the interview. If they choose to end the interview, they don't have to give any reason.

Further information and contact details:

If you have any questions about any part of the research, please let me or the school SENCo know, who can then inform me.

Email: mthurman@tavi-port.nhs.uk

Phone Number: 07864685487

Supervising Educational Psychologist email: ncollingwood@tavi-port.nhs.uk

Tavistock and Portman Trust Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Paru Jeram, Trust Quality Assurance Officer pjeram@tavi-port.nhs.uk

G4 – Pilot Information Sheet (Young Person/Participant)

Participant Information Sheet (Pilot Study)

The Tavistock and Portman **NHS**
NHS Foundation Trust

Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)**Who is doing the research?**

My name is Maisie Thurman, and I am a Trainee Educational Psychologist. This piece of research is part of my course and will be supervised by Educational Psychologist, Dr Nikki Collingwood.

**Would you like to part in this research?**

- Before you decide if you would like to take part, it is really important for you to understand why this research is being done, and what it would involve for you.
- Take some time to read through this information sheet so you can decide if you want to take part or not. You don't have to take part if you don't want to, it is up to you.
- If you are under 16, we will also need to get permission from your parent/guardians.
- You are free to withdraw (stop taking part) at any time up until 2 weeks after your interview and you don't need to tell me why. If you decide to withdraw, that is absolutely fine, and your choice will be respected without question.

What is the aim of the research and being in a 'pilot study'?

- The aim of this study is to understand more about the school experiences of young people who have a sibling with Autism Spectrum Disorder (ASD).
- At the minute, there isn't much research into ASD where the siblings are asked about their experiences and opinions.
- My hope is that in understanding these experiences better, young people who have a sibling with ASD can access support if they need it or can feel empowered to share their experiences with other people in their lives.
- You are being asked to be in a 'pilot study' which means you are involved in the very first step of this research! By being involved it can help me to understand if my questions need to be adjusted to help people share their thoughts, and you can share valuable feedback to me about what it was like

to take part.

Who has given permission for this research?

- X Educational Psychology Service (where I work) and the Ethics Board at the Tavistock and Portman NHS trust (where I study) have given me permission to do this research.
- A committee of people at the Tavistock have checked my research plans to make sure that your rights will be protected if you take part, and that the research will be carried out safely.



What will I have to do?

- You can choose to meet me at your home (in person or on Zoom using a laptop), or in school/college – wherever you feel more comfortable to speak to me.
- If we meet at school, someone in school will tell you where to meet me. It will be during the school day, and we can make sure it isn't during a time where you are having a break or lunch.
- Wherever we meet, we will be in a quiet room, and we can put a sign on the door to tell people not to enter during our conversation.
- I will ask you some questions about your experiences in school and at home, and you may also do some drawing if this helps you to think of what you want to share with me. This will last for around 1 hour.
- Our conversation will be audio recorded, but there will be no video recording. This is so that I can listen back and make sure I don't miss any parts of what you share.
- Only I will have access to the audio recording, and it will password protected on a computer to make sure it is safe.
- The recording will be deleted once I have typed it up, and a physical copy of your drawing will be shredded after I have scanned it onto a computer and password protected it.
- You will have the chance to choose a pseudonym (pretend name) so that your interview can be kept confidential and won't be identifiable as yours. Your school's name and any other names you share will be removed when I write up your interview.



What are the possible benefits of taking part?

- There isn't much research that looks at the experiences of siblings at the minute – sharing your thoughts increases the knowledge of people who help young people in schools.
- In sharing your experiences, you have the opportunity to reflect on how things have been for you. This might be really helpful for those who currently support



you in school and at home in case you feel you need more support, might be a chance to share your successes, or a bit of both.

Will taking part be kept confidential?



- Yes. If you take part, I follow all the ethical and legal practice guidelines for carrying out research. All information you share will be stored securely and password protected.
- Your identity on all records will be protected with the pretend name that you choose, rather than your own name.
- The audio recording will be written up, and then I will delete the recording.
- Any records related to you taking part will be stored for 6 - 10 years and then destroyed in line with the Tavistock and Portman NHS Trust Data Protection Policy [Trusts' s Data Protection and handling Policies](#).
- When the research is written up, it will be accessible to the public on the internet. Because I am only speaking to a small number of young people (around 4-6), it is possible that people who know you well, will be able to tell which answers are yours, even though your name, your siblings name, or the name of your school will not be included.
- **However**, if you tell me something that makes me concerned about your safety or the safety of others, I might have to share that information with someone who can help to keep you safe. I would always discuss this with you first, and we can discuss who will need to be informed.



What will happen to the findings of the research?

- The findings of my research will be typed up and will be my thesis which is a part of my Educational Psychology Qualification.
- After my thesis is completed, it will be accessible to the public on the internet.

Disclaimer

You don't have to take part in this research, and you are free to withdraw (stop) from the interview at any time. You don't have to give me a reason for withdrawing and no one will mind at all. If you decide to stop the interview, I will delete your audio recording and any other information that I have from you.

Further information and contact details:

If you have any questions about any part of the research, please let me or the school SENCo know, who can then inform me.

Email: mthurman@tavi-port.nhs.uk

Phone Number: 07864685487

Supervising Educational Psychologist email: ncollingwood@tavi-port.nhs.uk

Tavistock and Portman Trust Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Paru Jeram, Trust Quality Assurance Officer pjeram@tavi-port.nhs.uk

Appendix H: Consent Forms

The Tavistock and Portman 
NHS Foundation Trust

H1 – Parent/Carer

Parent/Carer Consent Form

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

In giving my consent, I state that:

- I have read and understood the information sheet and have had the chance to ask questions.
- I understand what is being proposed and the procedures that will be involved in this research.
- I understand that participation in this research is voluntary and that my child is free to withdraw (stop taking part) at any time until 2 weeks after their interview without giving a reason.
- I understand that my child's involvement in this study, and the data gathered, will remain confidential. Only the researchers involved in this study will have access to the data.
- I understand that my child's interview will be audio recorded and transcribed.
- I understand that any drawing completed will be included in the write up of the research.
- It has been explained to me how long this data will be saved for and what will happen to it after this time.
- I understand that the findings from this research will be written up as part of a thesis.
- I understand that my child's data will be anonymised to reduce the chance of people linking the data to them. This will involve using pseudonyms (alternative names) for your child, and the sibling they are speaking about. However, due to the small number of people involved in the research, it is possible that people who know your child well, may be able to identify them from answers given.

I hereby freely and fully consent to my child participating in the study which has been fully explained to me.

Participant's (child's) Name (BLOCK CAPITALS)

.....

Parent/Carer's Signature

.....

Investigator's Name (BLOCK CAPITALS)

.....

Investigator's Signature

.....

Date:

Participant Consent Form (Age 16-18)

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

Please read each statement carefully and tick the boxes below if you agree with them:

	Statement	Tick if yes 
1. 	I have read and understood the information sheet and have had the chance to ask questions.	
2. 	I understand what will be involved if I take part in this research.	
3. 	I understand that my participation in this research is voluntary and that I don't have to take part.	
4. 	I understand that I can withdraw (stop taking part) at any time until 2 weeks after my interview, without giving a reason	
5. 	I understand that if I take part in this research, my involvement will be confidential and my name, or any personal information won't be linked to the answers I give.	
6. 	I understand and agree to my interview being audio recorded, and that any drawing I complete will be included in the write up of the thesis.	
7. 	It has been explained to me how long my information will be saved for and what will happen to it after this time.	
8. 	I understand that the findings from this research will be written up as part of a thesis.	
9. 	I understand that because the research only involves a few people (4-5), people who know me well may be able to tell which answers are mine.	
10. 	I understand that my information will be kept and stored safely	
11. 	I understand that if I tell the researcher something that concerns them about my safety, or the safety of someone else, they will have to let someone know.	

a) I would like to see the researcher at (tick):

Home (in person) ☐

Home (online) ☐

School/college ☐

XXX ☐

b) I would like the researcher to send me a one-page summary when she finishes the study (tick).

Yes ☐

No ☐

Name

.....

Signature

.....

Investigator's Name

.....

Investigator's Signature

.....

Date:

Thank you for your help.

H3 – Young Person Assent (Under 16)

Participant Assent Form (Under 16)

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

Please read each statement carefully and tick the boxes below if you agree with them:

	Statement	Tick if yes 
1. 	I have read and understood the information sheet and have had the chance to ask questions.	
2. 	I understand what will be involved if I take part in this research.	
3. 	I understand that my participation in this research is voluntary and that I don't have to take part.	
4. 	I understand that I can withdraw (stop taking part) at any time until 2 weeks after the interview, without giving a reason	
5. 	I understand that if I take part in this research, my involvement will be confidential and my name, or any personal information won't be linked to the answers I give.	
6. 	I understand and agree to my interview being audio recorded, and that any drawing I complete will be included in the write up of the thesis.	
7. 	It has been explained to me how long my information will be saved for and what will happen to it after this time.	
8. 	I understand that the findings from this research will be written up as part of a thesis.	
9. 	I understand that because the research only involves a few people (4-5), people who know me well may be able to tell which answers are mine.	
10. 	I understand that my information will be kept and stored safely	
11. 	I understand that if I tell the researcher something that concerns them about my safety, or the safety of someone else, they will have to let someone know.	

a) I would like to see the researcher at (tick):

Home (in person) ☐

Home (online) ☐

School/college ☐

XXX ☐

b) I would like the researcher to send me a one-page summary when she finishes the study (tick).

Yes ☐

No ☐

Name

.....

Signature

.....

Investigator's Name

.....

Investigator's Signature

.....

Date:

Thank you for your help.

H5 – Pilot Parent/Carer Consent Form

Parent/Carer Consent Form (Pilot Study)

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

In giving my consent, I state that:

- I have read and understood the information sheet and have had the chance to ask questions.
- I understand what is being proposed and the procedures that will be involved in this research.
- I understand that participation in this research is voluntary and that my child is free to withdraw (stop taking part) at any time until 2 weeks after their interview without giving a reason.
- I understand that my child's involvement in this study, and the data gathered, will remain confidential. Only the researchers involved in this study will have access to the data.
- I understand that my child's interview will be audio recorded and transcribed.
- It has been explained to me how long this data will be saved for and what will happen to it after this time.
- I understand that the findings from this research will be written up as part of a thesis.
- I understand that my child's data will be anonymised to reduce the chance of people linking the data to them. This will involve using pseudonyms (alternative names) for your child, and the sibling they are speaking about. However, due to the small number of people involved in the research, it is possible that people who know your child well, may be able to identify them from answers given.

I hereby freely and fully consent to my child participating in the study which has been fully explained to me.

Participant's (child's) Name (BLOCK CAPITALS)

.....

Parent/Carer's Signature

.....

Investigator's Name (BLOCK CAPITALS)

.....

Investigator's Signature

.....

Date:

H6 – Pilot Young Person Assent Form

Participant Assent Form (Under 16) (Pilot Study)

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

Please read each statement carefully and tick the boxes below if you agree with them:

	Statement	Tick if yes ✓
1. 	I have read and understood the information sheet and have had the chance to ask questions.	
2. 	I understand what will be involved if I take part in this research.	
3. 	I understand that my participation in this research is voluntary and that I don't have to take part.	
4. 	I understand that I can withdraw (stop taking part) at any time until 2 weeks after the interview, without giving a reason	
5. 	I understand that if I take part in this research, my involvement will be confidential and my name, or any personal information won't be linked to the answers I give.	
6. 	I understand and agree to my interview being audio recorded and transcribed (written up).	
7. 	It has been explained to me how long my information will be saved for and what will happen to it after this time.	
8. 	I understand that the findings from this research will be written up as part of a thesis.	
9. 	I understand that because the research only involves a few people (4-5), people who know me well may be able to tell which answers are mine.	
10. 	I understand that my information will be kept and stored safely	
11. 	I understand that if I tell the researcher something that concerns them about my safety, or the safety of someone else, they will have to let someone know.	

a) I would like to see the researcher at (tick):

Home (in person) ☐

Home (online) ☐

School/college ☐

b) I would like the researcher to send me a one-page summary when she finishes the study (tick).

Yes ☐

No ☐

Name

.....

Signature

.....

Investigator's Name

.....

Investigator's Signature

.....

Date:

Thank you for your help.

H7 – Pilot Young Person Consent Form

Participant Assent Form (16-18 years) (Pilot Study)

Title: Understanding the educational experiences of young people who have a sibling with Autism Spectrum Disorder (ASD)

Please read each statement carefully and tick the boxes below if you agree with them:

	Statement	Tick if yes ✓
1. 	I have read and understood the information sheet and have had the chance to ask questions.	
2. 	I understand what will be involved if I take part in this research.	
3. 	I understand that my participation in this research is voluntary and that I don't have to take part.	
4. 	I understand that I can withdraw (stop taking part) at any time until 2 weeks after the interview, without giving a reason	
5. 	I understand that if I take part in this research, my involvement will be confidential and my name, or any personal information won't be linked to the answers I give.	
6. 	I understand and agree to my interview being audio recorded and transcribed (written up).	
7. 	It has been explained to me how long my information will be saved for and what will happen to it after this time.	
8. 	I understand that the findings from this research will be written up as part of a thesis.	
9. 	I understand that because the research only involves a few people (4-5), people who know me well may be able to tell which answers are mine.	
10. 	I understand that my information will be kept and stored safely	
11. 	I understand that if I tell the researcher something that concerns them about my safety, or the safety of someone else, they will have to let someone know.	

a) I would like to see the researcher at (tick):

Home (in person) ☐

Home (online) ☐

School/college ☐

b) I would like the researcher to send me a one-page summary when she finishes the study (tick).

Yes ☐

No ☐

Name

.....

Signature

.....

Investigator's Name

.....

Investigator's Signature

.....

Date:

Thank you for your help.

Appendix I: Interview Schedule

(1) Proposed Pre-Interview Questions

1. How old is your sibling?
2. What is your sibling's gender?
3. How would you describe your race/ethnicity/culture? (participants will be presented with the census groups)
4. How old were you when your sibling was diagnosed with Autism?
5. Does your sibling go to the same/different school to you?
6. How do you like to think of their Autism Diagnosis? (present options, ASC, person with Autism, autistic person, allowing the young person to share their own). *(Note: rationale for this question. Many young people think of Autism in different ways e.g., conceptualise it as a disability or an intrinsic part of them to be celebrated. I hope to check this language with the young person to ensure I am being sensitive to the way they think of their sibling).*
7. What do you expect from being involved in this research? (at the end of the semi-structured interview, participants will be asked how the experience was for them). *(Note: the rationale for these questions is to set the expectations of the space as being for research, rather than therapeutic).*

(2) Proposed opening statement.

During our conversation, we will be talking about your experiences of school, and your experiences at home with your sibling. I would like to invite you to draw a picture if you want to, of what comes to mind when you think about these things.

- 1) Thank you for drawing, would you like to tell me about it? (followed up with the below prompts if needed)
- a) What have you drawn?
 - b) Who is in the drawing?
 - c) What are they doing?

(3) Proposed Interview Schedule

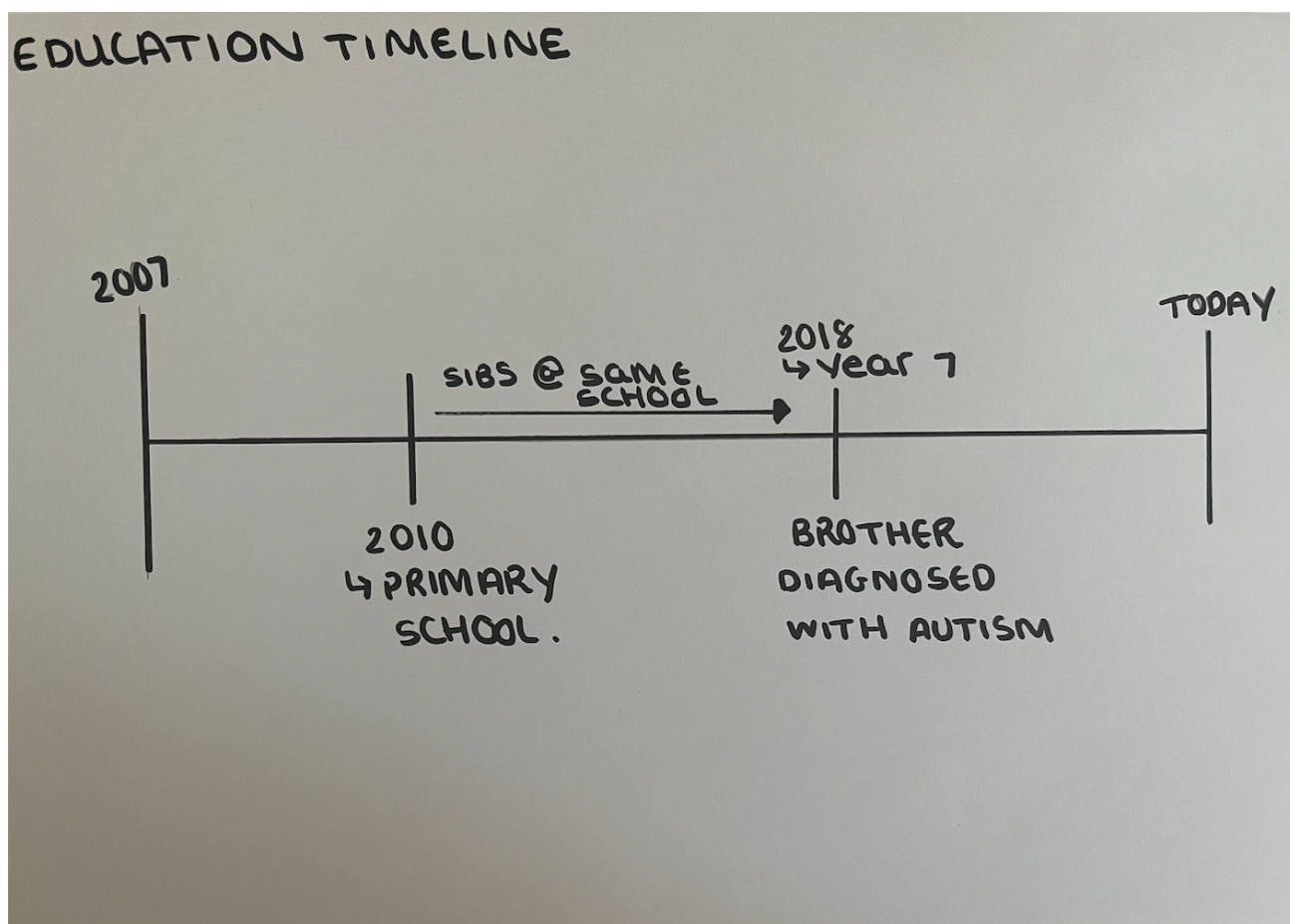
Proposed Semi-Structured Interview Questions	Potential Follow Up Prompts
Tell me about your experiences in school.	• Tell me more about... • What does a typical morning or evening look like for you?
Tell me about your experiences at home with X (sibling with Autism).	• What does that mean for you? • What do you think about that? • What is that like for you?
<i>(Note: language around ASD to be contracted with the participant before the interview begins)</i>	• How similar to or different do you think your experience is at school, compared to your friends?
Tell me about your experiences of how your home life with X (sibling with Autism), impacts on your experiences of school.	• What usually means you'll have a good day/bad day at school? • Give me 3 words to describe...

Tell me your favourite things about your sibling and your relationship.

(Note: a positive question to end on to support the participant to transition out of potentially emotive sharing)

- Is there anything you feel would support you in school?
 - Is there anything you wish your teachers or friends could understand about growing up with X?
 - What do you think others think/feel about that? (e.g. sibling, parent, teachers)
-

Appendix J: Example Visual Timeline



Appendix K: Reflective Log Example

Reflections Immediately Post Interview (excerpt)

As soon as the interview started, I felt that X was really confident and eager to share her experiences. She shared having been thinking about our interview all morning and what she might tell me about her school experiences as they related to her sibling with Autism.

As the interview progressed, I found myself hearing things that I wanted to follow up about, but then X naturally supplied this information. At times it left me feeling a little unsure where to go next with my questioning and so I wonder if sometimes we revisited a topic more times than necessary or if we stayed longer on a topic when we could have moved on. I also wonder what I connected with in terms of following up on certain parts of the conversation, for example maybe following up with information gathered from my literature searching. For context, prior to beginning this interview I had been emailing the research lead regarding a new supervisor being allocated to me as mine is leaving. I feel that this uncertainty is contributing more anxiety to the process of data collection, and I wonder if this is leading me more towards following up about things already confirmed within the literature and leaving comments behind which may allow a novel exploration [...].

Reflections After Transcription (excerpt)

I'm wondering why some participants are more impacted by their sibling than others...what are the protective factors? What aspects of identity, or what contextual factors would protect a sibling from experiencing some of the more challenging parts of their experiences? But then if this was prevented, would the benefits in the literature be as pronounced? Would the siblings themselves want to prevent the impact?

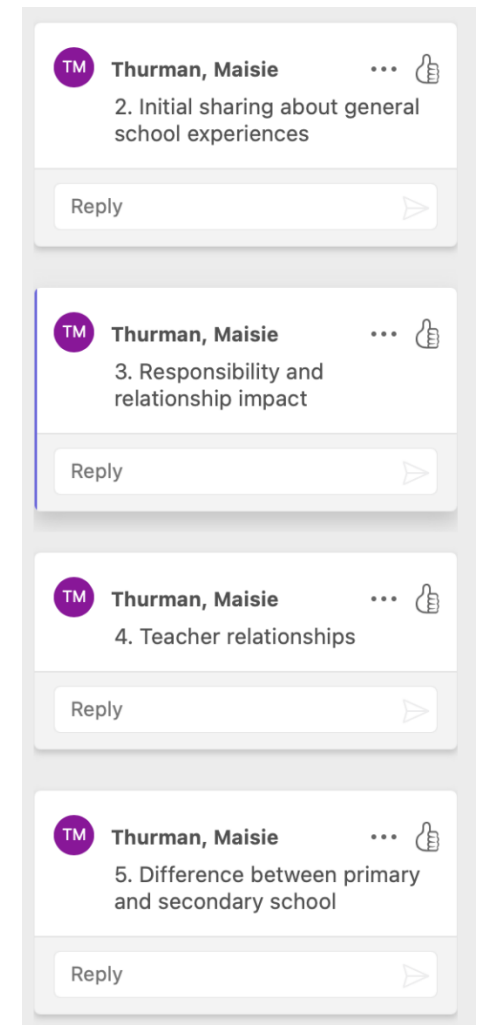
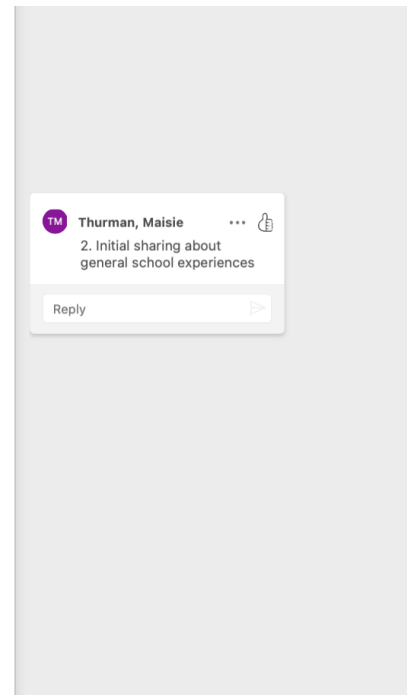
At 33.51 minutes, I felt that X was starting to advocate for her brother even to me as well as showing herself as the good child asking if I understood and questioning 'you know?'. She started to show examples of when she could live up to the 'good girl' label she feels she has. It felt to me like this label and role of advocate are so ingrained that X quickly takes them up with anyone she is with. I wonder if this is common across all my participants...they are taking part to help me...for no benefit of their own other than having their voice heard (e.g. there is no reward).

Appendix L: Data Analysis

Table L1. Example Data Analysis- IPA

Data Analysis Stage 1: Reading and Re-reading shown in comments (numbers indicate timeline)

was a challenge.	Interviewer: So you mentioned friends, and them kind of having a potentially different experience to you. So, if you think a bit more about school, then it'd be really, really nice to hear about your experiences of school and how kind of some of the things that you've shared about growing up with your brother have impacted on that, if they have. And so yeah, tell me a bit about what that's been like.	supporting her brother in school.	'I got a bit jealous (laughs)' – discomfort	X names jealousy here and it again feels like something to be 'pushed down' for her. She quickly advocates for her brother explaining it was not his fault.
7. Sibling experiences of being in school were enmeshed and intertwined with one another.	X: So I used to walk him to and from school every day. Erm I'd pick him up outside of class, he eventually, he'd be able to talk to his own class and so so. Break and lunchtime, he'd spend it with me and my friends. Erm he'd sit down at lunchtime, eat his lunch, tell me about how his day's been, erm give me a little summary of everything. Erm like, there were loads of positives to it, but there were also like lots of negatives, because I noticed like unintentionally, obviously, like it worsened my relationship with a lot of people because of the people he was erm having arguments within class – and so and so I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like... (laughs) "I don't know what you want me to do about it. Maybe speak to a teacher, because I can't always be there." As I got older, I started realising I've got my own stuff to focus on. But people didn't really understand it, erm or people didn't like stop speaking to me because of my brother, which at the at the end of the day, didn't really bother me. But it, at first, I was really confused, and I didn't feel like I had a lot of support either, because erm obviously, I- at the time, I couldn't understand like my other younger brother, who	Shared feelings of jealousy but not blaming her brother for something outside of his control.	'I also never blamed him for anything because he couldn't help it' – advocating for both self and brother?	
		X shares the support she provided to her brother across the school day.	'blah blah' 'so and so' 'x, y z' – general ways of indicating there is more information. Does this feel so self-explanatory/typical for her that she doesn't consider I might not know what she means? Or too painful to go into more detail?	At the start of this section, it feels hard for X to share her experiences, and she shares her brothers routine – as time progresses she shares more about her own feelings.
		X shares mixed positive and negative experiences of being in school with her brother.	'Erm he'd sit down at lunchtime, eat his lunch, tell me about how his day's been, erm give me a little summary of everything' – sharing brothers experiences not hers.	There feels like there is frustration and confusion here.
			'I noticed like unintentionally, obviously' – protecting him from my judgement?	
			'it worsened my relationship with a lot of people'	
8. Being positioned to help her brother affected peer relationships.		Her school day being so involved with her brother affected her relationships with others (peers and her brother).	'I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like... (laughs) "I don't know what you want me to do about it." – positioned as the 'fixer'	What happens if X admits it did really bother her?
			'As I got older, I started realising I've got my own stuff to focus on. But	



Note. This was repeated for each participant at stage 6 of data analysis

Table L2. (Data Analysis Excerpt: Stages 2 – 3)

Experiential Statements	Transcript	Exploratory Noting		
		Descriptive <i>Describing the content of what was said</i>	Linguistic <i>Exploring the specific use of language</i>	Conceptual <i>Interpretation and questioning</i>

	Interviewer: Okay, questions. So, the first thing then is I would like to hear about your brother. And you can talk about either, both, one of them. Just let me know which one. And any differences you've noticed linked to their autism. X: Erm, so what do you mean by differences? Interviewer: Yeah, so if you think of your brother and then somebody else his age without autism (oh!), what are some of the differences that your brother has? X: Erm, well, my middle brother, he's very like, he...he.. the way he processes information is a lot different. Erm he's unable to see what other people are saying, and he's a very stubborn person, and it's always (laughs), it's always to him his way or no way. Interviewer: Yeah. X: Which can cause him to have reactions sometimes. And I know that when it gets really bad, erm he does have a massive meltdown. Erm and you can't really like I've learned to talk to him th-through it and let him say whatever names he wants to say to me, so and so until he calms down and then he becomes very apologetic. Erm and also with like, his attention to learning, he's a he's a lot different in the aspect that like, if he doesn't enjoy something, he won't be fully engaged. Whereas if it's something he's fixated on, and he's more likely to know everything about that topic. Interviewer: Yeah.			
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	X: Yeah. Interviewer: So, he's got some really big interests. X: Yeah. Interviewer: Yeah, okay. So, tell me about his like, you said 'meltdowns'. What would that be like? X: So, it depends on how big it is. But if it's like, really, really big, like he ends up like screaming, shouting. Erm he kind of goes like really red in the face. He's crying his eyes out. Like, he'll erm...say things he doesn't mean like literally anything that comes to the top of his head, it's out. Erm he's not physically aggressive, he's just verbally aggressive. And he's ki-, you kind of just have to like, at least I- I remember teachers had to get me to come over if he was having a meltdown, because they knew that I could calm him down. And there'd be some teachers that could help, but I think me being there also helped him a lot. And he'd end up like crying on my shoulder or something at school until we'd fully like calmed down. And then he'd be able to like whoever he hurt or like ph- verbally or something he'd go up to straight way (laughs) and start apologising and being like, I'm really, really sorry, didn't mean anything I said (laughs). But yeah. Interviewer: Yeah, okay, so those are some of the things that kind of you've noticed that are a bit different about him compared to other people.			
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1. Relationships with parents were different when her brother was born – it was still good but they were learning. 2. Differing treatment and protection led to feelings of jealousy and then shame.	X: Yeah. Interviewer: And is this the brother that you mostly want to kind of think about your experiences around? X: Yeah. Interviewer: Okay, that makes sense! So, before we move on to kind of your school experiences, tell me a little bit about what it was like to grow up with him at home. X: It was a lot different at first because obviously I'm the oldest so I've never seen how my parents would parent another person blah, blah. Erm so I've noticed like the treatment I was getting which (higher pitch) is still like good, but like, and we've all got like a very healthy relationship with our parents, which is really good. But when because X was erm diagnosed really, like young, erm I remember our old primary school at the time, spoke to my mum and said like, "we think he has ASD". Interviewer: Yeah. X: So and so and she got him tested and the came back that he did. And I remember at first, my parents didn't know how to deal with it, so he was kind of almost like in a bubble wrap. And it'd always be like, "don't this this because of your brother, like he's autistic, he's not gonna understand". And I think like, at first, I didn't understand it, and like, as a kid, not understanding it, you become a little bit selfish and you're like, well, "why does he get special treatment, and I don't" (laughs). And then I	X shares the experience of growing up with her brother and noticing that things were different with her parents. X shares the uncertainty that came with her brother's diagnosis of ASD.	<i>'It was a lot different at first'</i> <i>'I've noticed like the treatment I was getting which (higher pitch) is still like good, but like, and we've all got like a very healthy relationship with our parents, which is really good.'</i> – managing the perception of her parents? Higher pitch tone = discomfort at sharing? <i>'he was kind of almost like in a bubble wrap'</i> – visual of her brother being fragile and being protected by her parents. <i>'you become a bit selfish'</i> – 'you' to distance self from a painful	Within this section X appears to be defending her parents' parenting techniques. Is she managing what I will think of them as a researcher?
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3. Adapting and becoming mature was quickly recognised as important – rather than being selfish.	quickly realised...erm as like, he was different. And I think my parents say as well, I don't know how (laughs), but I was very mature about the situation. And because we were so close in age as well erm I kind of easily like adapted to his needs. And so I knew kind of like, how to erm deal with him and how to like, like, if he was to have a meltdown at home, obviously, my parents would be there to like support him. But I knew that like, on like a sibling level, he had me to turn to whereas my other brother was, is three years younger. So, he doesn't, he didn't at the time, obviously understand because of how young he was. And so it took him a lot longer to come to terms with how my other brother was.	Sharing of jealousy around her brother being wrapped in 'bubble wrap' and then the shame that comes with this.	emotion/response she is not proud of?	X appears to share vulnerability in being selfish but then appears to attempt to manage the perspective I may take on this and share she became mature very quickly. What is X's experience of admitting a wish to be selfish or feeling jealous?
4. Closeness of sibling age is important for providing consistent and stable support.	Interviewer: So, you being the oldest sibling, what was that like, the older sibling of two younger brothers?	X shares being mature and adapting to her brothers needs quickly.	'I don't know how (laughs), but I was very mature about the situation.' – quick counteract to being selfish	
5. It was confusing for X to navigate her role of being a second parent.	X: (laughs) I kind of took on a lot because, erm especially with the middle brother, erm, because of like, erm the way, like, because we were so, because we were in the same year group as well. Erm because it's like, if he was to have a certain reaction for something, I'd have to be there for him. And because erm obviously, my parents weren't there, I kind of become like a second parent to him. And erm it was really hard to deal with as well, because I was trying to understand why my friends didn't have to like miss out on certain things, whereas I did. And I got a bit jealous (laughs) about it, but I also never blamed him for anything, because obviously he couldn't help it.	X explains why she was the one to support him as a sibling. Their other brother is younger so took longer to understand.	'But I knew that like, on like a sibling level, he had me to turn to' – imagery of being stable, there and predictable.	
6. Finding the balance between being jealous and not blaming her brother was a challenge.	Interviewer: So you mentioned friends, and them kind of having a potentially different	Sharing of experiences around taking on responsibility for supporting her brother in school.	'I kind of took on a lot'	There seems to be confusion and uncertainty here. Is it around knowing how to label her role? It feels as if this is one of the first times X has spoken about this and made the links.
			'I kind of became like a second parent to him' – repetition of kind of indicating a level of uncertainty	
			'it was really hard to deal with as well, because I was trying to understand why my friends didn't have to like miss out on certain things, whereas I did.' – confusion around why things were different to peers. 'deal with' indicates this did not feel like a choice.	X names jealousy here and it again feels like

	experience to you. So, if you think a bit more about school, then it'd be really, really nice to hear about your experiences of school and how kind of some of the things that you've shared about growing up with your brother have impacted on that, if they have. And so yeah, tell me a bit about what that's been like.		<i>'I got a bit jealous (laughs)' – discomfort</i> <i>'I also never blamed him for anything because he couldn't help it' – advocating for both self and brother?</i> something to be 'pushed down' for her. She quickly advocates for her brother explaining it was not his fault.
7. Sibling experiences of being in school were enmeshed and intertwined with one another.	X: So I used to walk him to and from school every day. Erm I'd pick him up outside of class, he eventually, he'd be able to talk to his own class and so and so. Break and lunchtime, he'd spend it with me and my friends. Erm he'd sit down at lunchtime, eat his lunch, tell me about how his day's been, erm give me a little summary of everything. Erm like, there were loads of positives to it, but there were also like lots of negatives, because I noticed like unintentionally, obviously, like it worsened my relationship with a lot of people because of the people he was erm having arguments within class and so and so I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like....(laughs) "I don't know what you want me to do about it. Maybe speak to a teacher, because I can't always be there." As I got older, I started realising I've got my own stuff to focus on. But people didn't really understand it, erm or people didn't like stop speaking to me because of my brother, which at the at the end of the day, didn't really bother me. But it, at first, I was really confused, and I didn't feel like I had a lot of support either, because erm obviously, I- at the time, I couldn't understand like my other younger brother, who wasn't diagnosed at the time, erm he, like If I said to him, "Oh, my friend's wanna hang out after school, erm we just want to go to the park	Shared feelings of jealousy but not blaming her brother for something outside of his control. X shares the support she provided to her brother across the school day. X shares mixed positive and negative experiences of being in school with her brother. Her school day being so involved with her brother affected her relationships with others (peers and her brother).	<i>'I got a bit jealous (laughs)' – discomfort</i> <i>'I also never blamed him for anything because he couldn't help it' – advocating for both self and brother?</i> <i>'blah blah' 'so and so' 'x, y z' – general ways of indicating there is more information. Does this feel so self-explanatory/typical for her that she doesn't consider I might not know what she means? Or too painful to go into more detail?</i> <i>'Erm he'd sit down at lunchtime, eat his lunch, tell me about how his day's been, erm give me a little summary of everything' – sharing brothers experiences not hers.</i> <i>'I noticed like unintentionally, obviously' – protecting him from my judgement?</i> <i>'it worsened my relationship with a lot of people'</i> <i>'I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like....(laughs) "I don't know what you want me to do about it.' – positioned as the 'fixer'</i> <i>'As I got older, I started realising I've got my own stuff to focus on. But people didn't really understand it' –</i> At the start of this section, it feels hard for X to share her experiences, and she shares her brothers routine – as time progresses she shares more about her own feelings. There feels like there is frustration and confusion here. What happens if X admits it did really bother her? Is X unsure about if she deserved her own targeted support?
8. Being positioned to help her brother affected peer relationships.			

9. Caring for her brother felt lonely and unavoidable.	down the road. Would it be okay if you could just walk him home?" And it was like a massive problem to him. "I don't want to walk him home, blah, blah, blah, blah, why do I have to? <i>That's your job,</i> " kind of thing. And I was like, "Oh," and so I'd miss out a lot on <i>friendship kind of things. I wouldn't go out as much.</i> And I remember one time that I got invited out, and I got asked to bring him along, just so like erm there wasn't any troubles with him getting home or something. And that was quite hard as well (laughs), because he didn't really understand like, obviously, how me and my friends talk and <i>blah, blah, blah.</i> And it felt like he was always there, and <i>I couldn't really like be my own self away from him...? It always felt like people would always be like, "Oh, X sister."</i> I still get it with teachers now, which I've actually spoken to my mum about (laughs). <i>It really annoys me that like there's a certain teacher at this school that always walks past and instead of acknowledging me, she says straight away, "Oh, how's your brother?"</i> And then I don't mind like some teachers asking, obviously, because of how big (laughs) of a personality he was. It makes sense. But I feel like mo-some of them, their motivation's more to talk about him rather than even say hi to me. And it kind of hurts sometimes, because it's just I'm not really seen as a person, <i>I'm kind of just seen as his carer or his sister.</i> And yeah (laughs).	Frustration grew as X got older and realised she had to focus on herself.	followed quickly with <i>'it didn't really bother me'</i>	Positioned as the one to care for their brother by her other brother. Is this a female's job? Or an older sister's job?
10. Being seen as one person and being invisible.		X shares missing out on friendships.	<i>'at first, I was really confused, and I didn't feel like I had a lot of support either'</i>	
11. Hurt and understanding around others actions.		Feeling like others only see her as her brother's sister – rather than her own person.	<i>"I don't want to walk him home, blah, blah, blah, blah, why do I have to? That's your job," – job/chore/unavoidable</i>	A sense of feeling invisible?
		Described the hurt and annoyance around not being seen as her own person.	<i>'I couldn't really like be my own self away from him...? It always felt like people would always be like, "Oh, X sister."</i>	There is some explaining on behalf of her teachers – empathy for why they might see through her.
			<i>'It really annoys me that like there's a certain teacher at this school that always walks past and instead of acknowledging me, she says straight away, "Oh, how's your brother?"</i>	Responsibility for the perceptions of others feels automatic and not just reserved for her brother/parents.
			<i>'And it kind of hurts sometimes, because it's just I'm not really seen as a person, I'm kind of just seen as his carer or his sister. And yeah (laughs).'</i>	
12. The responsibility	Interviewer: So, yeah, you've mentioned hurt and kind of not being seen as your own person at school. Are there times where that's been more difficult or easier? Has that changed over your school life?	As X has grown up, she has started to realise	Annoyance/hurt – first named emotions	X forgot what she was going to say – this is following an extended emotional sharing. Is

for protecting her brother has consumed much of her school life.	X: Yeah, so I think it was, it always has been quite difficult. I didn't really realise how much it affected me until earlier this year, to be fair, erm because it was more of what I always knew. So, to me, there was no other kind of experience. Erm and I would take on so much responsibility for him. And if he was to have meltdowns at school, if there were certain people involved, I'll go behind the scenes trying to see what I could do out, so it wouldn't fall back on him and know that I've done something about it. But it would just make his school life a little bit more easier. Erm and, yeah, I... er I don't know what I was going to say.... Erm (laughs)...erm... Interviewer: It's okay. X: Oh, God. Interviewer: You were telling me a bit about...well, you mentioned that you feel like it made you...having your brother here made your relationships with other people worse. X: Yeah. Interviewer: Was that teachers, friends, both? Tell me a bit about your relationships with others at school.	that her reality is unique. Her reality involved protecting her brother and taking on responsibility for him.	<i>'it was more of what I always knew. So, to me, there was no other kind of experience'- this is her 'normal'</i> <i>'it always has been quite difficult. I didn't really realise how much it affected me until earlier this year'</i> <i>'I would take on so much responsibility for him' – past tense. No longer in this role?</i> <i>'go behind the scenes trying to see what I could do out, so it wouldn't fall back on him' – behind the scene is like a performance. Protecting brother.</i> <i>'But it would just make his school life a little bit more easier'</i>	this out of the norm for X and feels difficult? Contrast – her brothers school life becomes easier, at the expense of her own.
13. Mediating between her peers and brother was a delicate balance.	X: It was more just, like...people in my year group, I guess, because it was like... I I I – used to be quite, like, well-liked. Erm like, I wasn't popular or anything, but just, like, acquaintances with everyone. And I remember he'd have, he was on the other side of the year group, so he'd have all these big, massive erm arguments with them in class. And sometimes when it was his	During conflict between her brother and peers, X would try and resolve this by explaining her	<i>'I I I – used to be quite, like, well-liked' – past tense, what changed? X stutters here. Is sharing self-positives difficult?</i>	Where has this motivation to find a common ground come from? Who gives this role to her? What happens if she doesn't do it?

14. Providing education about other's needs, perspectives and rationale for behaviour. 15. Relationships with teachers and peers have been influenced by having a brother.	fault, I'd also have to say to him, "X, why did you do that?" <i>blah, blah</i>. "This person wasn't trying to intentionally be like this to you." Obviously, he couldn't understand it, and to him, being quite stubborn as well, he was like, "No, I know exactly what they meant." <i>Blah, blah, blah</i>. <i>Erm and then people would start viewing me differently because it always looked as if I was defending him</i>. But I wasn't, it was just quite literally the case that <i>erm I was trying to understand his feelings as well as theirs and try and find like a common ground between it</i>. But obviously, people who didn't have <i>erm siblings of autism</i>, they didn't understand, which is fair enough, but...yeah, <i>it was al-almost, like, kind of frustrating in the end because I'd lost so many friendships with certain people who many didn't want to speak to me</i> or anything because of the way, like, the people he'd go for and all this kind of stuff (laughs). And I used to have to tell him, like, he had one of my friends go up to him once because he was having a really bad time outside the classroom. And one of my friends went up to him and said, "Are you okay?" <i>Blah, blah</i>. And he shouted at her and threw a tantrum. And I remember her coming up to me and questioning it. And I was like, "<i>Oh, he didn't know who it was. I'm so sorry.</i>" And I had to go up to him and kind of describe certain people and say, "<i>look not everyone has a bad intention, and they do want to help</i>" and try and try and tell him that when I'm not there and I physically can't be there, these people are always there to help. And then he slowly started to understand it, but it did take a while. Interviewer: And what about your relationships with teachers? What have those been like?	peer's behaviour to her brother. X's role is to find a common ground in conflict. Loss of friendships due to her brothers behaviour In conflict, X would apologise to her peers for her brother's reactions. She tries to educate her brother around how to respond.	<i>'Erm and then people would start viewing me differently because it always looked as if I was defending him.'</i> – the impact of defending her brother was that her peers would judge her. <i>'I was trying to understand his feelings as well as theirs and try and find like a common ground between it' – mediating between peers and her brother.</i> <i>'obviously, people who didn't have erm siblings of autism, they didn't understand, which is fair enough' - empathy for friends</i> <i>'it was al-almost, like, kind of frustrating</i> <i>'I'd lost so many friendships with certain people who many didn't want to speak to me or anything because of the way, like, the people he'd go for and all this kind of stuff (laughs).'</i> – laugh indicating painful memory sharing <i>'Oh, he didn't know who it was. I'm so sorry.'</i> – apologising on behalf of her brother. <i>'I had to go up to him and kind of describe certain people and say, "look not everyone has a bad intention, and</i>	Why did her brother's behaviour result in her own loss of friendships? Is it because they viewed her and her brother as one person?
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16. Feeling frustrated with, and 'not seen' by, teachers.	X: Erm...I didn't really see much of a change in them erm because we didn't really have the same teachers, especially because we were on the different sides of the year group as well. So, it was kind of almost refreshing (laughs), the fact that they didn't ask me about him or they didn't bring it up or something like that. But I think the odd teacher that's, that wasn't teaching us, that would work with him or something like that, I would, I at-at secondary had really good relationships with them, obviously because they looked after him and everything. But I think now that I've moved into sixth form, and like I was saying earlier, some of them are a bit inappropriate with the way they ask me (higher pitch). Erm, like I have no problem erm with teachers asking me how's he been, how's he finding his new college because they worked so closely with him. But I just think sometimes it's a little frustrating, the fact that they can't also ask me about myself or...not even have to ask me about myself, but just maybe just say hi (laughs). Interviewer: Yeah, absolutely. X: Yeah. Interviewer: And this is, the bit that we're talking about now is the secondary school part. X: Yeah. Interviewer: What about teachers and friends when you were at primary with him, what was that like?	Having teachers who did not know her brother felt refreshing – they didn't bring him up in conversation. When teachers do know her brother, they still ask about him rather than her. This feels frustrating. Teachers could just say hi and this would feel better than it currently is.	<i>they do want to help</i>” – teaching her brother <i>‘So, it was kind of almost refreshing (laughs), the fact that they didn't ask me about him or they didn't bring it up’ – not having the same teachers felt like she could be ‘seen’.</i> <i>‘some of them are a bit inappropriate with the way they ask me’ (higher pitch) – teachers ask about her brother when they see her. Inappropriate highlights this feels against their professional role.</i> <i>‘like I have no problem erm with teachers asking me how's he been, how's he finding his new college because they worked so closely with him’ – showing empathy for teachers here.</i> <i>‘But I just think sometimes it's a little frustrating, the fact that they can't also ask me about myself or...not even have to ask me about myself, but just maybe just say hi (laughs).’ – X lowers the bar with what she expects from teachers over this section</i>	X is frustrated and also sounds a little hurt. Does this come back to the feeling of jealousy and being selfish from earlier? Throughout the transcript so far, X shares feelings of hurt around others' reactions to her but quickly empathises and intellectualises why they may respond this way. X never blames her brother. Is her brother exempt from blame in her eyes? In this section, X was asked to share her primary school experiences but speaks at length about what her brothers experience with Tas
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17. Life feels easier when others understand her brother.	X: Erm...I can't really remember it, if I'm being completely honest. I know my second secondary, my friends were a lot more understanding, and funny enough, they're still in my life now (laughs). <i>So they've always known X to be different, erm and they work really well with him.</i> He'll sometimes say, because he hasn't seen them since primary school or something, because I normally go out with them, if he is to meet them, he'll say, "Oh, hi, I haven't seen you in a very long time. What's your name again?" Or something like that, and <i>he wouldn't intentionally mean</i> to... *Interview interrupted* X: He always said, "Oh, hi, I can't remember your name, but I'm X," and reintroduced himself or something, but they always knew, and <i>I think he also had a TA at that primary school that was really good for him, like really good, and she went everywhere with him.</i> She sat in class with him, because back then he was very dependent, erm so she was always there working with him, whereas when we came to here, he didn't have that, so...because he chose not to have that, and he wanted to have a bit more independence, so he was in the class on his own with just the primary teacher, erm which he did struggle with at first, but he eventually came to terms with it. Interviewer: And what about for you? What did that mean for you when he had somebody in the classroom with him? X: <i>It..it was more easier for</i> me, I think at primary school at least, because I knew that he-	The friends who understand and the ones that stay around. X shares the support that her brother had at primary school. When her brother had TA support, it was easier for X. She could relax.	<i>'So they've always known X to be different, erm and they work really well with him'</i> – the idea of 'working' with him is interesting. This responsibility can be shared with friends when they can be trusted to understand him. <i>'he wouldn't intentionally mean to'</i> – protecting brother from judgement (mine?) X shares quotes from her brother when asked about her own experiences. It feels like it is difficult for her to think about her own experiences, before sharing his.	and her peers were like. Is it hard for X to talk about herself? Is this less practiced? There is a contradiction in this section – her brother chose not to have the support and struggled to come to terms with it. Is he latter part X's experience? Without the TA there, was X the one who was 'fully' trained?
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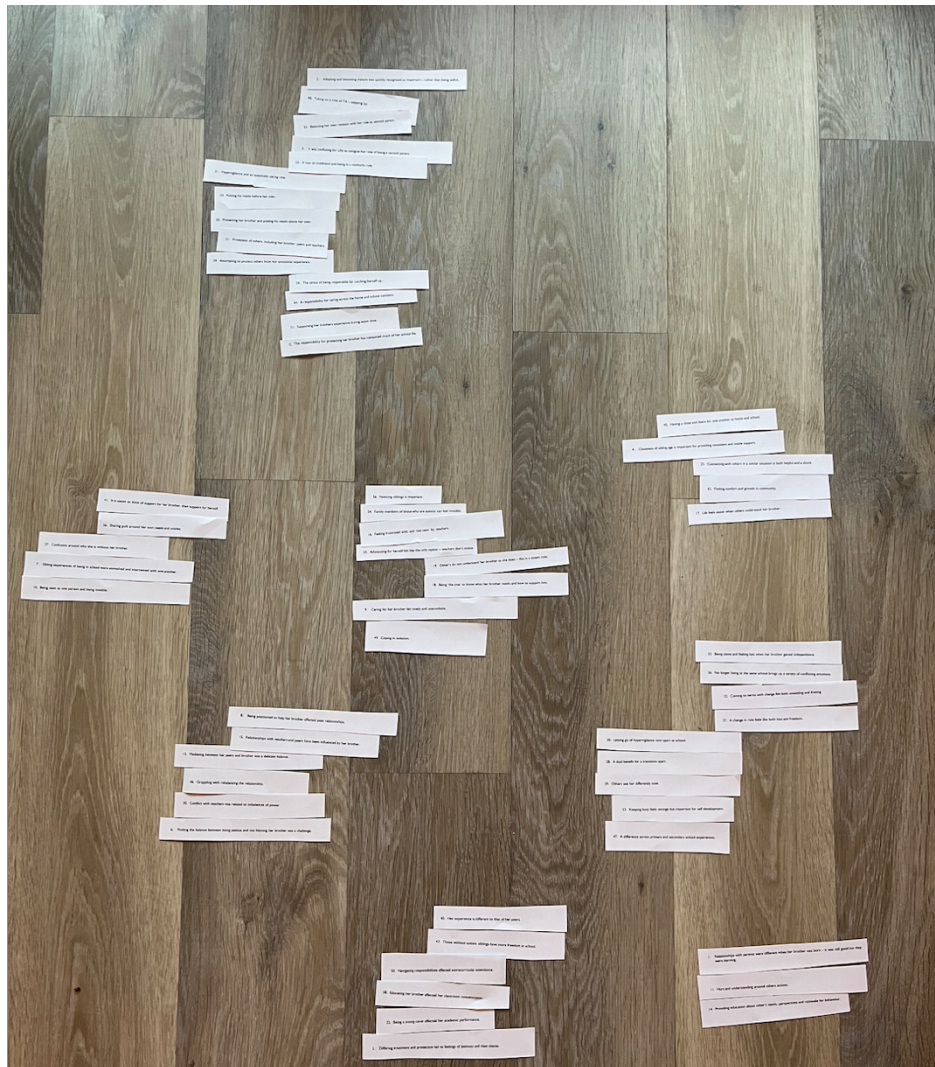
18. Being 'the one' to know what her brother needs and how to support him.	if something was to happen, someone was there and fully trained and knew how to deal with him, and knew, was able to be like, "Okay, X, don't stress, like erm we'll get through this." *Interview interrupted* Interviewer: Can you remember what you were saying, or do you want me to ask again? X: Um, primary school teachers... Interviewer: Yeah, what did it mean for you, that he had somebody who really knew him? X: Yeah, it was really good, because I knew that they could cater to his needs and know exactly how to support him erm, whereas teachers here, obviously this department is really good for it as well, but outside of this department, where he was just singly in that classroom alone, tea- see some teachers weren't qualified in how to deal with children's special (pause) needs, so they would like, they would try and help, but the most that they would do would send him out of class, which would aggravate him more and not listen to him and kind of speak over him, instead of giving him his voice and letting him explain his problems. Interviewer: And you mentioned sometimes they'd come and get you from the classroom. Tell me about that, give me an example. X: So, u..., I'm trying to think... Erm, there was one time erm when I got picked up and I remember it was, erm like, he was having a really bad meltdown, because they, the school	When her brother had a TA, they knew how to support him and meet his needs. Teachers who are not qualified to meet his needs would escalate the situation for her brother.	<i>'I knew that he- if something was to happen, someone was there and fully trained and knew how to deal with him' – someone else can take the role of responsibility. Change from 'he' to 'If something were to happen', X removing the responsibility from her brother?</i> <i>'it was really good, because I knew that they could cater to his needs and know exactly how to support him' – an additional adult for her brother made his school life easier. X does not reference her own experience.</i> <i>'Obviously this department is really good for it as well' – explains school perspective. Protecting another?</i> <i>'instead of giving him his voice and letting him explain his problems' – about her brother but I wonder if there is some of her own feeling here too about lack of voice?</i>	X is asked what it means for her and she shares her brothers emotional experience in the absence of this supportive adult. Again, X appears to so regularly consider her brothers perspective over her own, that it is automatic to share it before hers. A sense of frustration and confusion here about who needs and deserves what support. Is there a sense here that only X really knows and can support her brother – even if it feels difficult? There may be a sense of protectiveness over her role – what is she if she loses it?
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19. Other's do not understand her brother as she does – this is a sisters role. 20. Conflict with teachers was related to imbalances of power. 21. Protection of others (peers and teachers).	used to put me into counselling, be- over it, and I remember, I think I was on my way to counselling or something, and I saw an episode (laughs) and I was like, "oh, brilliant", erm and I'd like go over and I'd help out and sometimes some teachers would get frustrated at me, because they'd be like, erm I'm trying to deal with the situation, can you leave us alone? And I'm like, yeah, but you're <i>not</i> his sis- sibling, like, I know how to deal with him, I've grown up with him, I'm not in any way trying to get in between what you're work- what you're doing (laughs), but I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse. Especially if, like, in a hall like this erm, he'd be outside and if he's screaming, all the other classrooms can hear it, it's disturbing the lessons as well, so I'm trying my best to calm him down and get him out of the situation, erm instead of just kind of throwing his feelings to the side, but they- some teachers weren't really happy with me getting involved, which was a bit annoying, because I understand that, like, it's not always my place to, like, get involved, but at the same time, if I can see that they're not <i>doing</i> the right thing, I know that it's just going to make things worse for them, so I tried my best to, like, de-escalate the best that I could. Interviewer: So, with this kind of coming out of lessons or, you know, you knowing how to kind of de-escalate and help him, do you think, or what do you think about kind of an impact on your own learning and ability to kind of concentrate?	On the way to counselling, X noticed her brother needed support and attempted to provide it. X expressed frustration that teachers do not have the same insight as her as they are not his sibling. X shares concerns that her brother would disturb other lessons. Teachers aren't always happy with X's involvement, but X can see how they are escalating the situation for her brother.	<i>'Sometimes some teachers would get frustrated at me'</i> teachers would be frustrated at her for trying to help. Has she interpreted their frustration at her brother, and taken it to be towards her? <i>"I'm like, yeah, but you're not his sis-sibling, like, I know how to deal with him, I've grown up with him"</i> – being a sibling (particularly a sister) gives insight that others don't have. X self-corrected sister and made this more generalised. Emphasis on no highlighting the very different roles/knowledge. <i>'I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse'</i> – educating teachers, role reversal. <i>'it's going to make things worse for them'</i> (teachers). X explains a wish to help the teachers here. <i>'it's disturbing the lessons as well, so I'm trying my best to calm him down and get him out of the situation'</i> protecting peer learning and her brother.	There is a contradiction here as X shared earlier teachers would ask for her help but now, she shares where she takes autonomy and helps in a way that frustrates others.
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22. Being a young carer affected her academic performance.	X: Yeah, I struggled a lot, because I had erm, like I said with the counselling thing, that lasted a long time, I think it was three years or something, and I can like remember, like being out of so many lessons, and then my grades were, like, really bad, erm and I used to get really frustrated, because I was dealing with a lot, erm but to be fair, the counselling was very good, because I remember they had a video on young carers, and the counsellor that I had was also, had experience being a young carer, so she was able to, like, speak to me about it, and I was kind of, that was the first time, probably two years ago now, that I found out that there were people like me, that had the same situation as me, kind of thing. *Interview interrupted* X: Erm erm, Yeah, and it was kind of a shock, but it also felt, like, really helpful, because I knew that I wasn't alone, because I was fully convinced that I was, because I didn't see anyone else in my year group, like, experience what I went through, erm so, yeah. Interviewer: So, it was, I just want to check that I understand this, so kind of, being taken out of lessons to support him, and kind of missing some lesson time for the counselling, to manage	Being in counselling meant that X missed lessons. This had an impact on her school grades. Finding out that other people are young carers is helpful and meant that X felt less alone. Being out of lessons due to counselling resulted in missed lessons and	<i>'I understand that it is not always my place to get involved' – this sounds less like X, has this been said to her?</i> <i>'then my grades were, like, really bad'</i> <i>'I used to get really frustrated, because I was dealing with a lot'- sharing of a personal emotional experience.</i> Past tense here to signal that things are better now? <i>'to be fair, the counselling was very good' – rationalising why it was important to leave lessons.</i> <i>'the counsellor that I had was also, had experience being a young carer' – people in the same position can share experiences.</i> <i>Shock' vs 'helpful'.</i> <i>'because I knew that I wasn't alone' 'fully convinced I was' – there was a full 180 turn around in her experiences of being a young carer.</i>	Being a young carer in school is a label that X resonated with when it was presented to her. It could be that the stress of catching up was less heavy than her stress around being a carer? Or it could be that she puts less emphasis on her academics due to everything else she is balancing at school.
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Note. This was repeated for each participant at Stage 6 of data analysis

L3. Example Photo of PET Creation (Data Analysis Stage 4).



Note. This was repeated for each participant at Stage 6 of data analysis

Table L4. Excerpt of PET Table Example with Subthemes, Experiential Statements and Individual Contributing Quotes (Data Analysis Stage 5)

Personal Experiential Theme (PET)	Subthemes	Experiential Statements	Quotes (from directly near the experiential statement, from elsewhere in the data)
BALANCING SOCIAL RELATIONSHIPS IN SCHOOL	Peer and teacher dynamics	Being positioned to help her brother affected peer relationships	'Because I noticed like unintentionally, obviously, like it worsened my relationship with a lot of people' 'I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like.... (laughs) "I don't know what you want me to do about it' 'I'd miss out a lot on friendship kind of things. I wouldn't go out as much'
		Relationships with teachers and peers have been influenced by having a brother	'people would start viewing me differently because it always looked as if I was defending him' 'it was al-almost, like, kind of frustrating in the end because I'd lost so many friendships with certain people who many didn't want to speak to me' 'I would, I at-at secondary had really good relationships with them, obviously because they looked after him and everything' 'Erm, like I have no problem erm with teachers asking me how's he been, how's he finding his new college because they worked so closely with him.' 'But I just think sometimes it's a little frustrating, the fact that they can't also ask me about myself or...not even have to ask me about myself, but just maybe just say hi (laughs).' 'it really annoys me that like there's a certain teacher at this school that always walks past and instead of acknowledging me, she says straight away, "Oh, how's your brother?" 'I'd like go over and I'd help out and sometimes some teachers would get frustrated at me, because they'd be like, erm I'm trying to deal with the situation, can you leave us alone?'

	Balancing jealousy, mediation and blame.	Grappling with rebalancing the relationships	'He'd be like, "Oh, you care a lot for me, and I do see it, I wish I could do the same for you." And I always used to say to him, "I don't need it, don't stress out about it." But he always...although I wouldn't want to give him my problems on top of his problems' 'we are we are very close, and even when we argue and he's the most annoying person in the world (laughs), like he knows at the end of the day I'm always there for him, regardless if I'm physically there or not, which is always nice'
		Finding the balance between being jealous and not blaming her brother was a challenge.	'because I was trying to understand why my friends didn't have to like miss out on certain things, whereas I did. And I got a bit jealous (laughs) about it, but I also never blamed him for anything, because obviously he couldn't help it'
		Mediating between her brother and her peers was a delicate balance	'so he'd have all these big, massive erm arguments with them in class. And sometimes when it was his fault, I'd also have to say to him, "X, why did you do that?" blah, blah. "This person wasn't trying to intentionally be like this to you." 'Erm and then people would start viewing me differently because it always looked as if I was defending him. But I wasn't, it was just quite literally the case that erm I was trying to understand his feelings as well as theirs and try and find like a common ground between it' 'it was al-almost, like, kind of frustrating in the end because I'd lost so many friendships with certain people who many didn't want to speak to me or anything because of the way, like, the people he'd go for and all this kind of stuff (laughs)' 'And one of my friends went up to him and said, "Are you okay?" Blah, blah. And he shouted at her and threw a tantrum. And I remember her coming up to me and questioning it. And I was like, "Oh, he didn't know who it was. I'm so sorry." And I had to go up to him and kind of describe certain people and say, "look not everyone has a bad intention, and they do want to help'
		Conflict with teachers was related to imbalances of power	'I'd like go over and I'd help out and sometimes some teachers would get frustrated at me, because they'd be like, erm I'm trying to deal with the situation, can you leave us alone?' 'you're <i>not</i> his sis- sibling, like, I know how to deal with him, I've grown up with him, I'm not in any way trying to get in between what you're

			work- what you're doing (laughs), but I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse' 'they- some teachers weren't really happy with me getting involved, which was a bit annoying, because I understand that, like, it's not always my place to, like, get involved, but at the same time, if I can see that they're not <i>doing</i> the right thing, I know that it's just going to make things worse for them, so I tried my best to, like, de-escalate the best that I could.'
FOSTERING CONNECTION THROUGH GIVING AND RECEIVING SUPPORT	A close sibling relationship	Closeness of sibling age is important for providing consistent and stable support	'But I knew that like, on like a sibling level, he had me to turn to whereas my other brother was, is three years younger. So, he doesn't, he didn't at the time, obviously understand because of how young he was. And so it took him a lot longer to come to terms with how my other brother was'
		Having a close sibling relationship and being there for one another at home	'I think like our relationship like at the end of the day, because he's <i>really</i> close with me, and even now that we're not in the same school, like we're still really close' 'but no matter what, we were always like almost like attached at the hip kind of thing, and I was <i>always</i> there for him.'
	The importance of connection and understanding	Life feels easier when others understand her brother	'I know my second secondary, my friends were a lot more understanding, and funny enough, they're still in my life now (laughs).' 'they've always known X to be different, erm and they work really well with him.' 'I think he also had a TA at that primary school that was really good for him, like really good, and she went everywhere with him.' 'she was always there working with him, whereas when we came to here, he didn't have that, so' 'It..it was easier for me, I think at primary school at least, because I knew that he- if something was to happen, someone was there and fully trained and knew how to deal with him, and knew, was able to be like, "Okay, X, don't stress, like erm we'll get through this'

		Connecting with others in a similar situation is both helpful and a shock	'that was the first time, probably two years ago now, that I found out that there were people like me, that had the same situation as me, kind of thing. 'and it was kind of a shock, but it also felt, like, really helpful, because I knew that I wasn't alone'
		Finding comfort and growth in community.	'although it's not the same situation, there are people out there that know what it's like' 'I wasn't aware that people kind of had to deal with the same thing that I dealt with, and then as soon as I saw that, I kind of felt a little bit better' 'I was able to more come to terms with, okay, maybe I do need to start putting myself first as well, which I still struggled with, but I feel like I was able to cope with more'
THE COMPLEX ROLE OF CAREGIVING IN SCHOOL: BALANCING PROTECTION AND ADULTIFICATION	Adultification and Parentification	Balancing her own revision with her role as second parent	'I was trying to make sure that / was getting enough revision done, but also, I wanted him to do well, because I knew that he wanted to get back into here...but he wasn't listening. So, I I tried the hardest that I could' 'Erm and I'd say to him, "Are you not even going to do an hour for tomorrow's exam?" "No, no, I know I've got it. I know exactly what I'm doing." 'he'd come out of the exam, and he'd have extra time and everything. I'm like, "How did that go? You were out a bit early. "Oh, yeah, I didn't want to use that extra time. I didn't finish it, though." And I'm like, "Oh, X". I didn't really understand. And I think when he got his grades, he did understand, and he was like, "Oh, maybe I should listen." 'I always offered him to come into my bedroom and just study with me' 'Because I used to do mine quite later in the evening, because I'd have to deal with him in the morning, because obviously, with study leave as well, my parents weren't home' 'So obviously I'd deal with him, make sure he's eating and everything. He's cared for. Try and get him to revise (laughs). Wouldn't work. And

			then in the evening, I'd start revising, and then I'd end up staying up late revising' 'I was barely sleeping' 'I've got to navigate this, this and this, and then I've got to also make sure that I'm getting all of this revision done because I'm at the end of the school year now and I need to get the grades to get into sixth form if I really want to go.'" (near statement 50)
		A loss of childhood and being in a motherly role	'I was unintentionally a lot more mature for my age than I should have been' 'that someone of my age would want to do, like, "let's do this, let's do that", straightaway I'd be like, "no, I don't want to because X, Y and Z", and they'd be a bit, like, confused sometimes, like, "oh, why is that, like, why don't you want to go and have fun, why don't you want to go do this", and to me, I was kind of in that, like, motherly role already, and I was used to, like, caring for someone' 'I didn't really, like, live erm a lot (swallows) as when I was a lot younger' 'I can kind of start to be more of a teenager now' [after brother left] (near statement 27)
		Adapting and becoming mature was quickly recognised as important – rather than being selfish.	'I don't know how (laughs), but I was very mature about the situation. And because we were so close in age as well erm I kind of easily like <i>adapted</i> to his needs.' 'so I knew kind of like, how to erm deal with him and how to like, like, if he was to have a meltdown at home'
		It was confusing for X to navigate her role as second parent	'I kind of took on a lot' 'I kind of became like a second parent to. Him' 'erm it was really hard to deal with as well, because I was trying to understand why my friends didn't have to like miss out on certain things, whereas I did. And I got a bit jealous (laughs) about it, but I also never blamed him for anything, because obviously he couldn't help it.'

		Taking on the role of TA and stepping up.	'And then when we moved into secondary school, I kind of became that TA, and I felt like it was really hard to deal with in the beginning' 'I got stressed out with it, and I got almost, like, jealous in a way that certain people didn't have to deal with that at the same time.' 'by the end of it, because I was so used to it, erm I knew exactly what I was doing, I got on with it, I knew how to work around it.'
	Hypervigilance and Protection	Hypervigilance and an automatic caring role	'because if there was another, like, erm kid of special needs that was having a meltdown, I kind of got that pit in my stomach, thinking, "Oh, God, where is he?" And then I realised it's not him,'
		Protection of others (peers and teachers)	'and if he's screaming, all the other classrooms can hear it, it's disturbing the lessons as well, so I'm trying my best to calm him down and get him out of the situation' 'it's going to make things worse for them' (teachers). so I tried my best to, like, de-escalate the best that I could.' 'they could cater to his needs and know exactly how to support him erm, whereas teachers here, obviously this department is really good for it as well' (near statement 18)
		Attempting to protect others from her emotional experience	'and then try and not put my bad mood into, like, the conversation with my friends or something, and make them feel bad, because it's not their fault' 'erm be a bit, like, upset with my teacher, which I- I always, I feel like I dealt with pretty well, to be fair, I never took anything out on my teachers or my friends, but it was very hard to just, like, act like everything was okay,'
		Protecting her brother and putting his needs above her own	'then he eventually started coming over, and then I felt guilty for feeling like "I don't really want you here", so I never voiced it' 'I always made sure that they were okay with it, if not I was going to go sit somewhere differently with him, so he still had me' 'erm I was very supportive, because I knew to him he had to tell me about how his day's been, and how, even if it's, like, if he walked past a butterfly and he wants to tell me, like, little things like that, it meant that he could de-stress, and so he can go into his next lesson feeling okay.'

			Erm although it kind of put that stress on to me, it felt a lot better knowing that <i>he</i> was going to be okay' 'I'll go behind the scenes trying to see what I could do out, so it wouldn't fall back on him and know that I've done something about it. But it would just make his school life a little bit more easier' (near statement 12). 'I didn't even think about myself, I was straight away, like, "Is he going to be okay at his new school? How is he going to get there? Is he going to get the right support? Are they going to understand how to work towards his needs?" Like, straight away, I was just thinking about him, and I didn't even focus on the fact that I got into here (laughs), but yeah.' 'I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse' (near ststatement 21)
	Responsibility, Caregiving and Educating	A responsibility for caring across the home and school contexts	'I used to be like, "I can't, because I've got to take my brother home, and then I'm going to get there late, and then I don't know if I would even want to come by then", because then I've got to make sure that if he's had a bad day, he's all right at home'
		Supporting her brother's experience during exam time.	I used to work close with him and say to him, like...because he wanted to come here as well, and I used to say to him, "If you want to come here, erm you do have to work a little bit harder." 'Erm, and I used to be like, "That's not always guaranteed, X. You do need to put a little bit of effort in." I said, "Look, if you're struggling, we can work together. We're in the same year group. I know how to help you out." 'Because we were on study leave as well, which I think also helped with the stress, because we wasn't, we weren't at school having to <i>deal</i> with people and problems and issues that could have caused a meltdown, and we were more at home, away from everyone, which helped a lot, actually' So obviously I'd deal with him, make sure he's eating and everything. He's cared for' (near statement 53)

		The stress of being responsible for catching herself up.	'so I was missing quite a, quite a few lessons, and then I was having to play catch up, which stressed me out, and then I remember when it got to, like, sitting my GCSEs, I had to put a lot of effort (laughs) in to erm get good grades, which I did in the end, but I remember I just, like, stressing myself out way too much over it, but yeah.'
		The responsibility for protecting her brother has consumed much of her school life.	'it always has been quite difficult. I didn't really realise how much it affected me until earlier this year, to be fair, erm because it was more of what I always knew. So, to me, there was no other kind of experience. Erm and I would take on so much responsibility for him' 'I'll go behind the scenes trying to see what I could do out, so it wouldn't fall back on him and know that I've done something about it. But it would just make his school life a little bit more easier'
		Being a young carer affected her academic performance	'I can like remember, like being out of so many lessons, and then my grades were, like, really bad' 'I'd just be, like, completely stressed out, I'd be in a bad mood, and then I'd have to also focus on my lesson' (near statement 39)
		Providing education about others' needs, perspectives and rationale for behaviour	'And sometimes when it was his fault, I'd also have to say to him, "X, why did you do that?" blah, blah. "This person wasn't trying to intentionally be like this to you." 'And I had to go up to him and kind of describe certain people and say, "look not everyone has a bad intention, and they do want to help" and try and try and tell him that when I'm not there and I physically can't be there, these people are always there to help. And then he slowly started to understand it, but it did take a while.' 'I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse' (near statement 20). 'I'd be like, "okay, this is how you deal with the situation, this is the best thing that you can do without causing a massive problem, but don't let this kid walk all over you at the same time' (near statement 38)
THE CHALLENGE OF INVISIBILITY: A SISTER'S	Feeling invisible at school	Advocating for herself felt like the only option – teachers don't notice	'And if it wasn't for...like because I used to speak up against it as well at school. I used to tell teachers, "Look, I'm struggling. I need help because I'm having to deal with this and this." And then they started

ADVOCACY FOR RECOGNITION			putting me in counselling, but it wasn't like <i>they</i> noticed it and then they put me in it. I had to kind of go out of my way' 'And I know I had to chase for it'
		Feeling frustrated with, and not seen by, teachers	'some of them are a bit inappropriate with the way they ask me (higher pitch). Erm, like I have no problem erm with teachers asking me how's he been, how's he finding his new college because they worked so closely with him. But I just think sometimes it's a little frustrating, the fact that they can't also ask me about myself or...not even have to ask me about myself, but just maybe just say hi (laughs).' 'I'm not really seen as a person, I'm kind of just seen as his carer or his sister' (near statement 11)
		Family members of those who are autistic can feel invisible at school.	'I think people should also just focus on the people around them that have to deal with it, because it is like, we kind of get almost pushed to the side'
		Noticing siblings and providing support is important	'I think people just need to be more understanding that homework might take more time to be handed in, or they need a bit more extra help in lesson because they've got either stuff going on at home' 'and just be a bit more understanding when it comes to it. Like if they look burnt out in class, maybe give them a little bit more extra support or something, because I didn't have that'
	Isolation in knowledge: a sister's role	Caring for her brother felt lonely and unavoidable	(from other brother) 'That's your job,' kind of thing. And I was like, "Oh," and so I'd miss out a lot on friendship kind of things. I wouldn't go out as much.' 'at first, I was really confused, and I didn't feel like I had a lot of support either'
		Coping in isolation	'by the end of it, because I was so used to it, erm I knew exactly what I was doing, I got on with it, I knew how to work around it' 'I started realising I've got my own stuff to focus on. But people didn't really understand it'
		Being 'the one; to know what her brother needs and how to support him	'see some teachers weren't qualified in how to deal with children's special (pause) needs, so they would like, they would try and help, but the most that they would do would send him out of class, which would

			aggravate him more and not listen to him and kind of speak over him, instead of giving him his voice and letting him explain his problems' 'you're <i>not</i> his sis- sibling, like, I know how to deal with him, I've grown up with him'
		Others do not understand her brother as she does – this is a sisters role.	'you're [teachers] <i>not</i> his sis- sibling, like, I know how to deal with him, I've grown up with him' 'I couldn't understand like my other younger brother, who wasn't diagnosed at the time, erm he, like If I said to him, "Oh, my friend's wanna hang out after school, erm we just want to go to the park down the road. Would it be okay if you could just walk him home?" And it was like a massive problem to him. "I don't want to walk him home, blah, blah, blah, blah, why do I have to? That's your job,"' (near statement 8)
NAVIGATING DIFFERENCES AND MISSED OPPORTUNITIES	N/A	Those without autistic siblings have more freedom in school	'I've seen my other friends who haven't got any siblings at all or don't have siblings in their year, erm they were able to bei- like yeah, erm more carefree, or more like erm open about everything.' 'they might have been stressed out, but they didn't have loads of stress on them, and they were able to just go like, "Oh, do you want to go out?"'
		Her experience is different to that of her peers	'some people would be able to have break or lunch and just relax a bit, and be like, okay, we've got the next lesson, whereas I'd be like, "oh my gosh (laughs), I just want to get to the end of the day now."' 'I've seen my other friends who haven't got any siblings at all or don't have siblings in their year, erm they were able to bei- like yeah, erm more carefree, or more like erm open about everything.' (near statement 43) 'I got stressed out with it, and I got almost, like, jealous in a way that certain people didn't have to deal with that at the same time.' (near statement 48)
		Being a young carer affected her academic performance	'I can like remember, like being out of so many lessons, and then my grades were, like, really bad'

			'I was trying to make sure that I was getting enough revision done, but also, I wanted him to do well, because I knew that he wanted to get back into here...but he wasn't listening. So, I tried the hardest that I could' (near statement 52)
		Educating her brother affected her classroom concentration	'I'd get really stressed out, and I'd be in class, and I'd feel, like... bad, and that I can't, first of all, be there to help him, and take away all them problems' 'I'd just be, like, completely stressed out, I'd be in a bad mood, and then I'd have to also focus on my lesson'
		Navigating responsibilities affected extracurricular and learning experiences	'Erm so extracurricular-wise, I didn't really get the chance to join them because obviously they were all after school, and my main focus was him getting home properly and safely' 'Erm but when it came to, like, homework and erm revision, I think especially erm during GCSE time, I struggled because I was thinking, like, erm "I've got to navigate this, this and this, and then I've got to also make sure that I'm getting all of this revision done'
ENTWINED IDENTITY AND A SENSE OF SELF	Being 'one person'	Confusion around who she is without her brother	'So then, when I got it here, and I sat at the table for the first time with my new friends, and he wasn't there, I kind of was just, like, "what do I talk about? What do I? Like, what do I do? I don't know how to even go about this".' "why why are you acting a bit different (laughs)? Like, this is the normal thing to do." And I was, like, "no, I'm not used to this, you don't understand." (laughs)...but, yeah' 'my brother's in a different school to me now, so I remember starting in September, back here, and being so confused on how to even work things out' (statement 25) 'Erm and then having that shift to sixth form and him not being there was just... It was really like, "Oh, what do I do now?"' (statement 49)
		Sibling experiences of being in school were enmeshed and intertwined with one another	'So I used to walk him to and from school every day. Erm I'd pick him up outside of class, he eventually, he'd be able to talk to his own class and so and so'

			'Break and lunchtime, he'd spend it with me and my friends. Erm he'd sit down at lunchtime, eat his lunch, tell me about how his day's been, erm give me a little summary of everything' 'I'd have people come up to me and be like, "Oh, X has done X, Y, and Z." And I'd be like....(laughs) "I don't know what you want me to do about it.'
		Being seen as one person and being invisible	'I couldn't really like be my own self away from him...? It always felt like people would always be like, "Oh, X sister." 'there's a certain teacher at this school that always walks past and instead of acknowledging me, she says straight away, "Oh, how's your brother?"' 'it kind of hurts sometimes, because it's just I'm not really seen as a person, I'm kind of just seen as his carer or his sister.'
	Self-neglect and guilt	Sharing guilt around her own needs and wishes	'I kind of got that feeling in my stomach, like, and I felt, like I said, guilty about it, because I didn't want him to think that he's a burden or anything, because he's <i>not</i>, and he never will be, but I kind of felt also selfish for feeling the way that, like, I just wanted space.' 'it's refreshing in a way, which kind of sounds not the best (laughs), but erm it's nice that I can just walk freely in school' (statement 28) 'I felt guilty for fe-feeling like "I don't really want you here", so I never voiced it' (statement 35)
		It is easier to think of support for her brother, than support for herself.	'like, everything that's happened is what I've known' I wouldn't really know if anything could benefit me or could have, erm or maybe turn out for the worse or something. Erm but I think, like, the school did really well with, like, trying to deal with him' 'I I, I wouldn't really know, because everything that happened kind of made sense for me, in a way.' I didn't even think about myself, I was straight away, like, "Is he going to be okay at his new school? How is he going to get there? Is he going to get the right support? Are they going to understand how to work towards his needs?" Like, straight away, I was just thinking about

			him, and I didn't even focus on the fact that I got into here (laughs), but yeah.'
		Protecting her brother and putting his needs above her own	'then he eventually started coming over, and then I felt guilty for feeling like "I don't really want you here", so I never voiced it' 'I always made sure that they were okay with it, if not I was going to go sit somewhere differently with him, so he still had me' 'erm I was very supportive, because I knew to him he had to tell me about how his day's been, and how, even if it's, like, if he walked past a butterfly and he wants to tell me, like, little things like that, it meant that he could de-stress, and so he can go into his next lesson feeling okay. Erm although it kind of put that stress on to me, it felt a lot better knowing that <i>he</i> was going to be okay' 'I'll go behind the scenes trying to see what I could do out, so it wouldn't fall back on him and know that I've done something about it. But it would just make his school life a little bit more easier' (near statement 12). 'I didn't even think about myself, I was straight away, like, "Is he going to be okay at his new school? How is he going to get there? Is he going to get the right support? Are they going to understand how to work towards his needs?" Like, straight away, I was just thinking about him, and I didn't even focus on the fact that I got into here (laughs), but yeah.' 'I'm just telling you the way you're dealing with him is wrong and the way you're speaking to him is really wrong, and you're just going to make things worse' (near statement 21) 'Obviously I'd deal with him, make sure he's eating and everything. He's cared for. Try and get him to revise (laughs). Wouldn't work. And then in the evening, I'd start revising, and then I'd end up staying up late revising. And then I'd get up early to put more revision in, and I was barely sleeping (near statement 50).
AVOIDING JUDGEMENT THROUGH EMPATHY	N/A	Relationships with parents were different when her brother was	'It was a lot different at first because obviously I'm the oldest so I've never seen how my parents would parent another person blah, blah. Erm so I've noticed like the treatment I was getting which (higher pitch)

AND PERSPECTIVE TAKING		born – it was still good and they were learning	is still like good, but like, and we've all got like a very healthy relationship with our parents'
		Hurt and understanding around others' actions.	'And then I don't mind like some teachers asking, obviously, because of how big (laughs) of a personality he was. It makes sense. But I feel like mo-some of them, their motivation's more to talk about him rather than even say hi to me and it kind of hurts sometimes,' 'obviously, people who didn't have erm siblings of autism, they didn't understand, which is fair enough' (near statement 14). 'some of them are a bit inappropriate with the way they ask me (higher pitch). Erm, like I have no problem erm with teachers asking me how's he been, how's he finding his new college because they worked so closely with him' (near statement 16)
THE EMOTIONAL LANDSCAPE OF CHANGE IN EDUCATION: EMBRACING FREEDOM AMIDST LOSS	The difference in role across time in education	Relaxing feels strange and keeping busy is important for self-development.	'When they ended, I kind of was like, "Oh." And it was really (laughs) strange, because I got used to it In the end. And then obviously I didn't have that stress. And then I had that summer of just being able to chill. And then but I couldn't deal with it in a way, because I was so used to being occupied with something' 'I ended up getting a job which kind of got me out the house as well, which was nice and built up my confidence and social skills.' 'I was also really busy then over the summer and making sure that my mind was always working.'
		A dual benefit for a transition apart	'I think me and him being separated as well worked out better for him, because he is a lot more independent now, erm like, he knows how to travel, which is something that he could never even, didn't even know how to use a bus card at, like, the start of September. Erm he's a lot more just, like, yeah, mature, and it's really strange to see, because a year ago I wouldn't even, like, imagine him being in that way at all' 'it felt really strange, and it's refreshing in a way, which kind of sounds not the best (laughs), but erm it's nice that I can just walk freely in school without having to erm deal with...something, or I'm not getting pulled out of lesson for something, I'm able to be in all my lessons willingly, erm, I'm able to, like, get on with what I want to do, I can kind of start to be more of a teenager now, which it, like, it all really does feel weird'

		Letting go of hypervigilance now apart at school	'I think just not having that stress, and that kind of stigma, like, something could be happening right now, or erm how should I deal with this situation? Like depending on the person who's upset, how do I go about this?' 'if there was another, like, erm kid of special needs that was having a meltdown, I kind of got that pit in my stomach, thinking, "Oh, God, where is he?" And then I realised it's not him' (near statement 32).
		A difference across primary and secondary school experiences.	'I think especially in primary school, it was a lot easier for me, because I think in our first primary school, I think I was too young to like fully get it' I'd get jealous at first, because <i>they</i> didn't know how to deal with him, and instead of trying to deal with him in the classroom, they'd take him completely out of class, and you'd see out the window that he was in the playground playing with all the toys' 'we moved primary school, and then, like I said, he had a TA who was like qualified for his needs, and she was <i>perfect</i> for him. She worked really closely with my mum, made sure he had everything that he needed. Erm and then I didn't really...like, I still had that kind of stress, because I had people come up to me still, but I didn't have that much stress' 'And then when we moved into secondary school, I kind of became that TA, and I felt like it was really hard to deal with in the beginning. 'A shift to sixth form and him not being there was just... It was really like, "Oh, what do I do now?"'
	The emotional landscape of change	Coming to terms with change felt both unsettling and freeing	'Erm so now that when I walk past, and I don't have to, like, I don't even see him during a changeover, it's kind of, like, weird, but it's also refreshing, and I think at the start of September, I kind of, it confused me' 'It was really hard to, like, come to terms with for a while, which I eventually got, but, yeah.' 'I'm used to it, I think, erm'

			'... I think now, obviously, I'm able to sit back and be, like, "Okay, like, I'm on my own now, this is good." But at the start, I literally was very confused, and I felt kind of lost almost, because it was just all I knew, and it was <i>gone</i> '
		No longer being at the same school brings up a variety of conflicting emotions	'my brother's in a different school to me now, so I remember starting in September, back here, and being so confused on how to even work things out'
		Being alone and feeling lost when her brother gained independence	'obviously I get to go home, and he's still there, and he's not, like, at home, he's very independent, he don't even want to talk to any of us, he goes up into his room, he spends time, blah, blah' 'and I just think, like, being alone... in the same setting where he was, it's just, like, it really does shock me sometimes (laughs), but yeah.' (near statement 30) 'Erm he's a lot more just, like, yeah, mature, and it's really strange to see'
		A change in role feels like both a loss and freedom	'I'm having to, like... now kind of erm...like, if I, when I do go out with my friends, I still get a bit, like, oh, "I don't know if I want to do this, this and this", because of how mature I've had to be, but at the same time, like, when I kind of let go a little bit (laughs), I think it's a massive shock to everyone, and everyone's just, like, "oh my God, I never would expect this!", kind of thing.' 'walking home on my own, or being able to go out after school, it was all just really <i>massively</i> different for me, but it was also good in, like, in the end, but I think, like, I really did struggle at first to come to terms with it' 'it's really, really weird, and, like, sometimes it really confuses me, because it's, like, I've known that for the whole of my life, and then I've gone suddenly straight into not him being here.' 'really strange, and it's refreshing in a way, which kind of sounds not the best (laughs), but erm it's nice that I can just walk freely in school without having to erm deal with...something, or I'm not getting pulled out of lesson for something, I'm able to be in all my lessons willingly, erm, I'm able to, like, get on with what I want to do'

		Worrying about his future.	'I didn't even think about myself, I was straight away, like, "Is he going to be okay at his new school? How is he going to get there? Is he going to get the right support? Are they going to understand how to work towards his needs?" Like, straight away, I was just thinking about him, and I didn't even focus on the fact that I got into here (laughs), but yeah.'
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Note. This was repeated for each participant at Stage 6 of data analysis

L5. Photo of GET Creation (Data Analysis Stage 7)

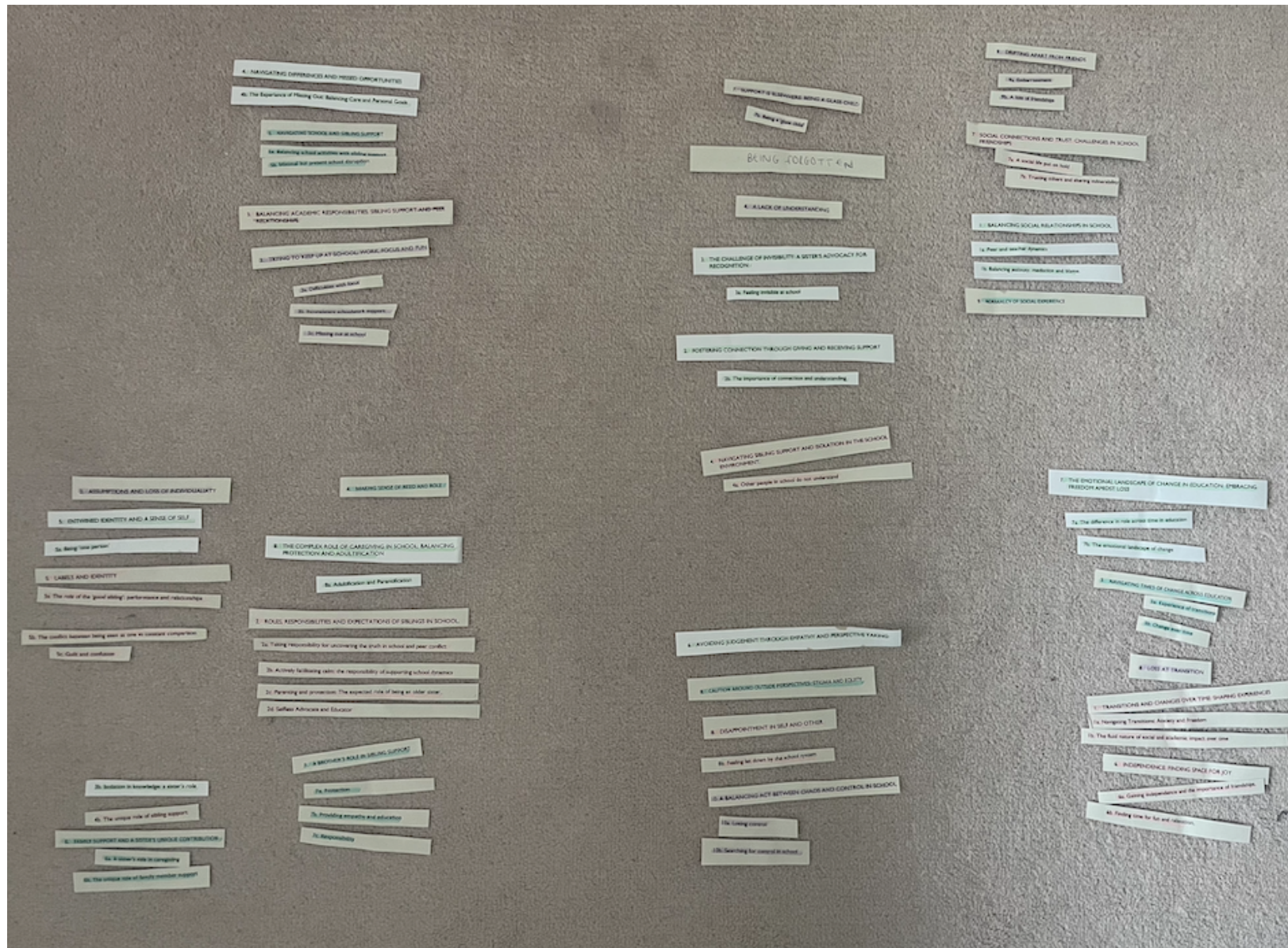


Table L6. Overall GET Table Showing Contributing PETs and Subthemes (Data Analysis Stage 7 Continued)

Cassandra
Lilly
Blue-Moon
Rian

GET	PETS
1. <u>PLAYING A PART AND BEING IN ROLE</u>	C5. LABELS AND IDENTITY • C5. 1 The role of the 'good sibling': performance and relationships. • C5.2. The conflict between being seen as one vs constant comparison. • C5.3. Guilt and confusion L6. ENTWINED IDENTITY AND SENSE OF SELF • L6.1. Being 'one person' BM 2. ASSUMPTIONS AND LOSS OF INDIVIDUALITY C2. ROLES, RESPONSIBILITIES AND EXPECTATIONS OF SIBLINGS IN SCHOOL • C2.1. Taking responsibility for uncovering the truth in school and peer conflict • C2.2. Actively facilitating calm: the responsibility of supporting school dynamics • C2.3. Parenting and protection: The expected role of being an older sister. • C2.4. Selfless Advocate and Educator L3. THE COMPLEX ROLE OF CAREGIVING IN SCHOOL: BALANCING PROTECTION AND ADULTIFICATION • L3.1. Adultification and parentification • L3.3. Responsibility, caregiving and educating. R3. MAKING SENSE OF NEED AND ROLE
• Identity	
• Role	

	R6. A BROTHER'S ROLE IN SIBLING SUPPORT • R.6.1. Protection • R.6.2. Providing empathy and education. • R.6.3. Responsibility.
• Gender	R5. FAMILY SUPPORT AND A SISTER'S UNIQUE CONTRIBUTION • R.5.1. A sister's role in caregiving. • R.5.2. The unique role of family member support. L4. THE CHALLENGE OF INVISIBILITY: A SISTER'S ADVOCACY FOR RECOGNITION • L.4.2 Isolation in knowledge: a sister's role C4. NAVIGATING SIBLING SUPPORT AND ISOLATION IN THE SCHOOL ENVIRONMENT • C.4.2. the unique role of sibling support
2. IN AND BEYOND THE CLASSROOM – LEARNING EXPERIENCES	L5. NAVIGATING DIFFERENCES AND MISSED OPPORTUNITIES R4. NAVIGATING SCHOOL AND SIBLING SUPPORT • R.4.1. Balancing school activities with sibling support. BM3. TRYING TO KEEP UP AT SCHOOL: WORK FOCUS AND FUN • BM3.3. Missing out at school C3. BALANCING ACADEMIC RESPONSIBILITIES, SIBLING SUPPORT AND PEER RELATIONSHIPS • C3.2. Looking for balance
• Extracurriculars/fun	
• Academic Responsibilities	

C3. BALANCING ACADEMIC RESPONSIBILITIES, SIBLING SUPPORT AND PEER RELATIONSHIPS

- C3.3. Academic Impact

BM3. TRYING TO KEEP UP AT SCHOOL: WORK FOCUS AND FUN

- BM 3.1. Difficulties with focus
- BM 3.2. Inconsistent schoolwork support

R4. NAVIGATING SCHOOL AND SIBLING SUPPORT

- R.4.2. Minimal but present school disruption.

L5. NAVIGATING DIFFERENCES AND MISSED OPPORTUNITIES

3. EXTERNAL VOICES: BEING JUDGED AND LET DOWN

R7. CAUTION AROUND OUTSIDE PERSPECTIVES: STIGMA AND EQUITY

L7. AVOIDING JUDGEMENT THROUGH EMPATHY AND PERSPECTIVE TAKING

C8. DISAPPOINTMENT IN SELF AND OTHER

- C8.1 Feeling that she let her brother down.
- C8.2 Feeling let down by the school system

BM10. A BALANCING ACT BETWEEN CHAOS AND CONTROL IN SCHOOL

- BM 10.1. Losing control
- BM 10.2. Searching for control in school

4. BELONGING AND SOCIAL VISIBILITY AT SCHOOL

- Social relationships

R8. NORMALCY OF SOCIAL EXPERIENCE

BM 9. DRIFTING APART FROM FRIENDS

- BM 9.1. Embarrassment
 - BM 9.2. A loss of friendships
-

C7. SOCIAL CONNECTIONS AND TRUST: CHALLENGES IN SCHOOL FRIENDSHIPS

- C7.1 A social life put on hold
- C7.2. Trusting others and sharing vulnerability

L1. BALANCING SOCIAL RELATIONSHIPS IN SCHOOL

- L1.1. Peer and teacher dynamics.
- L1.2. Balancing jealousy, mediation and blame.

- Isolation and visibility

BM 7. SUPPORT IS ELSEWHERE: BEING A GLASS CHILD

- BM 7.1. Isolation in school
- BM 7.2. Being a 'glass child'

C4. NAVIGATING SIBLING SUPPORT AND ISOLATION IN THE SCHOOL ENVIRONMENT

- C4.1. Other people in school do not understand.

L4. THE CHALLENGE OF INVISIBILITY: A SISTER'S ADVOCACY FOR RECOGNITION

- L4.1 Feeling invisible at school

BM 4. A LACK OF UNDERSTANDING

L2. FOSTERING CONNECTION THROUGH GIVING AND RECEIVING SUPPORT

- L2.1. A close sibling relationship.
- L2.2. The importance of connection and understanding.

BM 5. BEING FORGOTTEN

5. MAINTAINING A BALANCING ACT:

- Neglecting Self

R1. PRIORITISING BROTHERS AND NEGLECTING SELF

BM6. PUTTING OTHERS FIRST

C3. BALANCING ACADEMIC RESPONSIBILITIES AND SIBLING SUPPORT

- C3.1. Putting his needs first

L6. ENTWINED IDENTITY AND SENSE OF SELF

- L6.2. Self-neglect and guilt

BM 7. SUPPORT IS ELSEWHERE: BEING A GLASS CHILD

- BM7.3. The build-up of need and lacking attention

- Protecting Self

BM1. LIVING ON ALERT: SELF PROTECTION IN SCHOOL

- BM1.1. Self-protection
- BM1.2. Hypervigilance

L3. THE COMPLEX ROLE OF CAREGIVING IN SCHOOL: BALANCING PROTECTION AND ADULTIFICATION

- L3.2. Hypervigilance and protection

C7. SOCIAL CONNECTIONS AND TRUST: CHALLENGES IN SCHOOL FRIENDSHIPS

- C7.2. Trusting others and sharing vulnerability

C4. NAVIGATING SIBLING SUPPORT AND ISOLATION IN THE SCHOOL ENVIRONMENT

- C4.3. Isolation vs seeking calm
-

6. TRANSITIONS AND
TRANSFORMATION ACROSS
THE SCHOOL JOURNEY

BM 8. LOSS AT TRANSITION

C6. INDEPENDENCE: FINDING SPACE FOR JOY

- C6.1 Gaining independence and the importance of friendships.
- C6.2 Finding time for fun and relaxation.

C1. TRANSITIONS AND CHANGE OVER TIME: SHAPING EXPERIENCES

R2. NAVIGATING TIMES OF CHANGE ACROSS EDUCATION

- R.2.1. Experience of transitions.
- R.2.2. Change over time.

L8. THE EMOTIONAL LANDSCAPE OF CHANGE: EMBRACING FREEDOM AND LOSS

- L8.1. The difference in role across time in education
 - L8.2. The emotional landscape of change
-