Growing up with autism:

Experiences and perceptions of neuro-typically
developing sisters

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<th>Description</th>
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<td>NTD</td>
<td>neuro-typically developing</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>HFA</td>
<td>High-functioning Autism</td>
</tr>
<tr>
<td>LD</td>
<td>learning difficulties</td>
</tr>
<tr>
<td>LA</td>
<td>Local Authority</td>
</tr>
<tr>
<td>CEP</td>
<td>Child and Educational Psychologist</td>
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<tr>
<td>CAMHS</td>
<td>Child and Adolescent Mental Health Services</td>
</tr>
<tr>
<td>DAMP</td>
<td>Deficits in Attention, Motor control and Perception</td>
</tr>
<tr>
<td>SDQ</td>
<td>Strengths and Difficulties Questionnaire (Goodman, 1997)</td>
</tr>
<tr>
<td>PI</td>
<td>Participant Information</td>
</tr>
<tr>
<td>BPS</td>
<td>British Psychological Society</td>
</tr>
<tr>
<td>GCSE</td>
<td>General Certificate of Secondary Education, most typically sat at age 16</td>
</tr>
<tr>
<td>‘A’ Level</td>
<td>General Certificate of Education Advanced Level, most typically sat at aged 18</td>
</tr>
<tr>
<td>SEND</td>
<td>Special Educational Needs and Disability</td>
</tr>
<tr>
<td>TA</td>
<td>Thematic Analysis</td>
</tr>
<tr>
<td>SSI</td>
<td>Semi-structured Interviews</td>
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<tr>
<td>CCM</td>
<td>Constant Comparative Method</td>
</tr>
<tr>
<td>GT</td>
<td>Grounded Theory</td>
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<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>CA</td>
<td>Content Analysis</td>
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<tr>
<td>CCA</td>
<td>Cross-Case Analysis</td>
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<tr>
<td>Mid-childhood</td>
<td>used to denote an approximate age between 8 and 12 years (Education Encyclopedia)</td>
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<tr>
<td>Adolescence</td>
<td>used to denote an approximate an age between 13 and 18 (Education Encyclopedia)</td>
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Abstract

Research shows that raising a child with ASD makes considerable demands on family resources, yet the experiences of neuro typically developing (NTD) siblings of children and young people with ASD remain relatively unexplored. The findings of quantitative research are mixed and inconclusive and little is known about the processes that mediate and moderate the experience of living with a sibling with ASD (Hodapp et al., 2005; Meadan et al., 2010; Petalas et al., 2009).

Further descriptive and exploratory research is indicated with participants of different groups to illuminate the multi-factorial nature of the phenomenon and help understand the apparent differences in individual experiences and outcomes. This study uses semi-structured interviews and thematic analysis to explore the self-reported experiences and perceptions of eight neuro-typically developing sisters, aged 10-19, who are also the sole NTD siblings in their families. Their parents were also interviewed to provide contextual information and to ascertain their views on the sibling experience. In addition to looking at their family life and sibling relationships, this study also explores school life and peer group relationships.

Analysis suggests eight themes of sibling experience: Continuum of Perceived Challenge: Positively and negatively perceived aspects of having a sibling with ASD. Continuum of Acceptance; Coping and Resilience; Continuum of Relatability; Continuum of Positive Identity; Social world: Threats and Friends; Social Carer; Support.

NTD sisters adopt a social caring role towards their sibling with ASD, that is different to that fulfilled by parents and transcends home and school boundaries. NTD sisters can be negatively affected by tension between home and school regarding provision for the child with ASD.

Reconciling social persona with loyalty to one’s sibling, developing a mutually satisfying sibling relationship and findings strengths and positive meaning in one’s experiences, are associated with positive adjustment. Mother-daughter relationship and family beliefs and values are highly influential in the psycho-emotional adjustment of NTD sisters.

Implications for the practice of applied psychologists and school-based professionals, in response to these findings, are explored and areas for further research are suggested.
Declaration

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Finally, thanks to my family for their support and patience. To Richard for working so hard and then some, and to Evie, Alice and Grace - I dearly hope you don’t forever associate study with missed trips and wasted weekends.
Chapter 1: Introduction

1.1 Background

Current estimates suggest that 1 in 100 children in the UK has a diagnosis of Autistic Spectrum Disorder (ASD) (Baird et al., 2006). The number of children and young people (CYP) diagnosed with ASD has increased exponentially in recent years (Baio, 2012). Assuming the accuracy of historic and contemporary estimates, prevalence of the condition has increased 100 fold in the last 50 years (Holburn, 2008), with some data suggesting the rate of diagnosis is increasing between 10 and 17% a year (Meadan, Stoner, & Angell, 2010).

Debate continues as to whether this increase in diagnosis represents heightened awareness of the condition (Wing & Potter, 2002), more inclusive definitions of ‘autism’ (Chakrabarti & Fombonne, 2005; Wing & Potter, 2002), greater awareness of the presentation of ASD in girls (Gould, 2011) or the medicalisation of age-old ‘male’ traits that are viewed unfavourably by modern Western society (Timimi, Gardner, & McCabe, 2010). Most probably, the current ASD ‘epidemic’ is best understood as a complex combination of all these factors. As parental concerns about difficult behaviour and poor social interaction drive requests for diagnosis (Ambitious About Autism, 2014), one can assume that repetitive behaviours, sensory intolerance, resistance to change and disturbed domestic routines might also affect other children growing up in the household, and the nature and quality of sibling relationships (Kaminsky & Dewey, 2001).

There is no precise data on the number of neuro-typically developing (NTD) siblings living with children and young people with ASD in the UK. The National Autistic Society (Society, 2015) suggests as many as 2.8 million people in the UK either have, or live with someone who has, a diagnosis of ASD. Using most recent population data (Office for National Statistics, 2011) and the assumption 1 in 100 people in the general population have ASD, (Ambitious About Autism,
2014) an estimated 150,000 people aged 0-19 have a diagnosis of ASD in the UK. Atkinson and Crawforth (1995) found 80% of children with learning disabilities share their home with a NTD sibling. Assuming 80% of children and young people with ASD have just one NTD sibling, one can estimate at least 120,000 NTD children and young people live with a sibling of ASD in the UK.

1.1.1 Families and ASD

Although ASD is defined as impairments in social communication, social interaction and social understanding and imagination (Wing & Gould, 1979), degree of impairment varies significantly between individuals. Cognitive ability, method of communication and co-morbid medical conditions such as epilepsy and ADHD also influence the nature, and extent, of disability (Reiersen & Todd, 2008; K. R. M. Smith & Matson, 2010).

Research into familial experience of ASD has focussed primarily on parents (e.g.Bayat, 2007; Begum & Blacher, 2011; Nielsen et al., 2012). Raising a child with disability is considered more difficult than parenting a typically developing child (Bristol & Schopler, 1984; Dyson, 1997) and parents of children with ASD arguably face more challenges than parents of children with other life-long disabilities (Dumas, Wolf, Fisman, & Culligan, 1991; Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001; Sanders & Morgan, 1997). Families differ greatly in their personal, social and financial resources. Fisman et al. (1996) found that although protective factors, such as family cohesion and financial security, cushion against the impact of disability, raising a child with ASD remains comparatively challenging.

Many parents of children with ASD report relatively high levels of stress (Hastings, Daley, Burns, Beck, & MacLean, 2006; Rao & Beidel, 2009; Sanders & Morgan, 1997; Sharpley, Bitsika, & Efremidis, 1997). This is attributed to a combination of managing challenging and socially difficult behaviour, providing a
high level of care and supporting the social and communication needs of their child (Hastings, 2002). For many parents, gaining diagnosis and support for their child is also stressful (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Smith & Elder, 2010). Interactions with professionals can exacerbate stress (Hodge & Runswick-Cole, 2008; Osborne & Reed, 2008) and parents of children with ASD are at increased risk of developing mental health problems (Herring et al., 2006; Lainhart, 1999). There is a strong positive bi-directional association between poor parental mental health and the challenging behaviours of a child with ASD (Davis & Gavidia-Payne, 2009; Rezendes & Scarpa, 2011). This can prove a highly negative and entrenched cycle.

An understanding of the nature and extent of challenge faced by parents is pertinent to the study of the experiences of NTD siblings. Firstly, behaviours that challenge adults are also likely to be problematic for other children living in the household. Evidence suggests siblings of ASD are more likely to develop behavioural difficulties than siblings of children with other disabilities (Bagenholm & Gillberg, 1991; Hastings, 2003a) and these behaviours are more likely to be internalising in nature (Ross & Cuskelly, 2006). Siblings of children with ASD are more likely than both the normal population and the siblings of other disabled groups, to develop depression, anxiety and other mental illness (Gold, 1993; Lainhart, 1999; Ross & Cuskelly, 2006). Difficulties in social and psychological adjustment in childhood increases risk to mental health and emotional wellbeing in later life and many adult physical ailments contain psychological elements (Kinderman & Tai, 2009). Consequently, there is a clear need to understand the subjective sibling experience and better understand what supports the psychological wellbeing of children and young people growing up with ASD.

Furthermore, a parent who is stressed or experiencing mental health problems, is less likely to make the best parenting choices for their children (Cleaver,
Unell, & Aldgate, 2011). Any difficulties are further magnified by the demands that raising a child with disability places on social and financial resources (Parsons & Platt, 2013). Petalas, Hastings, Nash, Dowey, and Reilly (2009) suggest that siblings of CYP with ASD are especially vulnerable; the social, emotional and behavioural challenges presented by their sibling are exacerbated by having parents who are emotionally and psychologically stretched.

Additionally, society’s treatment of disability can create practical and psycho-emotional challenges for NTD family members “...social organization disables not just the family member who has an impairment, but the whole family unit, especially when that family member is a child” (Dowling & Dolan, 2001, p. 24).

In the course of conducting previous research with parents of children with ASD, and in my regular professional and personal contact with families of children with ASD, parents had often raised concerns about the wellbeing and lack of support for their NTD children.

1.1.2 Sibling relationships

Sibling relationships are central within families, taking second place only to the parent-child bond and often enjoying greater longevity that any other personal relationship (Buhrmester & Furman, 1990). Sibling relationships perform a key role in developing our “emotional understanding, self-regulation, and a sense of belonging and comfort” (Orsmond & Seltzer, 2007, p. 131). They provide young children with the blueprint for future peer-relations and opportunities to learn to share and develop friendship skills (Turnbull et al., 2005; Turnbull & Turnbull, 1990; Updegraff, McHale, & Crouter, 2002). Together, siblings learn to accept and manage rivalry, process a range of positive and negative emotions in a safe arena and offer, and receive, emotional support (e.g. Harris & Glasberg, 2012; Turnbull, Turnbull, Erwin, & Soodak, 2006).
Tucker, McHale, and Crouter (2001) found disability has a polarising effect on sibling relationships with some pairs driven apart and others drawn closely together. Some adult NTD siblings have frequent contact with their sibling with ASD and describe their relationship positively (Orsmond & Seltzer, 2007). Relationships between siblings can be warm and enriching irrespective of ASD (Fisman et al., 1996; Petalas, Hastings, Nash, & Duff, 2015) and this is beneficial for both parties. NTD siblings can support their brother or sisters’ acquisition of social behaviours (Bass & Mulick, 2007; Tsao & Odom, 2006; Walton & Ingersoll, 2012) and close sibling relationships correlate with lower levels of internalising behaviours for NTD children and young people (Gass, Jenkins, & Dunn, 2007).

1.2 Limitations of current research

Although the experiences of ASD siblings have been studied intermittently for 40 years or so, research has shed relatively little light on the phenomenon (Hodapp et al., 2005; Meadan et al., 2010; Petalas et al., 2009). Most research to date has been quantitative and focussed on ‘child variables’ rather than ‘child experiences’ and ‘outcomes for’ rather than ‘experiences of’ siblings. Quantitative research has concerned itself with distinct elements of “feelings, functioning, and relationships” (Hodapp et al., 2005, p. 334) and standardised measures of social, emotional and behavioural adjustment and relationship quality relying primarily on self, parent and teacher reports of behaviour. The cumulative findings of that body of quantitative research are inconclusive (Benson & Karlof, 2008; Macks & Reeve, 2007; Meadan et al., 2010; Orsmond & Seltzer, 2007; Petalas et al., 2009; Rivers & Stoneman, 2003). Whilst many siblings of ASD report both positive and negative aspects to their sibling relationships, some experience high levels of sustained conflict, especially in adolescence (Kim, McHale, Wayne Osgood, & Crouter, 2006). Petalas, Hastings,
Nash, Reilly, and Dowey (2012) outline one apparent contradiction: one set of research suggests siblings are more likely to experience adjustment difficulties than other children (Bagenholm & Gillberg, 1991; Fisman et al., 1996). Apparently contradictory studies suggest that ASD siblings are resilient and show enhanced levels of adjustment (Hastings, 2003). They have good social skills (Ferrari 1984), good self-image and enhanced psychological and social development (Macks & Reeve, 2007). A third body of research suggests no significant difference between the social adjustment of siblings of ASD and other children (Hastings, 2006; Kaminsky & Dewey, 2002).

Critical analysis of this body of quantitative research (Cuskelly, 1999; Hodapp et al., 2005; Meadan et al., 2010) attribute these inconsistent and, at times, contradictory findings to methodological issues. Firstly, researchers use different definitions and measures of key terms, including ‘ASD’ and ‘Adjustment’. Secondly, there is a suggestion that some quantitative research in this field has adopted an inherently negative stance, assuming experiences and outcomes will be harmful, ignoring evidence of resilience and failing to reflect positive aspects (Hodapp et al., 2005; Petalas et al., 2009; Stoneman, 2005).

Finally, differences in research design (including sampling without due reference to demographic factors such as gender, birth order, family size and severity of disability) make comparison of findings difficult. Studies that have shown greater sensitivity to socio-cultural factors show they are important in shaping perceptions and outcomes (Macks & Reeve, 2007). Recent reviews of the literature have called for research that develops our understanding of the complex and multi-dimensional nature of the NTD sibling experience (Meadan et al., 2010; Orsmond & Seltzer, 2007; Smith & Elder, 2010) and the interaction of cultural and socio-economic factors. Fisman et al. (1996) found evidence for…”
risk or protective factors in predicting sibling adjustment” (Fisman et al., 1996, p. 1352).

There is surprisingly little research that captures the first hand experiences and ‘voice’ of children and young people who have siblings with ASD (Hodapp et al., 2005; Petalas et al., 2009). Explanations for this omission include the general social exclusion of families with disability (Dowling & Dolan, 2001), within-child models of disability that focus exclusively on the child with ASD (Clarke, 2006), and the traditional indifference of research to the voice of child participants (Greene & Hill, 2005). Historically, researchers rarely asked children about their experiences. Young people were very much the subjects of, rather than participants in, research (Greene & Hill, 2005). As well as acknowledging NTD siblings as agents in their own lives, research about their experience “...respects and promotes [them] ... as persons of value and persons with rights. The focus shifts thereby to studying children and not child variables” (Greene & Hill, 2005, pp. 3, my italics). Eliciting the views of children and young people is therefore a political and moral act (Lansdown, 2011); capturing the first-hand experiences of NTD siblings not only promotes understanding of this complex phenomenon, but also raises the profile of this group of young people and any support needs they may have.

The relative absence of sibling voice concerns researchers in this field, “...the sibling viewpoint is conspicuously absent in the literature and the siblings themselves are seldom given the opportunity to provide first-hand information” (Petalas et al., 2009, p. 396.). We need to return to accounts “...from their own perspective...” (Dellve et al., 2000, p. 173), in order to “...give the true flavour of subjective experience...” (Masha and Boucher, 2006, p.20). Psychologists have long understood that our experiences shapes development and knowledge of the world we live in, “The person’s interpretation of experience is simultaneously the most significant product of an encounter and a spur to the next” (Kagan, 1984,
p. 279). By understanding the meaning that individuals attribute to their experiences we can start to anticipate the impact of this experience, and plan appropriate support.

1.2.1 The case for further qualitative research

In summary, researchers still lack a clear understanding of how, and why, some NTD siblings adjust better than others to living with a child with ASD, and why some sibling relationships are more successful than others (Rivers & Stoneman, 2003; Stoneman, 2005). To achieve positive outcomes for all children, we need to learn more about sibling experiences and the processes of effective adjustment. In order to better understand the factors and processes behind individual experiences, further research is needed with identified groups. This can be done by segmenting the population by gender, socio-cultural and economic group, by family characteristics and by the type and nature of ASD diagnosis (Hodapp et al., 2005; Petalas, Hastings, Nash, Reilly, et al., 2012). Gender and family characteristics are two such areas identified for further research by case study researchers in this field (Angell, Meaden, & Stoner, 2012; Petalas, Hastings, Nash, Reilly, et al., 2012; Sage & Jegatheesan, 2010). Quantitative research suggests that NTD brothers and sisters experience different short and long term consequences of having a sibling with ASD (Orsmond & Seltzer, 2009; Verté, Roeyers & Buysse, 2003) and that the nature of sibling relationships are shaped by the gender of both sibling (Orsmond & Seltzer, 2000; 2009). However, qualitative research in this field has yet to directly explore the role of gender in sibling experience and sibling relationships although it is an area identified for future research by qualitative researchers in this field (Petalas et al, 2009). In this study, I had the opportunity to focus solely on the experiences of a group of NTD sisters.

The essentially complex and multi-factorial nature of this phenomenon, and the inconclusive nature of existing research, underline the importance of returning to
the primary source of evidence; the first hand experiences of NTD siblings. Qualitative research methods are more effective in exploring relatively unknown topics and unpicking the factors and processes that influence both positive and negative outcomes. In turn, this will generate more focussed hypotheses for further qualitative and quantitative inquiry (Meadan et al., 2010; Petalas et al., 2009).

The limited research into NTD siblings’ experiences has focussed, understandably, on family experiences and relationships. Peer-group hostility and ignorance of ASD and peer support groups are referenced, but the social and school lives of NTD siblings have yet to be fully explored. As a Child and Educational Psychologist (CEP), my focus is often on the impact of home circumstances on behaviour, wellbeing and performance in school and on the negative impact of unhappy peer relations and school life on a young person’s mental health. Peer relations and social standing increasingly influence self-image and self-esteem in late-childhood and early adolescence (Brown, Eicher, & Petrie, 1986). As the mother of three daughters, I am continually reminded of the influence of the peer group on emotional wellbeing.

In order to better understand NTD sisters’ experience, this study will uniquely explore the interaction between the domains of home school and social life and offer a more holistic view of their experience. Recent Australian research has begun to chart the school-based experiences of secondary age NTD sisters. This study is the first to look at the experiences of a group of secondary age NTD sisters in the UK and the first internationally to also include the experiences of primary-age girls.
1.3 This study

RQ. What are the experiences and perceptions of NTD sisters growing up with a sibling with ASD?

This study is concerned with the first-hand accounts of a group of child and adolescent sisters who are also the only NTD siblings in their families. This thesis details the challenges NTD sisters perceive and their positive experiences and perceptions. I am interested in the meanings attributed to experiences, and in NTD sisters’ understanding and beliefs. This research explores the perceived impact of having a sibling with ASD and what supports siblings overcome any challenges. The focus of this research is on family life, sibling relationships and school and social life from mid-childhood to early adulthood. From these detailed accounts, I hope to describe the emotional and cognitive processes that appear to account for their individual experiences and outcomes. I also ask parents about their children’s sibling relationships and their perceptions of the impact that having a sibling with ASD has had on their NTD child. Underpinning this study is the wish to better understand what NTD sisters believe to be supportive of their wellbeing, any threats they perceive and to inform future support to develop resilience and positive self-identity and promote NTD sisters’ mental health and wellbeing.

The research question is refined and expanded in light of the literature review.

1.3.1 Structure of this thesis

Chapter 1: I have explained the rationale and purpose of this research, outlining the need for enhanced understanding of the sibling experience and further qualitative research in this field.

Chapter 2: I outline the rationale and method of the review, and illustrate how relevant literature and existing research has shaped my research questions.
Existing research is distilled and analysed and frameworks for considering the NTD siblings experience are discussed.

Chapter 3: Here I explain the theoretical underpinning of this study and justify my choice of data collection and analysis methods. I consider issues of research rigour, integrity and trustworthiness and outline the study in sufficient detail to allow for authoritative scrutiny and replication.

Chapter 4: Detailed themes are described and the links between them are explored.

Chapter 5: Findings are related back to research questions and to previous research. Links are made to wider psychological research and models. Implications for applied psychologists and school professionals are discussed and areas for future research are suggested.

Chapter 6: Finally, I reflect on the limitations of this research and summarise the contribution to knowledge.
Chapter 2: Literature Review

2.0 Overview

This section outlines the major themes in quantitative research regarding NTD siblings and considers the implications of that body of research for future qualitative research. I then look in detail at recent case study research in this field, which informs the focus and methodology of my own research. This review has four distinct sections:

2.1 Introduction including the rationale and review process and criteria for selecting key papers.

2.2 Critical review of current qualitative research

a. Presenting a balanced view of the sibling experience: a summary of current findings.

b. Factors and processes that shape individual sibling experiences:

   I. Knowledge and understanding

   II. Acceptance

   III. Family systems

   IV. Sibling relationships

   V. Balancing own needs with responsibility for sibling

   VI. Society and Social relations

   VII. Multifactorial model of sibling experience
2.3 Explanations of adjustment, coping and resilience suggested by current qualitative research.

2.4 Practical and applied implications of current qualitative research

2.5 Conclusion: Summary, Rationale and detailed Research Questions and how these have been shaped by current literature.

2.1 Introduction

2.1.1 Rationale for literature review

The rationale for further qualitative research regarding the experiences of NTD siblings of children with ASD, is established in Chapter 1. A qualitative researcher aspiring to understand the experiences of a given community should immerse herself in a wide range of current literature about the lives of that community from the very start of the research process (Yardley, 2008). My initial searches were therefore broad and included quantitative research and literature about adult sibling experiences.

In a study of this size, and nature, it is necessary to be selective in one’s frame of reference. This review needed to be substantial and comprehensive enough to inform my study, yet relevant to current context. I therefore searched for research published between 2000 and 2014. This field of has been described as “underdeveloped” (Hodapp et al., 2005, p. 334), so I understood that I should look beyond the UK for examples of relevant research. The following inclusion criteria were established:

- Published between 2000 and 2014.
- Published in English, in a peer-reviewed journal.
- Participants include NTD siblings, aged 10-19 years.
- Include open-ended data collection methods that ascertain perceptions and self-reported experiences of NTD siblings.
Include focus on all, or any, of the following: experiences, sibling relationships, behavioural, emotional and social adjustment, and psychological wellbeing.

2.1.2 Method for identifying literature

Electronic searches were conducted on PsycINFO, ERIC and Google Scholar using the key words: sibling, ASD, autism and experience. I read the abstracts of the papers returned by these searches and applied the inclusion criteria. Seven papers were identified by this process. I conducted an ancestral search on these papers, scrutinising their reference sections for papers not previously highlighted. I applied the inclusion criteria to the abstracts of newly identified papers and identified one more research study. Thereby, eight research papers, each meeting the full inclusion criteria, were identified. These are introduced in Table 2 and form the substantive part of this literature review. Papers excluded at this stage fell into the following categories:

- Focus on pre-school age siblings and their characteristics. These studies often aim to identify siblings ‘at risk’ of ASD rather than describe their experiences (e.g. Cassel et al., 2007; Goldberg et al., 2005; Presmanes, Walden, Stone, & Yoder, 2007; Yirmiya et al., 2006). Other studies with very young children focus on the formation of early sibling relationships (e.g. Bachraz & Grace, 2009).

- Include detailed, first-person accounts from parents only (e.g. Barak-Levy, Goldstein, & Weinstock, 2010; Bayat, 2007; Begum & Blacher, 2011; Nielsen et al., 2012).

- Describe only adult siblings’ experiences (e.g. Davys, Mitchell, & Haigh, 2011; Hodapp et al., 2005; Hodapp & Urbano, 2007; Tozer, Atkin, & Wenham, 2013).
• Detail only sibling mediated interventions (SMIs) that use NTD siblings to support the child with ASD’s skill-development (e.g. Bass & Mulick, 2007).

2.1.3 Relevant themes from recent quantitative research

As part of the process of learning as much as possible about the lives of NTD siblings of children with ASD, I read and reflected upon the findings of quantitative studies of child siblings of ASD, published since 2000. This body of quantitative research has been summarised a number of times in recent years (e.g. Gold & McCabe, 2012; Meadan et al., 2010; Orsmond & Seltzer, 2007; Smith & Elder, 2010). The purpose of my reading was to draw out themes that might gainfully be explored in exploratory and descriptive research.

Some suggest that having a sibling with ASD has no bearing on wellbeing (Tomeny, Barry, & Bader, 2012) or that NTD siblings ultimately adjust well to the challenges they face (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004). Others found that the severity of ASD has a detrimental impact on NTD sibling wellbeing (Hastings, 2003; Benson & Karlof, 2008; Meyer, Ingersoll, and Hambrick, 2011) yet, paradoxically, NTD siblings seem to benefit if their parents are closely involved in the care and education of their child with ASD (Benson & Karlof, 2008) or if their parents have a large number of children (Kaminsky & Dewey, 2002). Further research found that having a sibling with ASD can be especially challenging for younger children (Verté, Roeyers & Buysse, 2003) and results in increased risk of internalising behavioural problems (Ross & Cuskelly, 2006). Social support has also been shown to be beneficial for NTD siblings (Hastings, 2003).

Some suggest that gender is important in determining sibling experience. Quantitative research with families of children with learning difficulties (LD) found that whilst girls are more likely to care more for their sibling with ASD and
gain more satisfaction from their sibling relationship, NTD brothers are more influenced by the gender of their disabled sibling, engaging more with their disabled brothers than with disabled sisters (Orsmond & Seltzer, 2000). NTD sisters are more likely to invest in their sibling relationship irrespective of the gender of their sibling (Orsmond & Seltzer, 2009). There is some evidence that girls experience higher levels of anxiety and depression than boys (Orsmond & Seltzer, 2009) whilst others found that the experience can become positively beneficial for the sociability and self-image of older girls (Verté, Roeyers & Buysse, 2003). The role of gender, and the possible reasons for the difference in findings, has yet to be further explored in qualitative studies.

A summary of qualitative research and my reflections, are presented in Table 1.

2.1.4 Introduction to recent qualitative research

The eight papers in this review are case studies. Knowledge from case study research is cumulative, nuanced and context rich. Each paper has a subtly different research focus, with a unique set of participants and findings are best viewed as complementary rather than contradictory (Thomas, 2011). Together, this body of research provides a deeper, more holistic and context rich understanding of the experiences of NTD siblings. The utility of each study lies in its relative contribution to this emerging body of knowledge and the light it sheds on “...the complexities and contradictions of real life”(Flyvbjerg, 2006, p. 29). Research value is determined by the appropriateness of methods, the rigour and transparency with which findings are determined and presented, and the contribution to theoretical and practical knowledge. These studies are introduced in Table 2. I then discuss, in detail, their relative contribution to knowledge and their influence on my study.
**Table 1**: Table of themes for future qualitative research suggested by the findings of recent quantitative studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Summary of findings</th>
<th>Suggested themes for qualitative inquiry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orsmond and Seltzer (2000)</td>
<td>Girls score higher in the caregiving, companionship, and positive affect aspects of sibling relationships.</td>
<td>How do girls perceive their relationships/ caring responsibilities?</td>
</tr>
<tr>
<td>Kaminsky and Dewey (2002)</td>
<td>Siblings are as well-adjusted as comparison groups and reported low levels of loneliness. Siblings enjoy high levels of social support. Large family size supports adjustment in siblings of children with ASD.</td>
<td>What is the nature and extent of social and peer support? How do family dynamics impact NTD siblings? What is the nature and extent of family support?</td>
</tr>
<tr>
<td>Hastings (2003)</td>
<td>Siblings are behaviourally well adjusted. Social support moderates the impact of ASD. Siblings of children with less severe ASD have fewer adjustment issues.</td>
<td>What is the nature and level of social support received by siblings? What social support do / would they value?</td>
</tr>
<tr>
<td>Verté, Roeyers, and Buysse (2003)</td>
<td>Child siblings of children with HFA (age 6-11) experience adjustment issues. Sisters of children with HFA ascribed higher social competence to themselves. Sisters of children with HFA between 12 and 16 years old had a more positive self-concept.</td>
<td>What might account for the increased pressures be on younger siblings? What makes adjustment easier as they grow older? What impact does gender/ age have on the sibling experience of ASD?</td>
</tr>
<tr>
<td>Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004)</td>
<td>Most siblings report apparently stressful experiences yet are well adjusted.</td>
<td>Do siblings perceive these experiences as stressful? What supports adjustment?</td>
</tr>
<tr>
<td>Ross and Cuskelly (2006)</td>
<td>Siblings at increased risk of developing internalising behavioural problems.</td>
<td>Is support pro-active? What protects/ exacerbates risk?</td>
</tr>
<tr>
<td>Study</td>
<td>Summary of findings</td>
<td>Suggested themes for qualitative inquiry</td>
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<tr>
<td>-------------------------------------------</td>
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<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Benson and Karlof (2008)</td>
<td>Severity of ASD has a negative impact on sibling adjustment.</td>
<td>How do NTD siblings experience living with challenging behaviours?</td>
</tr>
<tr>
<td></td>
<td>Increased parental involvement in education and care of child with ASD child supports NTD sibling adjustment.</td>
<td>What role do family ethos and behaviours play in adjustment?</td>
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<td></td>
<td></td>
<td>How do NTD siblings perceive extra parental attention spent on child with ASD?</td>
</tr>
<tr>
<td>Orsmond and Seltzer (2009)</td>
<td>Sisters report higher levels of depression and anxiety than brothers.</td>
<td>Do girls perceive their experiences as stressful?</td>
</tr>
<tr>
<td></td>
<td>Siblings with ‘Broader Autism Phenotype’ (BAP), or stressed are more likely to experience anxiety and depression.</td>
<td>What might support siblings with stressful experiences?</td>
</tr>
<tr>
<td></td>
<td>Maternal depression increases depression and anxiety in NTD siblings</td>
<td>How do siblings perceive familial stress?</td>
</tr>
<tr>
<td>Meyer, Ingersoll, and Hambrick (2011)</td>
<td>Severity of ASD and maternal depression impede sibling adjustment.</td>
<td>Again, how do siblings perceive familial stress?</td>
</tr>
<tr>
<td></td>
<td>Siblings with BAP features have greater adjustment problems. This link is exacerbated by severity of ASD in their sibling</td>
<td>How do NTD sibling learn to manage ASD behaviours?</td>
</tr>
<tr>
<td>Tomeny, Barry, and Bader (2012)</td>
<td>Having a sibling with an ASD is neither risk nor protective factor for maladjustment.</td>
<td>No themes suggested</td>
</tr>
<tr>
<td>Petalas, Hastings, Nash, Hall, et al. (2012)</td>
<td>Sibling adjustment is negatively impacted by highly challenging behaviour in child with ASD, BAP features and parental mental health problems.</td>
<td>How do NTD siblings perceive their own adjustment?</td>
</tr>
<tr>
<td></td>
<td>Sibling relationships are harmed by challenging behaviours in child with ASD and family hostility to child with ASD</td>
<td>How do NTD siblings’ perceive family ethos and politics? How do family systems shape experience?</td>
</tr>
</tbody>
</table>
**Table 2: Summary of key qualitative studies**

*Key: SSI – Semi structured interview; CA- Content Analysis; CCM- Constant Comparative Method; GT- Grounded Theory; IPA- Interpretative Phenomenological Analysis;*

<table>
<thead>
<tr>
<th>Authors and country</th>
<th>Features of Participants</th>
<th>Features of ASD siblings</th>
<th>Focus</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mascha and Boucher (2006)</strong> UK</td>
<td>10 females, 4 males, 11 families. Aged 11-18</td>
<td>Range of ASD. Gender not specified</td>
<td>Experiences, thoughts and feelings</td>
<td>SSI CA (Powney &amp; Watts, 1987)</td>
<td>Support for positive and negative experiences and affect. Violent behaviours and social embarrassment damage relationship satisfaction</td>
</tr>
<tr>
<td><strong>Benderix and Sivberg (2007)</strong> Sweden</td>
<td>9 females, 6 males, 5 families. Aged 5-29 (3 of whom have children of their own)</td>
<td>ASD and learning difficulties; 10-11 years</td>
<td>Past and present experiences</td>
<td>SSI Qualitative content analysis (Burnard, 1991)</td>
<td>Seven themes: precocious responsibility, feeling sorry, exposed to frightening behaviour, empathetic feelings, hoping for relief, physical violence made siblings feel unsafe, friendships affected negatively.</td>
</tr>
<tr>
<td>Authors and country</td>
<td>Features of Participants</td>
<td>Features of ASD siblings</td>
<td>Focus</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Petalas et al. (2009) UK</td>
<td>5 boys and 3 girls Variety of birth orders and age gaps Aged 9-12.</td>
<td>Range of ASD &amp; cognitive levels All male</td>
<td>Siblings’ perceptions and experiences</td>
<td>SSI Interpretative Phenomenological Analysis (IPA)</td>
<td>Five themes: perceptions of the impact of their brother’s condition on their lives, perceptions of others’ attitudes, tolerance and acceptance towards their brothers, attitudes and experiences, views on support for themselves and their brothers.</td>
</tr>
<tr>
<td>Sage and Jegatheesan (2010) US</td>
<td>Two 7 year old boys 1 'European American'; 1 'Asian American' Older brothers Both pairs of parents</td>
<td>Autism 4 and 5 years Male</td>
<td>Perceptions and relationships</td>
<td>SSI ‘Draw and tell’ Participant observation CCM GT</td>
<td>Tentative conclusion regarding role of culture and family in shaping experiences</td>
</tr>
<tr>
<td>Moyson and Roevers (2011) Belgium</td>
<td>10 female 7 male From 15 families Age 6-14</td>
<td>ASD Mild-moderate impairment Aged 5-16 All male</td>
<td>Experiences</td>
<td>SSI using ‘in-depth phenomenological based interviews’ (Seidman, 2006). Focus groups GT</td>
<td>Nine domains of sibling quality of life: forbearance, mutual understanding, joint activities, private time, trust in sibling’s well-being, acceptance, exchanging experiences, social support, the outside world</td>
</tr>
<tr>
<td>Authors and country</td>
<td>Features of Participants</td>
<td>Features of ASD siblings</td>
<td>Focus</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Angell et al.</td>
<td>6 boys and 6 girls</td>
<td>Range of ASD &amp; cognitive levels</td>
<td>Experiences and self-reported support needs</td>
<td>Cross-case analyses Coding (Bogdan &amp; Biklen, 2007) and reference to family systems theory</td>
<td>Three themes: describing sibling subsystem; cohesion between and among siblings; adaptability of NTD siblings to ASD</td>
</tr>
<tr>
<td>(2012) USA</td>
<td>Aged 7 to 15</td>
<td>10 male, 1 female Aged 6-15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Petalas, Hastings,</td>
<td>6 boys and 6 girls</td>
<td>9 ASD with intellectual difficulties</td>
<td>Perceptions and experiences</td>
<td>SSI IPA</td>
<td>Six themes: difficulties and negative impact of ASD on NTD sibling and family; how others’ reactions to their brother negatively affects NTD siblings; relationship histories and current relationship; varying acceptance and tolerance towards their brothers; positive perceptions and experiences; thoughts about the future.</td>
</tr>
<tr>
<td>Nash, Reilly, et al.</td>
<td>Aged 14-17</td>
<td>3 with Asperger’s All male Aged 4-18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2012) UK</td>
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</table>
2.2 Critical review of current qualitative research

2.2.1 A ‘balanced view’ of sibling experience

Hodapp et al. (2005) stress that studies should present a ‘balanced’ view of the NTD sibling experience. Existing qualitative research attempts this in two ways; by including positive experiences alongside negative aspects and by authentically representing the experiences of a range of individuals (Angell et al., 2012; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012).

2.2.1.1 Positive and negative perspectives

My analysis of existing qualitative research suggests that the sibling experience is somewhat polarised. Some NTD siblings are generally dissatisfied with their sibling relationship and describe a predominantly negative experience (e.g. Benderix & Sivberg, 2007). Others are fond and tolerant of their siblings and describe predominantly positive experiences (e.g. Angell et al., 2012). Positively perceived aspects include sharing fun times (Angell et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012) and admiring siblings’ qualities and strengths (Angell et al., 2012; Petalas et al., 2009). Some NTD siblings show pride in, and affection for, their sibling (Angell et al., 2012; Petalas et al., 2009) and believe that having a sibling with ASD makes them more mature and sensitive (Petalas et al., 2009).

Negatively perceived sibling behaviours include damaging one’s possessions, emotional ‘melt downs’, verbal abuse, threatened or actual physical abuse, faecal smearing and howling (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Hall, et al., 2012). Such behaviours generate irritation, fear, anxiety and embarrassment and are attributed by NTD siblings with causing domestic disruption and impaired social relations (Angell et al., 2012; Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Nash,
Reilly, et al., 2012). Benderix and Sivberg (2007) also found that NTD siblings experience sorrow, fear, and anxiety and wished for relief and respite.

The negative aspects reported in current qualitative research suggests can be divided into those directly caused by siblings, such as physical violence and irritating behaviours, and those caused by the social context in which behaviours occur. Petalas et al. (2009) find that whilst some blame their sibling for being embarrassing, others attribute their own embarrassment and discomfort to the ignorance of outsiders.

2.2.1.2 Authentic representation of experience

Presenting an authentic representation of the sibling experience is essentially a matter of research trustworthiness. In order to show that findings represent the genuine experiences of siblings, qualitative researchers must ensure rigour at every stage of research, from determining research questions, through data collection and analysis to the presentation of findings (Yardley, 2008). Although no single research practice confers research trustworthiness, certain methodological processes and concerns are associated with rigour (Barbour, 2001). Publishing participant characteristics helps the reader understand what this is a study of, and what, if any, claims can made regarding the generalisability of findings. Dellve et al. (2000) combine the experiences of NTD siblings of children with ASD with those of siblings of children with deficits in attention, motor control and perception (DAMP). The failure to distinguish between the two groups of participants raises doubts about whether findings pertain equally and fully to the experiences of siblings of ASD.

Despite evidence suggesting that the gender of sibling pairs influences the nature of their relationships (Orsmond & Seltzer, 2000), other studies omit information about the gender of siblings with ASD and the gender mix in sibling pairs (Benderix & Sivberg, 2007; Mascha & Boucher, 2006). Studies provide
significantly different information about the nature of ASD diagnoses and
tendant disabilities. ASD diagnoses can be non-specific or contentious, and
diagnosis varies between professionals (Avdi, Griffin, & Brough, 2000). However,
as a reader, it is useful to have some indication of the nature of difficulty and
the nature of sibling interaction, to help one understand how this might impact
on the NTD sibling.

In published papers detail is curtailed by the limits imposed by publishing
journals (Hart, 1998). However, some studies provide evidence of appropriate
methodological rigour and transparency. Three studies explicitly state
researchers’ professional perspectives and research credentials (Benderix &
Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Hall, et al., 2012).
Petalas, Hastings, Nash, Hall, et al. (2012) reflect on the likely impact of
researchers’ professional backgrounds and describe inter-researcher coding.

Occasionally, assumptions are made of the data that suggests a lack of
reflexivity or consideration of alternative views. Mascha and Boucher (2006)
found only two categories of positive experience, ‘playing’ and ‘having fun’. They
conclude this “no doubt reflects the difficulty” participants have in building
relationships with their ASD siblings (Mascha & Boucher, 2006, p. 25). When
findings are based on researcher interpretation there is always an element of
doubt; conclusions are based on the most plausible and substantiated argument,
not absolute certainty. Cognitive research shows that negative events are more
keenly felt than positive ones (Rozin & Royzman, 2001). The effect is
cumulative; the more negative experiences one has, the more one anticipates,
and perceives, negativity. We dwell for longer on negative events and can
describe negative experiences in more detail than equivalent positive events
(Kanouse & Hanson, 1972). Mascha and Boucher (2006)’s findings might,
perhaps, reflect the universality of ‘shared fun activities’ for children of that age,
or be explained by methodological issues including over-generalised coding,
failure of researchers to prime participants to expect discussion on positive experiences and the place of the question in the interview schedule.

One might argue that Mascha and Boucher (2006)’s study adopts an inherently negative stance. They aim to devise an eight item universal measurement of NTD sibling experience, to use when devising support packages. This assumes that support will be needed and that this can be ascertained by a small number of self-reported indicators. Research that focuses solely on difficult areas of experience is useful in outlining problems but offers little insight into potential solutions. Examples of resilience and positively perceived impact also help to develop understanding of factors and processes that support coping. Mascha and Boucher (2006)’s study uses quantitative definitions of validity to critique case study methodology and semi-structured interview methods. Such a juxtaposition can leave one unaware of the relative strengths, and true weaknesses, of qualitative research.

Benderix and Sivberg (2007) describe a more negative sibling experience than other studies. They interviewed NTD siblings of children about to enter residential care. As the researchers were involved in establishing the care home, internal researcher effects and positive research bias should be considered. However, residential care is intended for children with the most challenging level of behaviours and other research has also found evidence that challenging behaviours corrode sibling relationships and the wellbeing of NTD siblings (Benson & Karlof, 2008; Dodd, 2004; Mascha & Boucher, 2006). Whilst acknowledging the challenge that many NTD siblings face, Angell et al. (2012) also focus on identifying themes that suggest resilience and cohesion: “coping strategies...”; “adaptability...”; “emotional bonds...”; “cohesion between siblings” (Angell et al., 2012, p. 4).
2.2.1.3 Other 'balanced perspectives’

A third way to achieve balance would be to gather experiences from as many areas of sibling lives as possible. Current research understandably focuses on experiences within the family. Relatively little is known of the impact on NTD siblings’ social lives and school careers and I was unable to identify any published research regarding the school-based experiences of NTD siblings. This may, in part, be explained by the fact that previous research has been conducted by practitioners from clinical backgrounds (Benderix and Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Hall, et al., 2012). As an applied psychologist working in education, I am especially interested in siblings’ experiences with peers and in school, and the interaction between home, school and peer group systems.

A fourth way of achieving a balanced research is through informant triangulation. These eight studies are multiple case studies, gathering data from more than one sibling. One includes views of parents (Sage & Jegatheesan, 2010). Finally, inclusion of a lifelong perspective on sibling experience is advocated in the literature (Hodapp et al., 2005). This would show how experience changes over time. Such a perspective might be gained by longitudinal research, or by asking parents and older NTD siblings to recall childhood experiences and feelings.

2.2.2 Factors that shape experience

Recent case studies in this field identify a number of factors that influence the experience and adjustment of NTD siblings: knowledge and understanding; acceptance; family system including sibling subsystem; balancing own needs with responsibility for sibling; society and social relations. I now consider each factor in turn.
2.2.2.1 Knowledge and understanding

Knowledge and understanding of ASD is positively associated with sibling acceptance and adjustment (Dellve et al., 2000; Frydenberg, 2008; Petalas et al., 2009; Sage & Jegatheesan, 2010) and positive sibling relationships (McHale, Sloan, & Simeonsson, 1986). Research suggests that siblings in mid-childhood have an insecure grasp of the pervasive nature of ASD which impedes acceptance and causes frustration at their sibling’s perceived failure to control ASD type behaviours (Moyson & Roeyers, 2011; Petalas et al., 2009). Petalas et al. (2009) found that children extrapolate from first-hand experience to develop their own working definitions of ASD. They benefit from programmes of information and explanation to clarify concerns or misunderstandings but it is important for the nature, detail and timing of any formal input to match their particular experiences and needs. With appropriate and sensitive input, siblings can respond to their sibling’s diagnosis of ASD by proportionately adjusting their own behaviour and behavioural expectations. However, superficial explanations of this complex, pervasive and dynamic disorder can generate confusion and doubt about the veracity of the diagnosis. Explanations might contradict children’s own experiences or children may recall incidents when their sibling has behaved differently (Moyson & Roeyers, 2011). Some NTD siblings are reluctant to ask parents for clarification for fear of exacerbating parental worry or stress (Moyson & Roeyers, 2011). The most useful information is sensitive and responsive to individual need.

2.2.2.2 Acceptance

Acceptance is learning about, and acquiescing to a situation and is a central component of sibling adjustment (Angell et al., 2012; Dellve et al., 2000; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Moyson and Roeyers (2011) describe acceptance as a staged process: “... in the first stage siblings swallow the message, in the second stage
they are going along with it, and in the third stage siblings resign themselves to their special situation and even begin to consider it as ‘normal’” (2011, p. 49).

Petalas et al. (2009) suggest that acceptance in mid-childhood is often partial, selective and context dependent. NTD children love their sibling whilst simultaneously wishing for change. Petalas et al. suggest that this tension might be characteristic of children who are still coming to terms with their situation and “…evidence of ongoing cognitive processing and appraisal” (Petalas et al., 2009, p. 389). Research with adolescents suggests that they experience “a continuum of acceptance ranging from positive acceptance, to wishing for change” (Petalas, Hastings, Nash, Reilly, et al., 2012, p. 309). Age does not, automatically, confer acceptance; some adolescent siblings retain unresolved and negative attitudes into adulthood (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012). However, distance from diagnosis and enhanced understanding of the pervasive nature of ASD, means that adolescents are more likely to wish for greater understanding in themselves and in other people (Petalas, Hastings, Nash, Reilly, et al., 2012). Adolescents acknowledge that a change in their sibling might result in the loss of qualities they love and admire (Petalas, Hastings, Nash, Reilly, et al., 2012). Identifying positive meaning in one’s experience also appears to promote sibling acceptance (Moyson & Roeyers, 2011). Some celebrate their siblings’ particular strengths, including musical and artistic talent and ‘being cool’ (Angell et al., 2012) or their tenacity and computer know-how (Petalas et al., 2009).

2.2.2.3 Family systems

Parental behaviours and attitudes strongly influence siblings’ attitudes to ASD (Angell et al., 2012; Sage & Jegatheesan, 2010). Familial influences can be both positive (Angell et al., 2012) and negative (Benderix & Sivberg, 2007; Dellve et al., 2000; Sage & Jegatheesan, 2010).
Parents who espouse a strengths-based view of ASD and treat their children fairly, appear to promote sibling cohesion and acceptance (Angell et al., 2012; Sage & Jegatheesan, 2010). There is evidence that NTD siblings in mid-childhood are more likely to complain that their sibling takes priority and is treated leniently (Petalas et al., 2009; Sage & Jegatheesan, 2010). They may even mimic ASD-type behaviours in the hope that they too will receive special treatment (Moyson & Roeyers, 2011; Sage & Jegatheesan, 2010). Sage and Jegatheesan (2010) found that in cultures with negative views of disability, parents compensate by indulging their child with ASD. Undue leniency can aggravate behavioral problems in the sibling with ASD, generate sibling resentment and impede sibling cohesion (Petalas et al., 2009; Sage & Jegatheesan, 2010).

Updegraff et al. (2002) use the term ‘familistic values’ to describe a commitment to support family, and a sense of familial solidarity and duty. They found that girls are most likely to adopt familistic values and behaviours. In families of children with disabilities, family time and shared routines, family problem-solving and effective communication between family members are positively associated with family resilience and sibling adjustment (Giallo & Gavidia-Payne, 2006). Other research shows that some parents perceive that having a child with disability bestows benefits on the entire family (Turnbull & Turnbull, 1990). Benefits include improved family dynamics, increased self-confidence and assertiveness, increased emotional sensitivity and enhanced religious faith (Taunt & Hastings, 2002). Emphasising the positive contribution of a disabled child is beneficial to family cohesion and resilience (Hastings, Beck, & Hill, 2005; Heiman, 2002). Adolescent NTD siblings have a heightened awareness of all that their parents do to support their sibling and, sometimes, the responsibility appears daunting (Benderix & Sivberg, 2007). NTD siblings who are close to their parents are more sensitive to any parental “struggle” (Benderix & Sivberg,
and this feeds their own negative attitudes to their sibling. Perhaps, in order to protect their parents, NTD siblings perceive the need to ‘be good’ and do well in school (Angell et al., 2012; Moyson & Roeyers, 2011; Sage & Jegatheesan, 2010).

NTD siblings often model their behaviour towards their sibling on that of their parents. Many parents encourage appropriate and positive ways of interacting with, and managing, the child with ASD (Angell et al., 2012). However, Dellve et al. (2000) found some parents denigrate NTD siblings’ attempts to reach out to their brother or sister, which damages the sibling relationship.

Angell et al. (2012) use Family Systems Theory (FST) (Turnbull, Summers, & Brotherson, 1984) to understand the impact of family relationships and dynamics on NTD siblings. FST suggests families can be understood in terms of the interaction between relationships, functions, and characteristics which interact to create the family system. A family systems perspective is especially useful when studying the impact of life-long pervasive conditions, such as ASD, as it can accommodate changes to context, and the changing needs of family members (Swenson, 2005). FST can also generate ideas about ways of supporting siblings and enhancing resilience (see Figure 1.)

Angell et al. (2012) found that relationship cohesion and sibling adaptability are inter-related and cyclical; NTD siblings who share activities with, and feel close to, their siblings with ASD are more willing to change, and seem happier and better adjusted.
2.2.2.4 Sibling relationships

Sibling pairs of all ages share positive experiences, from being playmates at a young age (Sage & Jegatheesan, 2010) to watching movies and going out together as adolescents and young adults (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012). Joint activities are important (Moyson & Roeyers, 2011; Petalas et al., 2009) and can be mutually rewarding and enjoyable (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012). Although activities typically follow the interests of the sibling with ASD (video gaming and trips to favourite venues), NTD siblings enjoy them too.
NTD siblings are disappointed if they do not share activities with their sibling (Angell et al., 2012; Dellve et al., 2000; Moyson & Roeyers, 2011). For some NTD siblings, their own enjoyment of the activity is secondary to the intrinsic satisfaction they get from their siblings’ apparent enjoyment and experiencing a shared connection, “...we can get along and there’s no problem, just me and him” (Angell et al., 2012, p. 5). Some NTD siblings describe their sibling with ASD as their friend whilst others are concerned that they haven’t expressed their love clearly enough, “I’d like to tell him how much I appreciate him because I really don’t do that enough” (Petalas et al., 2009, p. 389).

NTD siblings variously report feeling love, empathy, compassion and pride towards their sibling (Angell et al., 2012; Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). They show forbearance (Moyson & Roeyers, 2011; Petalas et al., 2009) and affection (Benderix & Sivberg, 2007) in the face of challenging and annoying behaviours. NTD siblings are highly motivated to understand the thoughts and feelings of their sibling with ASD (Dellve et al., 2000; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012) even when their sibling’s behaviour is highly challenging (Benderix & Sivberg, 2007; Dellve et al., 2000). Some NTD siblings express this as a wish to experience life as their sibling does, “It would be much better if I had ASD too, because then I could understand and handle him better” (Moyson & Roeyers, 2011, p. 49).

Although aggression does erode the quality of sibling relationships, even siblings who feel anxious and physically threatened by their siblings remain empathetic (Benderix & Sivberg, 2007). NTD siblings manage negative feelings about their siblings with a range of coping strategies and behaviour management techniques to calm and redirect their sibling or to teach them new skills. These are most often learned from their parents (Angell et al., 2012).
NTD siblings compare their relationships to those of ‘normal’ sibling pairs, and reach varied conclusions. Some siblings believe they have a more harmonious sibling relationship than those enjoyed by their friends (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012) and value their sibling’s uniqueness; “If Pete wasn’t so unique I probably wouldn’t have a brother I could talk to” (Angell et al., 2012, p. 5). Others draw negative comparisons between their friends’ relationships and their own and are envious of ‘normal’ sibling relationships (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012).

Angell et al (2012) found some NTD siblings see bickering and irritation as typical of ‘normal’ sibling relationships. Seeing one’s situation as normal is an important part of acceptance (Moyson & Roeyers, 2011; Petalas et al., 2009; Stalker & Connors, 2004).

Having a sibling with ASD can disrupt typical birth order relationships. Some younger NTD siblings dislike this, “I never felt like the youngest, even when I was small” (Petalas et al., 2009, p. 386). Older siblings appear to adapt more readily to having a sibling with ASD, perhaps because they might typically anticipate caring for younger siblings, “...to me it’s no different to a normal brother sister relationship, because I’ve never had a little brother that doesn’t have autism”(Angell et al., 2012, p. 5). Moyson and Roeyers (2011) suggest that there is reduced pressure on children in families with two or more NTD siblings whilst Angell et al. (2012) suggest that sole NTD siblings are more likely to be close to their sibling with ASD.

2.2.2.5 Balancing own needs with sibling responsibility

As siblings become adults, personal independence is often balanced with an ongoing commitment to supporting one’s sibling (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012). Dellve et al. (2000) suggest the sibling experience is essentially defined by the tension between one’s own needs and care and concern for one’s sibling. Caring responsibilities include ‘babysitting’
and looking out for one’s sibling in social situations, feeling responsible for them, keeping them safe and even attending school parents’ evenings (Angell et al., 2012; Benderix & Sivberg, 2007; Dellve et al., 2000; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Some NTD siblings supervise their siblings’ interactions with peers (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). Those with siblings with additional medical needs experience worry when their sibling requires emergency medical intervention or hospitalisation (Petalas, Hastings, Nash, Reilly, et al., 2012).

Aldridge and Becker (1999) describe children and young people who provide emotional or physical care usually undertaken by adults as young carers. A young carer “becomes vulnerable when the level of care-giving and responsibility... becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances” (The Children’s Society, 2013, p6). Whole-family assessment is necessary to understand personal, social and familial context, the nature of impact and any subsequent support needs (Aldridge & Becker, 1999).

There is considerable range in the level of involvement that NTD adolescents anticipate having with their siblings in adulthood (Angell et al., 2012; Dellve et al., 2000). Many adolescents become increasingly concerned with their sibling’s future welfare and their own role in safeguarding this (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). Some plan to distance themselves from their sibling, ASD and disability issues in general (Benderix & Sivberg, 2007). Others worry about making an indefinite commitment to support their siblings. Perhaps not surprisingly, those with siblings with the highest level of additional need are most concerned about the future (Benderix & Sivberg, 2007).
Girls are more likely to anticipate taking on a caring role for their sibling (Dellve et al., 2000; Dyson, 2010; Seltzer, Greenberg, Orsmond, & Lounds, 2005). Research with families of children with LD found that sisters as young as three years old assume caring responsibilities for their sibling (Dyson, 2010). Whilst some perceive they gain from the process (Angell et al., 2012; Petalas et al., 2009), others struggle with the “precocious responsibility” (Benderix & Sivberg, 2007, p. 414) which can only be met at considerable personal cost (Angell et al., 2012; Dellve et al., 2000; Moyson & Roeyers, 2011). Sisters are more likely to anticipate co-residing with their disabled sibling in adulthood, and begin anticipating this prospect from an earlier age. This is not necessarily problematic, as deciding to become a carer can contribute to positive adjustment (Midlarisky, Hannah, Shvil, & Johnson, 2008). Taking responsibility for one’s sibling is part of the family task (Turnbull et al., 1984) and helps strengthen family bonds (Angell et al., 2012). Moyson and Roeyers (2011) found that NTD siblings’ wellbeing is enhanced by knowing that their sibling’s needs are met.

NTD siblings appear more accepting of any special attention their sibling with ASD may receive if they feel it is warranted and their own needs are, at least, acknowledged by their parents (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012; Sage & Jegatheesan, 2010).

2.2.2.6 Society and social relations

Many NTD siblings believe that having a sibling with ASD has impeded their social life (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Petalas, Hastings, Nash, Reilly, et al. (2012) describe a common conflict between sibling loyalty and protecting one’s own social standing, “I would just think, well sod them, but deep down I feel, oh no, I don’t want them to see me” (p. 307). Some believe that outsiders attribute their sibling’s atypical behaviour to bad parenting and judge other family members accordingly.
Peer ignorance and prejudice causes feelings of isolation, anger and anxiety (Benderix & Sivberg, 2007; Petalas et al., 2009). NTD siblings commonly protect their brother or sister from bullies (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012) and some perceive that their own association with ASD increases their vulnerability to bullying (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012). Social ignorance about ASD means that outsiders are also unaware of the potential impact of ASD on siblings (Moyson & Roeyers, 2011; Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012). Some siblings socially withdraw and some attempt to explain their situation (Petalas et al., 2009). Others are reluctant to educate peers for fear of being doubted, pitied or misconstrued (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012), and some fear that drawing additional attention to their sibling, or themselves, will increase their vulnerability to bullying (Petalas, Hastings, Nash, Reilly, et al., 2012). Young children, and those in cultures where disability is hidden, are ill-prepared to educate others about ASD (Angell et al., 2012; Sage & Jegatheesan, 2010).

Supportive friendships and peer support are valued. NTD siblings appreciate opportunities for social activity outside of the home and sharing their experiences with peers (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009). Although some NTD siblings are happy for their friends and sibling to mix (Petalas, Hastings, Nash, Reilly, et al., 2012) others avoid bringing friends home as they perceive that their parents don’t have the resources to accommodate them (Benderix & Sivberg, 2007) or because they are concerned about peers’ reactions to, and ignorance of, ASD (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). This concern is well-founded, “One day a friend came over to play with me on the computer, but once he saw my brother was at home too, my friend said that he had to go
home” (Moyson & Roeyers, 2011, p. 500). Consequently some siblings impose
strict divisions between home, school and peer group. They are wary of who
they invite home and of sharing problems (Angell et al., 2012; Petalas et al.,
2009; Petalas, Hastings, Nash, Reilly, et al., 2012). This can result in NTD
siblings keeping to a relatively small circle of trusted friends (Benderix &
Sivberg, 2007).

2.2.2.7 Multi-factorial model of sibling experience
The multifactorial nature of the sibling experience is emphasised in this body of
research (e.g. Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings,
Nash, Reilly, et al., 2012). Moyson and Roeyers (2011) propose that sibling
quality of life comprises nine elements: Forbearance, Mutual Understanding,
Joint Activities, Private Time, Trust in [their sibling’s] Well-Being, Acceptance,
Exchanging Experiences, Social Support and Dealing with the outside World. This
model is comprehensive in range, but lacks any indication of weighting. Is
satisfaction in one dimension more important to quality of life than another? The
dimensions are of different type and order; some of the dimensions are practical
(Private Time, Exchange Experiences, Joint Activities) whilst others describe
psycho-emotional states (Mutual Understanding, Forbearance, Acceptance).
Nonetheless, Moyson and Roeyers (2011)’s model includes both realist and
subjective elements and provides a starting point for researchers and
practitioners to appreciate the needs of individual siblings.

2.2.3 Adjustment, coping and resilience
2.2.3.1 Coping
Having looked at the different factors that influence NTD sibling experience, I
will now consider the models of adjustment coping and resilience indicated by
recent case study research. Three studies (Moyson & Roeyers, 2011; Petalas et
al. (2009); Petalas, Hastings, Nash, Reilly, et al., 2012) link their findings to Coping Theory (Lazarus & Folkman, 1984). Coping Theory defines stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19). Stress appraisals are the simultaneous assessments of perceived demand in relation to perceived capacity to meet those demands. Appraisals are dynamic and fluid, shaped by prior experience of similar situations, environmental and contextual factors and current perception of one’s own personal resources.

Lazarus and Folkman (1984) distinguish between emotion-focussed and problem-focussed coping. Problem-focussed coping strategies are associated with better psycho-emotional outcomes than emotion-focussed coping (Angell et al., 2012; Petalas et al., 2009; Won, Greenberg, Seltzer, & Krauss, 2003). Petalas et al. (2009) found examples of effective problem-focussed coping, including the NTD sister who fixed a lock to her bedroom door to stop her brother interrupting her at night. They also found more self-damaging examples of problem-focussed coping, such as the boy who stayed indoors to appease his brother’s apparently insatiable need for attention. Other common coping strategies include taking time out, having one’s own space, spending time with friends, talking to peers who have similar experiences, and accessing online support.

NTD siblings who attribute positive intent to their siblings’ behaviour appear to cope more effectively (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Dellve et al. (2000) suggest that the focus of coping is also important and found that family-focussed coping supports NTD sibling wellbeing. This involves enhancing one’s understanding of ASD, supporting the family task of caring for the child with ASD, and balancing one’s
own needs with those of one’s sibling and parents. Family-focussed coping has clear parallels with the concept of ‘familistic values’ (Updegraff et al., 2002).

2.2.3.2 Adjustment

Successful emotional and cognitive adjustment is defined as “the ability to sustain and modify illusions that buffer not only against present threats but also against possible future setbacks” (Taylor, 1983, p. 1161). These ‘illusions’ are beliefs that shape the attributions siblings make about their experiences. Dellve et al. (2000) propose a three stage model of sibling adjustment:

- Involvement: an experience led, bottom up but incomplete understanding of ASD and their situation.
- Integration: encompassing much of childhood, siblings seek to make sense of experiences, emotions, family beliefs and formally acquired knowledge of ASD, whilst also dealing with growing up, building friendships and going to school.
- Reconciliation: mature and confident understanding and acceptance of what ASD means to their family, their sibling and themselves.

By adolescence most siblings have reached a level of logical and emotional acceptance and use their prior experience to allay any concerns (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012). Some find ways to positively accept, or merely tolerate, their sibling’s behaviours whilst others resolve to have very little contact with their sibling in adulthood (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012).

2.2.3.3 Gender and adjustment

Some researchers in this field have called for further study of gender and NTD sibling experiences and adjustment (Hodapp et al., 2005; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Other
research suggests NTD sisters are more likely to experience poor self-esteem, anxiety and depression than NTD brothers (Damiani, 2009; Orsmond & Seltzer, 2009). Some found this to be higher than the normal population (Damiani, 1999) whilst others report levels to be in-line with the general female population (Orsmond & Seltzer, 2009). Orsmond and Seltzer (2000) suggest that the nature and level of personal investment in the sibling relationship influences ultimate adjustment. Their longitudinal study found that NTD sisters offer greater care and companionship than brothers and enjoy enhanced positive affect from their sibling relationships.

### 2.2.3.4 Resilience

Researchers use the concept of resilience to describe sibling adjustment (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Resilience is the “manifestation of competence in children despite exposure to stressful events” (Garmezy, Masten, & Tellegen, 1984, p. 98). Challenges provide opportunity for “...self-confidence and social competence to increase through mastery and appropriate responsibility” (Rutter, 1985, p. 608). Resilience is dynamic, rather than absolute and fixed, and is influenced by social and contextual factors that change over time (Rutter, 2012). Resilience is best assessed by eventual life-outcomes rather ‘one-off’ behaviours or snapshot assessments (Masten, 1994; Rutter, 2012).

Using self-report questionnaires, Barak-Levy et al. (2010) explored sibling adjustment in families of children with severe ASD. They found that whilst parents consider that caring for their sibling with ASD benefits their NTD children, NTD siblings themselves often feel distressed or put upon by this responsibility. This discrepancy in perception underlines the importance of gathering siblings’ own accounts of their experiences.
Rossiter and Sharpe (2001) found that the impact of having a sibling with developmental disability becomes more positive over time. Child and adolescent NTD siblings are marginally more likely than the normal population to experience depression and anxiety, and display negative internalizing and externalizing behaviours. However, by adulthood, they were marginally better adjusted than the normal population, using the same measures. Rossiter and Sharpe (2001) postulate that adult siblings of people with disability are more resilient; they have faced considerable challenge but have developed more effective coping strategies. By adulthood, they have accepted their situation.

2.2.3.5 Family resilience

Some suggest family resilience is a more reliable indicator of sibling resilience than individual coping behaviour (Giallo & Gavidia-Payne, 2006). Rooted in positive psychology, Family Resilience Approach (Walsh, 2003) is the “...active process of endurance, self-righting and growth in response to crisis and challenge...affirming [families’] potential for repair and growth” (Walsh, 2006, p. 206). There are three components of family resilience:

1. A shared, socially-constructed family belief system that helps make meaning of adversity, affirms strength and maintains a positive outlook.

2. Positive organisational features including flexibility, connectedness and social and economic resources.

3. Effective communication that ensures clarity, open emotional expression and collaborative problem solving.

(Adapted from Strengthening Family Resilience (2 ed.), (p131), by F. Walsh, 2006, New York: The Guilford Press.)
In resilient families, adversity is acknowledged, assimilated and used to power positive development. Scorgie and Sobsey (2000) describe the personal and relational transformations that occur in resilient families. Examples of personal transformations are taking on new roles and developing skills in volunteer groups and becoming an advocate or campaigner for disability. Relational transformations include stronger marriages, closer relationships with one’s own parents and stronger friendships. Walsh (2006) dismisses the concept of “super kids” (p.5) who apparently breeze, untouched, through life-challenging events. It is better to identify ways in which families forge resilience and “integrate the fullness of a crisis into the fabric of our individual and collective identity” (Walsh, 2006, p. 6).

Bayat (2007) found evidence of these features in families of children with ASD, specifically pulling resources together and being connected, making meaning out of adversity, affirming strengths, becoming more compassionate and relating experience to the family belief system.

### 2.2.4 Applications of current research

Existing research recommends a number of practical measures to support sibling wellbeing. These divide into direct interventions with NTD siblings and indirect interventions which, consequently, support NTD siblings. Recommended indirect interventions include, ASD awareness training for pupils in schools; further awareness-raising about the needs of NTD siblings amongst parents, school staff and other professionals (Petalas et al., 2009); enforcing child protection procedures for siblings living with violent siblings (Benderix & Sivberg, 2007); parenting programmes to help manage and reduce extreme behaviours in children with ASD (Dellve et al., 2000).
Suggestions for direct support with NTD siblings include, peer support and group training to enhance sibling knowledge and understanding of ASD (Dellve et al., 2000; Petalas et al., 2009); respite (Angell et al., 2012); programmes to teach behaviour management strategies (Petalas et al, 2009); support to deal with social prejudice and ignorance (Petalas, Hastings, Nash, Hall, et al., 2012); counselling (Benderix & Sivberg, 2007; Angell et al., 2012), with particular focus on their sibling’s future (Petalas, Hastings, Nash, Reilly, et al., 2012).

2.3. Summary

Most NTD siblings report both positive and negative aspects to having a sibling with ASD but the emphasis varies greatly between individuals. In mid-childhood, views are often mixed and inconsistent, whilst adolescent siblings are more likely to adopt predominantly positive or negative views about their sibling. Individual perception is determined by a complex interaction of social, familial and personal factors.

NTD siblings show a range of emotion- and problem-focussed coping strategies. Appraisal-focussed coping is associated with longer-term adjustment. Current research strongly suggests that understanding and acceptance, positive attributions about one’s sibling and one’s own situation and balancing one’s own needs with those of other family members are positively associated with mutually rewarding sibling relationships and personal and familial resilience. Studying the personal accounts of NTD siblings can enhance knowledge of the processes by which they develop understanding and acceptance, positive attributions and beliefs and a family focus.

Many NTD siblings adopt caring responsibilities towards their sibling with ASD and evidence suggests that NTD sisters are more likely to adopt a long term caring responsibility towards their sibling. For some, this responsibility becomes
onerous, whilst others appear to develop a closer relationship with their sibling as a result. There is a need to better describe the caring role and the broader sibling relationship, especially with regard to school and social life, and to understand the factors that determine the differences in individual perceptions of the role.

Family relationships are important in supporting and modelling behaviours for NTD siblings and developing their understanding and beliefs about ASD. Research suggests that large family size is associated with “better psychosocial development” in NTD siblings (Kaminsky & Dewey, 2002, p. 231). There is a need to explore family relationships in smaller families and to consider the influence of gender on the NTD sibling experience.

Evidence indicates that children with ASD often experience hostility and bullying from their peers, and that family members experience social prejudice by association. However, relatively little is known about school life and peer group experiences of NTD siblings, especially those who share school placement with their sibling with ASD.

2.3.1 Implications for this study

This study will describe and explore the perceptions and reported experience of a group of NTD sisters. Previous research has indicated the need to segment the general population of NTD siblings by gender, socio-economic group and family characteristics. Qualitative research suggest that gender is an important factor in shaping sibling experience and the sibling relationship yet qualitative research has yet to describe the respective experiences of boys and girls and explore the reasons behind any differences. Therefore, this study is concerned with the experiences of a group of NTD sisters who are the sole NTD siblings in their family group.
It is imperative to present balanced research. Although parental views are informative, they are essentially different from the views of NTD sisters themselves. To this end, I will ask participants to share positive and negative experiences and collate perceptions of the impact of ASD on family, social relations and school life from current and retrospective perspective. I am also concerned with their views about what the future will bring. Given the suggestion in earlier research (Moyson & Roeyers, 2011) of a staged model of acceptance, I am interested in exploring participants’ perceptions of acceptance and their views on the factors that influence this.

This study will explore participants’ perceptions of the sibling relationship, the roles they fulfil towards their sibling and factors that seem pertinent to the building and maintaining of successful sibling relationships. This study will also explore NTD sisters’ relationships with other family members and the family’s role in imparting behaviours, values and beliefs about ASD and the role that NTD sisters develop within the family. I will also consider the usefulness of family adaptability and cohesion to explain sibling adjustment.

This research is concerned with the perceived social impact of having a sibling with ASD, the ways in which NTD sisters manage any apparent conflict between their sibling’s needs and their own social lives. It also considers the factors that seem to make this more of an issue for some siblings than others.

If challenge seems almost inevitable, this study is concerned with the ways NTD sisters cope with these challenges and their perceptions of their families’ and their own resilience. I will also explore what factors appear to influence NTD sisters’ coping and longer term sibling wellbeing and the processes that underpin it.

It is important to consider the practical implications of this research. I will explore how family factors and social are perceived to influence the experiences
of NTD sisters and the support they gain from these sources. Having ascertained participants’ understanding of ASD, I will ask about the ways they manage any challenges, how they learn behaviour management skills, participants’ experiences of, and views about, support and any perceived gaps in their support, skills and knowledge base. My previous research suggests that parents value formal courses, informal peer support and online support (Callaghan, 2012). I am interested to see if these are also potentially beneficial to NTD siblings.

As an applied psychologist working in education I am interested in the influence of home, school and peer group on NTD siblings. I am also concerned with NTD siblings’ perceptions of support and the practical implications of my research for educational professionals and psychologists.

2.3.2 Research questions

What are the experience of NTD sisters growing up with a sibling with ASD?

- What do NTD sisters perceive are the positive and negative aspects of growing up with a CYP with ASD?
- What are NTD sisters’ experiences of family life, school life, and relationships with friends and the wider peer group?
- How do NTD sisters perceive their relationships with siblings with ASD?
- How do NTD sisters cope with, and adjust to, having a sibling with ASD?
- What supports, or could support, the wellbeing of sisters growing up with a sibling with ASD?

This study contributes to the small but important body of phenomenological research into the perceptions of NTD siblings of ASD and explores experiences,
family relationships and influences, peer group and school life and caring responsibilities of a group of sole NTD sisters.

2.4 Recent research in this field

As this review of recent literature strongly indicates, there is a need for further research of perceptions and personal accounts of NTD sisters of children with ASD, and a noted lack of research into the school-based experiences of NTD siblings. In recent months, two papers have been published that contribute to the limited knowledge in this field. These papers were, of course, not available to shape the design, implementation and analysis of my research, but have informed the discussion of my findings and my conclusions (Chapters 5 and 6).

As part of a wider American study on the use of technology, Diener, Anderson, Wright, and Dunn (2015) interviewed six mothers and seven NTD sisters of boys with ASD. The girls were aged between 7 and 14 years old and their brothers attend mainstream schools. The researchers found that developing a shared focus on an area of the boys’ relative strength encourages NTD sisters to develop more positive opinions about their brothers. In general they found that although siblings share fun times, NTD sisters often see themselves as their brother’s nurturer and helper. Focussing on relative strengths increases their pride in their sibling and makes sibling roles more reciprocal. The authors suggest that sibling relationships can be enhanced by providing opportunities for sibling pairs to share activities in which the child with ASD can excel.

Cridland, Jones, Stoyles, Caputi, and Magee (2015) interviewed family members, including the child with ASD and their adolescent NTD sisters, in three Australian families. The sibling pairs in this study were older NTD sisters and younger brothers with ASD, who both attend mainstream school. They used multiple family perspectives to explore NTD sibling role and responsibilities at
home and school. They identified caring responsibilities that are generally in line with those in previous studies: dealing with other students; protector from bullies; educator of others about ASD. Cridland et al. (2015) also found that NTD sisters ease communication between home and school and advocate for their brothers in discussions with teachers. At home, girls feel they have more chores than their brothers. In line with existing research, girls have mixed feelings about their responsibilities, and experience between conflict between meeting their own needs and family loyalty. Caring duties are perceived as increasing as the girls get older.

An ancestral search of the reference sections of these very recently peer reviewed and published papers confirms that my own literature research has successfully identified all other relevant studies.
Chapter 3: Methodology

3.0 Overview

In this chapter, I restate my research aims, and establish the theoretical basis for this study. I go on to establish the principles by which this research can be considered trustworthy and justify my choice of case study design and research methods. Finally, I describe, in detail, the design, recruitment, data collection and data analysis stages of this research.

3.1 Introduction

This study sets out to describe the first-hand experiences of a group of NTD sisters of children with ASD. I am interested in experiences and the meanings attributed to these, and in beliefs about one’s sibling and one’s own situation. This research also explores the perceived impact of having a sibling with ASD, the ways that NTD siblings cope with, and adjust to any challenges they face and the factors that are perceived as supporting resilience. This research is concerned with family life, sibling relationship, school and social life from mid-childhood to early adulthood. I will now justify my methodology and describe the research process in detail.

3.2 Theoretical basis and approach

3.2.1 Ontology

Much has been made of “paradigm wars” (Gage, 1989, p. 4) that have pre-occupied social scientists in recent decades (Robson, 2002). A full exploration of the relative strengths and failings of various research paradigms is beyond the scope of this thesis. However, I will now outline and justify the assumptions
about phenomena, knowledge, and research validity upon which this thesis rests.

This research is post-positivist with its concern with personal experiences and perceptions. Given the interpretivist nature of my research, I initially assumed I should adopt a social constructivist approach to my research, as I have for previous phenomenological research (Callaghan, 2012). However, “Realism and constructivism both recognise that our ability to know the world is constrained by the need for interpretation by researchers of data” (Fox, 2008, p. 661). Willing (2001) suggests that the important distinction is between relativism and realism. Relativists assume phenomena are created and personal, whilst realists believe there are ‘fixed’ structures and processes that underlie experience. Being a sibling of ASD is a social ‘reality’. Fox (2008) explains the “realist ontological compromise” (p.662) whereby powerful, pervasive and relatively stable socially-created phenomena can be considered social ‘realities’, independent of individual constructs.

…the social world has the appearance of objective reality, with a semblance of continuity that also limits the meanings that can be attributed to objects. This renders the social world available to enquiry independent of the human agency that constitutes it. Subsequent realist perspectives have built on this, to argue that society is not created by individuals, though it is reproduced and transformed by them.

(Fox, 2008, p. 662)

Family, socio-cultural context, school, peer group, the behaviours of a sibling with ASD and the reaction of society to one’s sibling and one’s self are powerful social realities that impact on NTD sisters. On reflection, I determined that my focus is not solely on individual experience and constructs but also on what such experiences, views and beliefs indicate about the ‘social reality’ of having a
sibling with ASD, and, importantly, what might support other young people living with similar realities.

### 3.2.2 Epistemology

Whilst loyal to the concept of ‘social reality’ and the principle of rigorous inquiry, post-positivist research acknowledges that the social world is so complex, dynamic and all-pervasive that researchers cannot hope to attain a ‘true’ view of that reality. Rather we should gather experiences, views and outcomes of phenomena in order to better understand its features “…social realities need to be understood from the perspective of …active subjects who are productive of their social reality” (Fox, 2008, p. 664). The more perspectives we gather, the more complete our understanding becomes.

The focus is on gathering participants’ meanings “…rather than that of the observer, and in totality rather than in isolation...“(Fox, 2008, p. 662). To this end, researchers should be mindful of the relative limitations and potential pitfalls of their chosen methods and the layers of subjectivity and bias that they themselves brings to research.

...realism recognises that when it comes to studying the social world, our tools (human understanding and interpretation) are inevitably value-laden, theory-laden and context-dependent. All that can be hoped for is that by continual efforts towards methodological rigour, triangulation from various data sources and meticulous analysis of data that an approximation to truth can be derived, and generalised.

(Fox, 2008, p. 663)

Researcher bias can be reduced by describing a phenomenon in the words of those closest to it, through open ended research questions and responsive research methods (e.g. Elliott & Timulak, 2005).
Whilst quantitative research sets out to “generate explanations”, good qualitative research should “generate understanding” (Stenbacka, 2001, p. 551). When complex and multi-faceted phenomena are relatively unexplored and unknown or where existing literature suggests contradictory or unclear findings, exploratory and descriptive research methods are useful in ‘mapping out’ the topic (Barker, Pistrang, & Elliott, 2002). Having gathered accounts and experiences, there is a need to ‘interpret’ the data, to find patterns and consider those patterns with reference to existing research findings and theory. Through this process, our understanding of social phenomenon, and the factors and processes that underpin it, is enhanced.

There are implicit challenges in planning and executing trustworthy interpretivist research. The complex, multi-dimensional and context dependent nature of social phenomena requires researchers ‘drill deep’ into experiences, and are mindful of the social context in which experiences occur. Data collection methods should capture the richness of experience and data analysis should distil the key themes from individuals’ accounts as transparently as possible. Findings should be made with reference to context and researchers’ own perspectives should be acknowledged (Fox, 2008).

### 3.3 Research methods and design

The three main methods in descriptive qualitative research are observation, survey and case-study (Robson, 2002). I considered their relative strengths and shortcomings with reference to my research aims (Table 3).
Table 3: Comparison of observation, survey and case study methods

<table>
<thead>
<tr>
<th></th>
<th>Observation</th>
<th>Survey</th>
<th>Case Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths</strong></td>
<td>Naturalistic</td>
<td>Cheap and easy to administer</td>
<td>Can probe past events</td>
</tr>
<tr>
<td></td>
<td>Provides a rich picture</td>
<td>Uniform delivery</td>
<td>Accommodates constructs, views and experiences</td>
</tr>
<tr>
<td></td>
<td>Appropriate to complex situations</td>
<td>Uniform data leading to straightforward analysis</td>
<td>Provides rich and detailed data</td>
</tr>
<tr>
<td></td>
<td>Suited to small sample size</td>
<td>Suited to large sample size</td>
<td>Provide multiple perspectives on phenomenon</td>
</tr>
<tr>
<td><strong>Limitations</strong></td>
<td>Invasive of family life</td>
<td>Questions might be misunderstood with no opportunity to correct</td>
<td>Time consuming</td>
</tr>
<tr>
<td></td>
<td>Assumes phenomenon is observable</td>
<td>Time consuming Low response rates</td>
<td>Care required to ensure processes of data analysis and interpretation is rigorous</td>
</tr>
<tr>
<td></td>
<td>No opportunity to probe previous events</td>
<td>Closed questions – will tightly limit scope of participants’ responses</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus on behaviours rather than constructs and opinions</td>
<td>Open questions - no opportunity to probe and clarify responses</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Care required to ensure processes of data analysis and interpretation is rigorous</td>
<td>limited usefulness when investigating complex phenomenon</td>
<td></td>
</tr>
</tbody>
</table>
Case study methodology was adopted for its flexibility in gathering rich and detailed accounts of past and current experiences, attitudes, beliefs and aspirations from a number of participants, in their own terms.

### 3.3.1 Case study methodology

“...an in depth multifaceted investigation...of a single social phenomenon... The study of the single case, or an array of several cases, remains indispensable to the progress of the social sciences”


The latter years of the twentieth century saw the emergence of the case study as a research design in its own right, rather than merely an exploratory precursor to positivist research. Its tolerance of small sample sizes makes it ideally suited to small scale, applied, naturalistic research, generating applied, ‘real world’ solutions (Yin, 2009). It creates, essentially “…a rich picture- with boundaries”(Thomas, 2011, p. 21).

Some have suggested the case study is simply a framework for other methods, or a strategy within another method, rather than a method in its own right (Platt, 1992; Stake, 2005). However, Yin (2009) asserts that the case study fills a research void that cannot be successfully addressed by either experiments (which reduce phenomena to a limited number of variables) or surveys (which can only effectively focus on phenomena). Case studies interrogate both the phenomenon and its context, to gain a better understanding of both and, importantly, the blurred boundary between the two. For this reason, Yin (2009) asserts that case study is a distinct methodology defined both by its “purpose” and its “technical properties”(p. 18). The purpose of a case study is to investigate contemporary phenomenon in its natural context, where the boundaries between the two are unclear. In terms of research design, case studies have multiple things of interest to the researcher and relatively few
participants, relying on multiple pieces of evidence providing cumulative support for findings. Case study research requires prior theoretical understanding of the phenomenon to guide data collection and analysis (Yin, 2009).

Early clarity about the boundaries, purpose and ‘logic’ of choosing a case makes it more likely that a piece of research will be successful in its research aims (Yin, 2009). Thomas (2011) implores researchers to be clear of the nature of their case, or cases, from the outset; to choose a case that will meet the research goals and, conversely, to understand the limitations placed on a piece of research by the decision to study a particular type of case. Once the purpose of a case has been determined, one must establish the boundaries of a case (Thomas, 2011). Boundaries are set by the subject (in this cases, TD sisters of children with autism) and the analytical framework (the self-reported experiences, views and perceived impact of growing up alongside ASD).

3.3.2 Case study and applied educational research

Applied psychology is essentially concerned with real world problems and, most importantly, real world solutions (Patton, 2002). One must first understand the nature of the phenomenon and the nature of any desired change. Case studies that are both contemporaneous and rooted in a familiar or local context can be particularly influential, especially if researchers show a strong chain of evidence (Yin, 2009). In addition to giving a voice to a rarely heard, but psychologically vulnerable, group of young people, this research can provide information for support groups, and inform self-help and professional support and training materials.

3.3.3 Multiple case studies

Single case studies base their trustworthiness on the characteristics of the sample case, which is highly typical, or perhaps highly exceptional, in a given population. When research is still at an exploratory stage and ‘typical’ and
‘exceptional’ features are not known, studying more than one case helps ensure that findings are not “wholly idiosyncratic” (Miles & Huberman, 1994, p. 172). Multiple, or collective, cases studies are inherently instrumental and used to “investigate a phenomenon, population, or general condition” (Stake, 2000, p. 437). Constituent individual cases are less important for their own characteristics than they would be in single case design. The selection of more than one case ensures that the research focus is on the phenomenon itself rather than the characteristics of any given case (Stake, 2005). By identifying commonalities and difference across cases one can begin to separate out phenomenon from context. This can enhance both understanding and theorising about a subject (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Knowledge is cumulative and nuanced. Thoughts and experiences may be shared by many or by only one or two participants yet each perspective complements and enhances our understanding of the phenomenon and its interaction with contextual factors. The exploratory nature of the research means multiple case studies usually have more than one research question and the complex inter-relation of themes and data means they “…are so complex that they almost need to be done by one person!” (Stake, 2006, p.18).

Comparison between cases describes typical and exceptional features within the sample. As the participant sample makes no claims to be representative of the population as a whole, findings cannot be generalised to the wider population. It is rather a case of ‘making comparisons between what these particular cases show us about the phenomenon’ in the given contexts (Thomas, 2011, p. 141). Findings can, however, be linked back to theories and findings from other research, a process Yin (2009) terms “analytical generalisation” (p.203).

This study identifies findings within, and across, families. Using cross-case analysis (Stake, 2006), the multiple case study becomes more than a collection of individual case studies. Cross-case analysis focuses on comparisons between
cases to identify and explore similarities, differences and exceptions within and between them. This is valuable in extending knowledge by drilling deeper about a topic, in a range of contexts and utilising the otherwise “under-mined” data (Khan & VanWynsberghe, 2008, in title) of single cases. Like all case study research, cross-case analysis sets out to establish a “logical chain of evidence” (Miles, Huberman, & Saldana, 2013, p. 290) both within and, importantly, across cases.

Although, in multiple case studies there is no need to identify the characteristics of ‘typical’ or ‘outlier’ cases, it is important to be aware of the key contextual features of individual cases. Yin (2009) advises researchers to select their cases carefully, and use existing theory and research to anticipate similarities, differences and exceptional findings, across the cases. Barbour (2001) argues for the purposeful reporting of demographic data in qualitative research studies in order to explore the factors, mediators and processes behind findings. This extra dimension of analysis can generate future hypotheses and contribute to the development of psychological models.

3.3.4 Devising a robust case study

A case study should allow both an “in depth understanding of the entity” (Borg & Gall, 1989, p. 402) and create “a polyhedron of intelligibility” (Foucault, 1991, p. 77), reflecting complexity and nuance but also bringing clarity and explanation to a phenomenon. This is achieved through collating multiple perspectives on a phenomenon and showing the “chain of evidence” (Yin, 2009, p. 124) that takes the researcher from existing theory to research design and raw data, then via existing literature, research beliefs and focus, to reasoned and justifiable conclusions.

Designing case study research is a recursive, reflective process. Each stage in the protocol influences the ones before and afterwards and the researcher must
continually check the compatibility of purpose, research questions and design. I adopted Thomas’ (2011) protocol for case study design as it incorporates the principles of other researchers (e.g. Yin, 2009) in a format designed for, and used in, applied educational research (see Figure 2).

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Questions</th>
<th>Literature Review</th>
<th>Research Approach &amp; Methods</th>
<th>Design &amp; Process</th>
<th>Kind of study</th>
</tr>
</thead>
</table>

Figure 2: *Case study design process.* Adapted from *How To Do Your Case Study: A Guide For Students And Researchers* (p.27), by G. Thomas, 2011, London: SAGE.

Case study design can be understood in terms of the *nature of the subject:* a special, key or ‘instrumental’ example (an instrumental case is one that is not exceptional in its own right, but chosen to illuminate an issue); *the purpose of the study:* intrinsic, instrumental, evaluative, explanatory or exploratory; *the approach of the research:* theory testing, theory building, illustrative, descriptive, interpretative and experimental; *or the process:* single or multiple and nested, parallel, sequential, retrospective, snapshot or diachronic (Thomas, 2011). Using Thomas’ typology, my study adopts a local ‘instrumental’ case as its subject, chosen simply to explore and illuminate a relatively unknown topic, the purpose is exploratory and the approach is descriptive and interpretative. The process of analysis is multiple and parallel, looking for similarities and differences between cases.
3.4 Data methods

3.4.1 Data gathering

A number of data gathering methods were compared for their relative utility in addressing my research questions. My reflections are summarised in Table 4. Semi-structured interviews were chosen to capture rich and powerful personal accounts from participants of different ages, whilst maintaining a clear focus on my research questions.

3.4.2 Data analysis

Interpretive researchers should present “their interpretations of other people’s interpretations” (Walsham, 1995, p. 78) in ways that enhance understanding of phenomena, and illuminate the interaction between phenomenon and context. Robust analysis should make explicit the process by which ‘data’ becomes ‘findings’, the theoretical assumptions that underpin any claims, the relative strength of support for claims and any limitations, or exceptions also evident in the data (Toulmin, 1953).

A review of recent research in this field indicates five methods of data analysis have been used to explore and identify patterns between cases. Thematic Analysis (TA) (e.g. Braun & Clarke, 2006), Cross-Case Analysis (CCA) (Stake, 2006), Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003), Grounded Theory (GT) (Strauss & Corbin, 1998) and Content Analysis (CA) (Krippendorff, 1980). Each of these approaches was considered and reflections are presented in Table 5.
Table 4: Comparison of data gathering methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing records</td>
<td>Non-invasive of family life</td>
<td>As the participants in this study are a non-clinical population, very limited records exist and likely to vary greatly from family to family.</td>
</tr>
<tr>
<td>Focus groups</td>
<td>Efficient use of resources</td>
<td>Not appropriate for sensitive issues</td>
</tr>
<tr>
<td>Consensus</td>
<td></td>
<td>Difficulty in finding time and place to suit all participants</td>
</tr>
<tr>
<td>Dynamic and problem solving</td>
<td></td>
<td>Can be difficult to ensure all participants have a voice with child participants of different ages</td>
</tr>
<tr>
<td>Some findings are immediate</td>
<td></td>
<td>Tendency to form a consensus opinion rather than the full range and nuance of individual contributions</td>
</tr>
<tr>
<td>Interviews</td>
<td>Generates data on experiences and views</td>
<td>Requires participants to recall and reflect on historical and potentially sensitive topics</td>
</tr>
<tr>
<td>Rich and vivid data</td>
<td></td>
<td>Interviewer can exert undue influence or ask leading questions.</td>
</tr>
<tr>
<td>Can be structured to ensure common ground is covered but tailored to ensure responsive to participants</td>
<td></td>
<td>Time consuming for researcher– conducting and analysis</td>
</tr>
</tbody>
</table>
### Table 5: Comparison of data analysis methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Aims</th>
<th>Epistemology</th>
<th>Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thematic analysis</td>
<td>Seeks patterns between cases</td>
<td>Not wed to any one theory or epistemology; suited to relatively inexperienced researchers.</td>
<td>Accommodates realist and constructivist themes and explanations in one data set. Accommodates similarities and differences between cases. Focus on qualitative evaluation of data (Marks &amp; Yardley, 2004) and interpretation of themes. Keyness is not a solely numeric concept Able to use chunks of data in more than one category (Braun &amp; Clarke, 2006)</td>
</tr>
<tr>
<td>IPA</td>
<td>Seeks patterns between cases</td>
<td>Ideologically bounded to phenomenologic al epistemology. Focus on lived experience only.</td>
<td>Best suited to a group of homogenous participants. Aim to generate plausible and useful theory rather than to explore and describe phenomena as is the aim of this research</td>
</tr>
<tr>
<td>Grounded Theory</td>
<td>Seeks patterns between cases</td>
<td>Appropriate to interpretivist and post- positive epistemologies (Ghezeljeh &amp; Emami, 2009)</td>
<td>Focus on quantitative evaluation of data (Marks &amp; Yardley, 2004) which can then be verified using other means e.g. interviews (Stemler, 2001) Concerned with establishing ‘valid’ inferences made about reality. Single code for data (Cohen, Manion, &amp; Morrison, 2000)</td>
</tr>
<tr>
<td>Content Analysis</td>
<td>Seeks patterns between cases</td>
<td>Not wed to any theory.</td>
<td>Works with data that is numeric or otherwise categorised. Most useful for research deploying mixed methods and non-phenomenological data Compiles evidence from mixed sources and cases to support assertions about the data. Can be case or phenomenon focussed.</td>
</tr>
<tr>
<td>Cross Case Analysis</td>
<td>Seeks patterns between cases</td>
<td>Not wed to any theory.</td>
<td></td>
</tr>
</tbody>
</table>

Marks & Yardley, 2004; Stemler, 2001; Cohen, Manion, & Morrison, 2000; Ghezeljeh & Emami, 2009; Braun & Clarke, 2006.
Thematic Analysis is not tied to any particular theoretical position and is a flexible enough tool to combine both experiences and attributed meanings, beliefs and views. Braun and Clarke (2006) assert that if used appropriately and applied rigorously, TA is a robust technique that retains the ‘authentic’ voice of participants whilst allowing the researcher to distil and draw together common threads in experience. TA is unhindered by the ideological presumptions of either IPA, which is rooted solely in phenomenological epistemology, or Grounded Theory, which is concerned with the generation of plausible and useful theory. I chose TA over non-specific Cross Case Analysis for its structured and transparent approach to analysing text and rejected Content Analysis for its focus on numeric counts and its inability to include phenomenological data.

3.4.3 Thematic Analysis

TA has been criticised for being too flexible and non-prescriptive in both process and rationale to enable necessary peer scrutiny (e.g. Braun & Clarke, 2006). Until recently, the lack of an explicit published protocol made it difficult for would-be researchers to acquire the basic techniques to conduct TA rigorously (e.g. Floersch, Longhofer, Kranke, & Townsend, 2010). However, the last decade has seen a formalisation of TA protocols. A search of the literature produced three not-dissimilar protocols for conducting TA: Braun and Clarke (2006), Fereday and Muir-Cochrane (2006) and Bricki and Green (2007). The demarcation of stages differed somewhat between the models; for example Fereday and Muir-Cochrane (2006) describe transcription of data as a precursor to analysis, whereas Braun and Clarke (2006) see it as an integral part of initial coding. I adopted Braun and Clarke’s (2006) protocol as I considered it a clear and detailed description, I had used it in previous research and had relative confidence in my own skill in using it again. It is also the model most familiar to the peers I had enlisted to scrutinise my coding.
Braun and Clarke (2006) identify a number of key strengths of TA but also identify limitations and possible pitfalls which the researcher should be mindful of. These are summarised in Table 6.

**Table 6: Strengths and limitations of Thematic Analysis**

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility – wide range of topics and constructivist and realist themes</td>
<td>Flexibility – can be open to slippage of process and rigour, and become anecdotal</td>
</tr>
<tr>
<td>Organises and summarises findings from large, diverse body of research – yet can produce ‘thick’ data</td>
<td>How and when are themes identified? Need to be transparent and reflective</td>
</tr>
<tr>
<td>Can handle qualitative and quantitative data, similarities and differences</td>
<td>Frequency of codes – does this alone equate to ‘keyness’?</td>
</tr>
<tr>
<td>Responsive to context; can be inductive (Boyatzis, 1998) or deductive (Crabtree &amp; Miller, 1999)</td>
<td>A priori/ ‘emergent’ themes can take research to different places – need to be reflective about what researcher brings to the process</td>
</tr>
<tr>
<td>Can generate unanticipated insights</td>
<td>Potential lack of transparency if coding if process isn’t sufficiently explicit and ‘thick’</td>
</tr>
<tr>
<td>Allows for social as well as psychological interpretations of data.</td>
<td>Failure to ensure a genuine ‘fit’ of data to themes and codes. Ensure data as a whole fits the themes, not just select excerpts - although data that fits too neatly, without any exceptions is suspect</td>
</tr>
<tr>
<td>Useful for producing qualitative analyses suited to informing policy development.</td>
<td></td>
</tr>
</tbody>
</table>

Adapted from “Using Thematic Analysis in Psychology” by V. Braun & V. Clarke, 2006, in *Qualitative Research in Psychology, 3*, p. 94-97.

Braun and Clarke (2006) distinguish between semantic and latent analysis. Latent-level analysis is concerned with underlying ideologies but in semantic-level analysis “themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said” (Braun & Clarke, 2006, p. 84). Patterns are identified and interpreted. The job of the researcher is to “theorise the significance of the patterns and their broader meanings and implications ... often in relation to previous literature”
(Braun & Clarke, 2006, p. 84). This is through the identification of ‘key’ themes that pull the data back together in a new way that enhances understanding. The analysis in this study is at the semantic level.

Web-like thematic networks show links between codes and how codes contribute to themes to “make explicit the procedures that may be employed in going from text to interpretation” (Attride-Stirling, 2001, p. 388). Thematic networks are easily accessible, giving a clear, one page, overview of the data. They can also show the complexity and nuance of findings, suggest alternative claims that might be made of basic and organisational themes, indicate the beliefs and assertions from which claims are made and show any exceptions or rebuttals to claims.

3.5 Research integrity

In this section, I outline the theoretical principles used to guide my research, illustrated with examples from my study.

3.5.1 Research trustworthiness

“How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?” (Lincoln & Guba, 1985, p. 290).

In qualitative methodologies, the personal, experiential, interpretive and dynamic nature of knowledge render the keystones of quantitative research defunct; “…reliability and validity have been subtly replaced by criteria and standards for evaluation of the overall significance, relevance, impact, and utility of completed research” (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 3). ‘Tests’ of these standards are less well established but include following accepted protocols for emergent methodologies, peer scrutiny and the use of ‘thick’
description to substantiate findings. Such measures “...act as a self-correcting mechanism to ensure the quality of the project” (Morse et al., 2002, p. 14). Yardley (2008) proposes four principles to guide qualitative researchers from the initial research idea, through collecting and analysing data, to the writing up and dissemination of findings; sensitivity to context, commitment and rigour, coherence and transparency and impact and Importance as summarised in Table 7.

**Table 7: Principles of qualitative research**

<table>
<thead>
<tr>
<th>Principle</th>
<th>Evidenced by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity to context</td>
<td>• Relevant theoretical and empirical literature</td>
</tr>
<tr>
<td></td>
<td>• Socio-cultural setting</td>
</tr>
<tr>
<td></td>
<td>• Participants’ perspectives</td>
</tr>
<tr>
<td></td>
<td>• Ethical issues</td>
</tr>
<tr>
<td></td>
<td>• Empirical data</td>
</tr>
<tr>
<td>Commitment and rigour</td>
<td>• Thorough data collection</td>
</tr>
<tr>
<td></td>
<td>• Depth and/or breadth of analysis</td>
</tr>
<tr>
<td></td>
<td>• Methodological competence and skill</td>
</tr>
<tr>
<td></td>
<td>• In-depth engagement with topic</td>
</tr>
<tr>
<td>Coherence and transparency</td>
<td>• Clarity and power of argument</td>
</tr>
<tr>
<td></td>
<td>• ‘Fit’ between theory and method</td>
</tr>
<tr>
<td></td>
<td>• Transparent methods and data presentation</td>
</tr>
<tr>
<td></td>
<td>• Reflexivity</td>
</tr>
<tr>
<td>Impact and importance</td>
<td>• Practical and applied focus of research</td>
</tr>
<tr>
<td></td>
<td>• Theoretical</td>
</tr>
<tr>
<td></td>
<td>• Socio-cultural</td>
</tr>
</tbody>
</table>


I will now discuss these principles in relation to my research.
3.5.1.1 Sensitivity to context

The empirical and theoretical context for this research is detailed in Chapter 2. Limited consensus regarding the experiences of NTD siblings and the absence of any research about school life coupled with the importance of this study to the local community addresses Yin’s first requirement that “The case study must be significant” (Yin, 2009, p. 185). Devising research that is mindful of, and sensitive to, existing research ensures that research is purposeful, necessary and respectful of the target community (Strauss & Corbin, 1998).

The original aim of this research was to respond to requests from parents to represent the rarely-heard voices of NTD siblings in the hope that they might receive appropriate and timely support. However, “...qualitative research does not inherently lead to social justice outcomes...” (Lyons et al., 2013, p. 21) and in order to have credibility, research must be both rigorous and ethical. Stone and Priestley (1996) propose a number of principles for research that aspires to promote the needs of its participants. Firstly, research topics should be of concern to the community in question, with the implicit aim of overcoming barriers faced by the community. Research should focus on broader systems and societal factors and adopt a social model of disability; for example asking about systemic barriers and other people’s reactions that cause embarrassment and anger, not simply assuming that NTD siblings are embarrassed and angered by their siblings. Finally, in order to encourage optimum participation, research methods should be flexible and responsive to participants’ circumstances and needs.

3.5.1.2 Commitment and rigour

Yin (2009) asserts that “The case study must be complete” (p. 186). Researchers should be mindful of resource limitations and choose a suitably proportionate focus and design, rather than impose superficial limits on a case
that warrants much more detailed study. Initially, I had planned to recruit male and female NTD siblings. Despite a wide-ranging and varied recruitment strategy, I attracted only female volunteers. Asking schools and groups to re-advertise for participants seemed unlikely to prove fruitful and, I felt, might make some families, or individual family members, feel pressured to take part. As this is a relatively small scale piece of research, I felt it was reasonable to redefine what this was actually a ‘case’ of. On reflection, I decided to continue with a female only CYP participant group and to describe the experiences of NTD sisters with reference to existing theory and research. I also noted that these participant sisters were the sole NTD children in their families.

“The case study must consider alternative perspectives” (Yin, 2009, p. 187). Triangulation is the process by which researchers “...map out, or explain more fully, the richness and complexity of human behaviour by studying it from more than one standpoint” (Cohen et al., 2000, p. 112) to produce “...a more balanced picture of the situation” (Altrichter, Feldman, Posch, & Somekh, 2008, p. 147). I have used ‘data triangulation’ and ‘investigator triangulation’ (Denzin, 1978) in this study.

3.5.1.2.1 Data Triangulation I gathered perspectives from eight families to help ensure that findings relate, at least in part, to the phenomenon, rather than contextual features of a single case. This number is within the desired range for research of this type (Stake, 2006) and similar to the other studies in this field e.g. Petalas et al (2009) and Angell et al. (2012). Semi-structured interviews also provide a large and rich data set with multiple references about topics of focus. Each participants mentions their sibling relationships or peers dozens of times, and each quote provides a different perspective on the topic.

Parental interviews also provide an alternative yet highly informed perspective to supplement younger participants’ recall of events, and provide key contextual
information. Parents are attuned to their children’s needs and are instrumental in accessing support for their child, so their views are important when creating support for this group.

Some studies in this field rely solely on the perspectives of parents to shed light on the sibling experience (Begum & Blacher, 2011), sibling relationships (Nielsen et al., 2012), sibling adjustment (Hastings, 2003), and resilience (Bayat, 2007). Although interviewing adults is ethically less problematic than talking to children, research shows that parent-only studies are likely to present a more negative picture than those that include both parental and child perspectives (Dew, Balandin, & Llewellyn, 2008; Rivers & Stoneman, 2003).

Consideration was given to gathering the perspective of teachers. This would have provided a third perspective and increased triangulation (Stake, 2006, p37). I discussed this with peers and in supervision. I decided that maintaining family privacy was a key concern; some participants attended schools where their sibling with ASD was not known, and some families had made a conscious decision to educate their children in separate schools. There were also concerns about the possible impact of negatively labelling the participant by singling them out for discussions about their wellbeing with school staff. Finally, there were practical issues with identifying staff with adequate and comparable knowledge about each young person, especially for girls at secondary school.

3.5.1.2.2 Investigator triangulation I conducted and transcribed all the interviews personally. This allowed me to listen carefully to the accounts many times over and brought an element of consistency to the interviews and analysis, which is important in a multiple case study (Stake, 2006). However, in analysing and coding data, it is also vital to consider alternative explanations of the data and the most obvious way to do this is through investigator triangulation (Yin, 2009). Excerpts of transcribed and coded interviews, and
themes with their collection of codes were looked at by colleagues and fellow doctoral students and any feedback considered.

### 3.5.1.3 Coherence and transparency

Research methods should be consistent with the research epistemology and claims and findings, including generalisability to a wider population, must be consistent with, and justifiable within, the methodology. Findings should be evidenced by thick description (Lincoln & Guba, 1985) and “The case study must display sufficient evidence” (Yin, 2009, p. 188). However, it is a popular misconception that a complete case study should contain mixed methods. This research is phenomenological, concerned with the experience of having a sibling with ASD. There is no ‘gold standard’ instrument to assess resilience in children and young people (Windle, Bennett, & Noyes, 2011), and I was concerned that quantitative instruments such as the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) would dilute the phenomenological nature of this research and risked overshadowing qualitative data. Hence, I rejected standardized self-report measures in favour of asking participants about the areas covered by those sub-scales of the SDQ indicated for non-clinical groups, namely their internalizing and externalizing behaviours and pro-social skills (see Appendix 2b for details).

Robson (2002, p. 460) outlines a number potential weaknesses of human analysis, including the tendency to treat data inconsistently, with a bias towards early or positive examples. To counter this, accepted methods and protocols should be used and the evidence behind claims laid open for peer scrutiny. Silverman (2000) warns against including only exemplary instances of coding and asks for research to provide worked examples of analysis. In order to understand how others view the phenomenon “…the researcher should regard their expectations lightly, in a way that is open to unexpected meanings” (Elliott & Timulak, 2005, p. 148).
Recognising one’s positionality allows one to consider alternative interpretations. “The research in which I engage is shaped by who I am, and as long as I remain reflective throughout the process, I will be shaped by it, and by those with whom I interact” (Bourke, 2014, p. 7). Researcher positionality includes status and relationship to research topic and participants, and personal and professional beliefs and assumptions that influence research and analysis. My own research positionality is explored in Appendix 11. In order to provide scrutiny of my own inherent expectations and bias, I shared sections of coded data with my supervisor and with fellow doctoral students and psychologists, asking them if my coding seemed justifiable and for suggestions of any alternative interpretations of data.

3.5.1.4 Impact and importance

The topic is important to the local ASD community and identified as necessary by published researchers in this field. The rigour with which an argument is built and justified influences the impact of research. “The case study must be composed in an engaging manner” (Yin, 2009, p. 189). The primary audience for such research are interested and informed fellow practitioners, therefore chapter drafts were shared with practising CEPs and their feedback was used to enhance it ‘readability’ and relevance.

3.5.2 Research ethics

I conducted this research in line with BPS (2009) and University of Manchester (2014) guidelines for research integrity and ethical behaviour. I took care to ensure that my research was robust and useful, that participants were recruited in an ethical manner and that they were in a position to give informed initial and continued consent. I made sensitive arrangements for conducting the interviews and storing data in ways that protected confidentiality and anonymity. I fed back
my findings appropriately. The inclusion of participants under the age of 18 raises particular ethical issues which I will now address.

### 3.5.2.1 Consent of minors

Researchers should ensure that children, in particular, understand the nature and purpose of participation and give their informed consent, understanding they can withdraw that consent at any point during the research process (BPS, 2009; Morrow & Richards, 1996). For this reason NTD sisters are at least ten years old and without any special educational need or disability (SEND). Three Participant Information (PI) sheets were prepared, one for use with parents and carers, and two for use with NTD sisters; one in language appropriate for use with participants aged 10-13 and one intended for those aged 14-19 (Appendix 1). These were piloted with young people of similar ages and adjusted in light of their feedback. At the start of the interview sessions, sibling participants were reminded that they could stop the interview at any point.

### 3.5.2.2 Interviews with children

In order to put young participants at ease, and to ensure that interviews garnered as much useable data as possible, I looked to best practice guidance regarding the effective and ethical interviewing of children (Alderson & Morrow, 2011; Shaw, Brady, & Davey, 2011). To allay anxiety and enable informed consent, NTD sisters and their parents had prior knowledge of the items in the interview. In line with the University of Manchester ‘Guidelines on Research Integrity’ (University of Manchester, 2014), interview sessions with NTD sisters were limited to 30 minutes. Robson (2002) suggests interviews much shorter than 30 minutes are unlikely to provide adequate data.

To minimise disruption and maximise sense of security and privacy, interviews were conducted in a quiet room in a naturalistic and familiar setting, namely the child’s school or home, as the family preferred. Most interviews took place in the
child’s school during the standard working day. Although interviews in school might be considered lower risk and less invasive of family life, some suggest that conducting research in school makes it harder to ensure meaningful consent; children may feel obliged to consent simply because they are used to doing as they are told in school (Morrow & Richards, 1996). I was conscious of this and took pains to ensure the young person was happy to meet with me. Interviews were arranged with minimum disruption to the child’s education and family life. Interviews could be chaperoned by a ‘friendly face’ from school, or parent, if the child wished.

A picture drawing activity was deployed as a non-threatening means to facilitate thinking time, to allow young people to express tentative ideas in ways other than speaking, and to allow for breaks in eye contact if the CYP found this intimidating (Shaw et al., 2011). Drawing pictures can help children describe their current situation and imagine the changes they would like to see in their lives (Moran, 1996). Drawing has successfully been used in this field to support very young children discuss experiences (Sage & Jegatheesan, 2010). To ensure language was readily understood, I scripted the introduction to the drawing activity and prompt questions, and piloted these beforehand with young people of similar ages. (See section 3.7.2.1. below and Appendix 2 for details of interview schedule and drawing activity).

3.6 Summary of methodology

This research is post-positivist and interpretative in its assumption that first-hand experiences and the attributed meanings of those close to a phenomenon can enhance our understanding of social ‘realities’. The exploratory and descriptive nature of the research questions suggests qualitative methods and a multiple case study design to help tease apart context and phenomenon and
illuminate underlying factors and processes. Multiple cases provide data triangulation, are ideally suited to single-researcher studies and help protect the confidentiality of vulnerable participants drawn from a relatively small community. Semi-structured interviews elicit participants’ experiences in their own words whilst keeping a focus on the key areas of research, and parental interviews help triangulate data and provide contextual details. Thematic analysis, using the constant comparative method, provides a tried and tested protocol to make sense of powerful personal experiences in relation to existing theories and existing research.

3.7 This study

3.7.1 Participants

The participants in this study are NTD sisters aged 10-19 who have a brother or sister with ASD, and one of their parents or carers. Using accepted protocol (Stake, 2006) and the example of other research in this field (e.g. Angell et al., 2012), I set out to recruit between six and ten families using a varied recruitment strategy. Email can be effective in engaging geographically isolated populations or those busy caring for a family which includes a child with SEND (McCoyd & Kerson, 2006). An outline of the research was emailed to parents who had previously expressed an interest in taking part. Details were included in the electronic and paper newsletters of local parent support groups across five local authorities, and I attended their meetings to discuss my research. I also attended parent information ‘drop-ins’ at local schools with ASD provision and details were included in school newsletters. The study was included on the National Autistic Society register of creditable research, which is accessible to all their members.
Following the review of relevant literature, participant selection criteria was drawn up (Table 8). I screened families who expressed interest at this stage, to ensure they met the ‘essential’ components of this criteria.

**Table 8: Participant selection criteria**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Rationale</th>
<th>Essential/ Desirable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child with <strong>diagnosis</strong> of ASD in family</td>
<td>to ensure ASD is a factor</td>
<td>E</td>
</tr>
<tr>
<td>Sibling aged 10-19</td>
<td>Able to understand, verbalise and give meaningful consent (Gillick ‘test’ (Morrow &amp; Richards, 1996)</td>
<td>E</td>
</tr>
<tr>
<td>Siblings currently share home</td>
<td>To ensure sibling effect</td>
<td>E</td>
</tr>
<tr>
<td>NTD sister has no SEND</td>
<td>To ensure consent is meaningful, To ensure sibling effect rather than impact of own SEND</td>
<td>E</td>
</tr>
<tr>
<td>Less than 4 yrs. age difference between siblings</td>
<td>To ensure sibling effect</td>
<td>D</td>
</tr>
<tr>
<td>Sibling group of no more than 3</td>
<td>To ensure sibling effect - larger family groups dissipate impact (Kaminsky &amp; Dewey, 2002)</td>
<td>D</td>
</tr>
<tr>
<td>Parents report that behaviour of child with ASD is ‘challenging’ (≥ 3 on a scale of 0-5)</td>
<td>Challenging behaviour threatens sibling wellbeing (Hastings, 2007)</td>
<td>D</td>
</tr>
</tbody>
</table>
Eleven families expressed an interest in taking part in the project and eight met the essential criteria. One was exclude because the child did not have formal diagnosis of ASD, and two because the NTD children were younger than ten years old. As outlined above, three versions of the PI sheet were prepared; one for parents, one written in language appropriate for use with children aged 10-13 and one for use with CYP aged 14-19, respectively. These eight families were sent the relevant Participant Information (PI) sheets outlining full details of the study including the topics to be covered in the interviews and details of the consent required. Having read the PI information sheets, all eight families agreed to go forward with the study. As this number of participants was manageable within the resources of this research, I decided to proceed with these eight families. Written consent was taken from NTD sisters and their parent. When NTD sisters were younger than 18 years old, parent participants were asked to consent both to their child’s participation and to their own. In cases where participants elected to be interviewed in school, respective head teachers were approached for consent to conduct interviews in school (Appendix 1e). Participant details are summarised in Table 9. Detailed participant pen portraits, using pseudonyms for all participants, are presented in see Appendix 3.
**Table 9: Participants’ details**

<table>
<thead>
<tr>
<th>Case</th>
<th>NTD sister participant’s name</th>
<th>NTD sisters’ school</th>
<th>Child with ASD’s school</th>
<th>Size of sibling group</th>
<th>Age of NTD sister</th>
<th>Older or younger than sibling with ASD?</th>
<th>Age of sibling with ASD</th>
<th>Gender of sibling with ASD</th>
<th>Parent’s name</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Grace</td>
<td>primary</td>
<td>Same primary</td>
<td>2</td>
<td>11</td>
<td>older</td>
<td>9</td>
<td>male</td>
<td>Jane</td>
</tr>
<tr>
<td>#2</td>
<td>Ellie</td>
<td>primary</td>
<td>Special</td>
<td>2</td>
<td>11</td>
<td>younger</td>
<td>14</td>
<td>female</td>
<td>Mary</td>
</tr>
<tr>
<td>#3</td>
<td>Harriet</td>
<td>primary</td>
<td>Dual : Same primary and special</td>
<td>2</td>
<td>10</td>
<td>older</td>
<td>8</td>
<td>male</td>
<td>Debbie</td>
</tr>
<tr>
<td>#4</td>
<td>Keira</td>
<td>primary</td>
<td>Same primary</td>
<td>2</td>
<td>10</td>
<td>younger</td>
<td>13</td>
<td>male</td>
<td>Paula</td>
</tr>
<tr>
<td>#5</td>
<td>Bella</td>
<td>secondary</td>
<td>Same secondary</td>
<td>3</td>
<td>12</td>
<td>twin</td>
<td>(12) twin</td>
<td>male</td>
<td>Kim</td>
</tr>
<tr>
<td>#6</td>
<td>Rhiannon</td>
<td>secondary</td>
<td>Special</td>
<td>2</td>
<td>18</td>
<td>older</td>
<td>13</td>
<td>male</td>
<td>Jack</td>
</tr>
<tr>
<td>#7</td>
<td>Rachel</td>
<td>university</td>
<td>Other secondary</td>
<td>3</td>
<td>19</td>
<td>younger</td>
<td>21</td>
<td>male</td>
<td>Joanne</td>
</tr>
<tr>
<td>#8</td>
<td>Polly</td>
<td>secondary</td>
<td>Special secondary</td>
<td>3</td>
<td>16</td>
<td>older</td>
<td>14</td>
<td>male</td>
<td>Nicola</td>
</tr>
</tbody>
</table>
3.7.2 Data collection

3.7.2.1 Interview schedules

The review of the literature review provided a number of topics to cover in the interviews. These were:

- positive and negative aspects of having a sibling with ASD
- knowledge and beliefs about ASD
- sibling relationships
- other family relationships
- support from family and other sources
- school-based experiences and other peer issues
- caring responsibilities
- coping and resilience

A draft interview schedule was drawn up and shared with peer CEPs and parents from a local support group, who did not meet criteria for this study. Questions were revised in light of feedback, primarily to make them more easily understood and to remove duplication. I looked to the interview tools used by other studies and noted my topics closely matched the questions used in Angell et al. (2012)’s study with the additional focus on peer relations and support arrangements.

During the session CYP participants were asked to draw two pictures. The first, a representation of their current life with their sibling(s) with ASD and the second a representation of their ideal life with their sibling(s) with ASD.
This draft schedule was piloted with non-participant children and young people aged 10-19 years of age, to ensure appropriateness of task and language and to check the schedule could be completed within 30 minutes. The schedule was modified in response to piloting, most significantly in simplifying the language used to introduce the drawing activity (see Appendix 2a).

The parental interview schedule comprises items about the perceived experiences of, and impact on, their NTD daughters and contextual information and behavioural challenge presented by the sibling with ASD (Hastings, 2007). Prior to interviews, this schedule was shared with peers to check for clarity of questions (see Appendix 2b).

3.7.2.2. Interview protocol and procedure

NTD sisters elected to be interviewed either in school, during the school day or at home, during the school holidays. By participant choice, all parental interviews took place in the family home. Sibling interviews lasted between 28 minutes and 45 minutes and parental interviews lasted between 55 minutes and 90 minutes. All interviews took place in quiet rooms where we would be undisturbed. In one case, a child chose a learning mentor to join the interview. Sessions were audio taped and later transcribed by me.

Sessions followed a five stage format:

- Building rapport (e.g. Bogdan & Biklen, 2007)
- Explaining the interview and reaffirming consent (BPS, 1993)
- Semi-structured interview schedule
- Invite participant questions or points of clarification
- Explanation of next steps in research process, signposting, if required, and thank you
I was aware of the need to facilitate participants’ accounts and views, whilst avoiding leading questions or comments (Yardley, 2008). In addition to the use of planned and piloted questions, participants were encouraged to expand and develop their comments with verbal probes (Table 10).

**Table 10: List of interview probes**

<table>
<thead>
<tr>
<th>Type of probe</th>
<th>Description of probe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Silent</td>
<td>Interviewer remains silent and allows the participant to think aloud.</td>
</tr>
<tr>
<td>Echo</td>
<td>Repeat the participant’s point, encouraging them to develop it further</td>
</tr>
<tr>
<td>Verbal agreement</td>
<td>Express interest in the participant’s views; ‘uh-huh’, or ‘yes, okay’.</td>
</tr>
<tr>
<td>‘Tell me more’</td>
<td>The interviewer clearly asks the participant to expand on a particular point – without the use of echoing.</td>
</tr>
<tr>
<td>Long question</td>
<td>Ask a lengthier question that suggests a detailed response is sought.</td>
</tr>
<tr>
<td>Leading</td>
<td>Ask the participant to explain their reasoning.</td>
</tr>
</tbody>
</table>


As recommended by Yin (2009), the interview schedules were used with Family#1, reviewed, then rolled out to other participants, in turn. Following the interview with CYP participant #1, I revised the end of the interview schedule to include a check that those girls interviewed in school were happy to explain their absence to curious peers when they returned to class. If necessary we worked on an explanation or, if they wished to conceal the reason for our interview, a plausible alibi.
3.7.2.3 Managing data

Interviews were audio taped and transcribed. Paper and electronic copies of interview transcripts were used for analysis and research notes were kept. NVIVO 10 was used to support the data analysis process. Electronic documents, which included the audio recordings, were stored on an encrypted laptop and paper documents were stored in a locked filing cupboard, in a locked office.

3.7.3 Analytic strategy

As explained in 3.4.3 above, I used Braun and Clarke’s six-phase model of Thematic Analysis (2006, pp. 16-23) to analyse the interview transcripts.

3.7.3.1 Phase 1: Familiarization and transcription of verbal data

I conducted and transcribed all sixteen interviews personally. This ensured accurate and consistent transcription and afforded the opportunity to listen repeatedly and closely to participants’ accounts. Although not adhering to a formal transcription system, all audible communication that conveyed meaning, such as hesitations, silences and laughter, were noted. Some girls elected to draw pictures to illustrate their ‘current life’ and ‘dream life’ and we discussed their picture during the interview (See Appendix 4 for examples of pictures). The transcription contains my description and any discussion about the thoughts and feelings represented by the picture (see Appendix 5 for transcription extract). Interview transcripts were kept whole to retain context and participants’ intended meaning. Transcripts were scrutinized for contextual information and pen portraits were written.

3.7.3.2 Phase 2: Generating Initial Codes

I conducted an inductive, data driven analysis of the text, based on the semantic meaning. To maintain the primacy of NTD sisters’ views I coded their interviews before those of their parents. To balance my own bias and the themes underpinning the interview items, I completed the initial coding without the use
of a priori codes and before writing the detailed review of the literature. I used Thomas’ constant comparative method (Thomas, 2013, p. 236) which provides detailed instructions on the iterative process by which to generate codes from multiple sources. First, I read the transcript for NTD sister #1 and identified 58 quotes pertaining to sibling experience. I sorted quotes into groups based on meaning, generating a first draft of 17 codes. Next, I read the transcript for NTD sister #2, identifying a further 47 quotes. I allocated some of these quotes to existing codes, modified some codes to better describe the quotes from both participants, and generated some new codes. I coded all 16 interviews in this way, generating 168 initial codes (see Appendix 6 for full list of initial codes).

Reviewing and revising codes. During the process, quotes were recoded, and codes were merged, divided, redefined and renamed to better reflect their revised content. Table 11 shows how a quote from NTD sister #1 was coded. The initial code was revised to include a quote from NTD sister #2. This revised code was then confirmed by a quote from NTD sister #3. The code being second priority is subsequently sub-divided into two codes being second priority and ceding priority. Being second priority is passive and even resentful, describing how others prioritise one’s sibling over oneself. The second code, ceding priority is active and positive, choosing to cede priority to one’s sibling.

Table 11: Example of revising codes using constant comparative method.

<table>
<thead>
<tr>
<th>Quote</th>
<th>Initial code</th>
<th>Revised code</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CYP #1</strong> the child with autism is the centre of attention all the time</td>
<td>sibling(ASD) is centre of attention</td>
<td>being second priority</td>
</tr>
<tr>
<td><strong>CYP #2</strong> if I wanted to do something and she wanted to do it as well then she would probably get to do it because mum would say to me ‘E you can do it anytime’</td>
<td></td>
<td>being second priority</td>
</tr>
<tr>
<td><strong>CYP #3</strong> sometimes I want to go out but we won’t go out because X is tired or something</td>
<td></td>
<td>being second priority</td>
</tr>
<tr>
<td><strong>CYP #8</strong> I just got used to doing my own thing. I don’t blame my parents or my brothers... You just go, yes that’s fine.</td>
<td>Being second priority</td>
<td>ceding priority</td>
</tr>
</tbody>
</table>
Coding for intended meaning. Quotes were kept relatively lengthy to include context and nuance, making it easier to code for function and viewpoint (Braun & Clarke, 2006). Table 12 illustrates how longer quotes support coding for meaning and avoid superficial analysis. The common act of grandparents inviting the TD sister to stay with them is perceived quite differently by two participants.

Table 12: Example of coding for intended meaning

<table>
<thead>
<tr>
<th>Quote containing keyword or topic</th>
<th>Expanded quote showing intended meaning</th>
<th>Interpreted Meaning</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>My nan. I go there a lot and during my exams.</td>
<td>Interviewer: Is there anyone outside of your immediate family who helps you? My nan. I go there a lot and during my exams. They let me use their house to revise. It’s always been like that CYP #8</td>
<td>Invitations to grandparents’ house are welcome and supportive</td>
<td>extended family support</td>
</tr>
<tr>
<td>my grandparents they invite me over to stay</td>
<td>My grandparents they invite me over to stay...but have never asked M...They care about him, but ...they don’t understand him at all.... I sometimes feel there is favouritism there CYP #7</td>
<td>Invitation omits brother - evidence of perceived intolerance and misunderstanding of ASD in unsupportive family</td>
<td>divided family</td>
</tr>
</tbody>
</table>

Coding to multiple codes and themes. Quotes which are long enough to contain intended meaning often pertain to more than one code. Table 13 illustrates how quotes were appropriately coded at multiple codes.

See Appendix 7 for an example of a code supported by quotes.
Table 13: Example of coding to multiple codes

<table>
<thead>
<tr>
<th>Quote</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt that they [school] knew where I was coming from(^1) so that if I had HW and I was too upset to do it 'cos my brother kicked off,(^2) I could just go in and say 'nightmare' and they would say 'no worries, hand it in tomorrow'.(^{1, 2}) A lot of my teachers knew about my little brother 'cos he was the one who made a big impact on my high school time.(^3)</td>
<td>1 School's pastoral support</td>
</tr>
<tr>
<td></td>
<td>2 Academic impact</td>
</tr>
<tr>
<td></td>
<td>3 Shared schooling</td>
</tr>
<tr>
<td>Apparently my friends are like me very kind and caring(^1). They are very bold and very gentle at the same time. And they are very nice to D and they understand him and when he comes to sit with us we will all get involved with him(^1, 2, 4)…We all get along really well.(^1, 4)</td>
<td>1 Right kind of friends</td>
</tr>
<tr>
<td></td>
<td>2 Social minder</td>
</tr>
<tr>
<td></td>
<td>3 Mature and caring for others</td>
</tr>
<tr>
<td></td>
<td>4 Sibling is friend</td>
</tr>
<tr>
<td>People just tend to stare, like little kids and things you see them just looking, just staring(^1) and I don’t like that because I think it is a bit mean.(^4) There was a girl once and we were going on the aeroplane and she was in front of us and she just kept turning around and just looking(^1) and it made me feel embarrassed and it made mum and dad feel embarrassed(^2) and M noticed and it made her more loud(^3)</td>
<td>1 Society's ignorance</td>
</tr>
<tr>
<td></td>
<td>2 Embarrassment</td>
</tr>
<tr>
<td></td>
<td>3 Understanding sibling’s behaviour</td>
</tr>
<tr>
<td></td>
<td>4 Empathy for sib</td>
</tr>
</tbody>
</table>
3.7.3.3. Phase 3: Searching for Themes

With quotes and basic codes stored on NVIVO10, I found it easier to move onto flipchart paper to group codes into potential themes. Codes and candidate themes were written on post-its and grouped and regrouped, with arrows used to denote links between themes (see Appendix 8).

Codes are semantic labels for quotes but themes represent patterns and key ideas within the text and say “…something important about the data in relation to the research question…” (Braun & Clarke, 2006, p. 82). Braun and Clarke (2006) caution against over-simplistic analysis, for example basing themes on the most frequently used words in a data set. In my study, siblings frequently used the word ‘frustration’ in their accounts. On closer analysis, participants’ frustration was generated by a multitude of people and events, and, in fact, conveyed a range of meanings including amusement, mild disgruntlement, inconvenience and anger. Adopting a theme of ‘frustration’ would not have enhanced understanding of the data.

By the end of this phase, I had a network of candidate themes, each supported by codes which in turn, were supported by quotes. I also had a number of ‘miscellaneous’ codes, and associated quotes, that stood alone. These generally pertained to one or two cases whose experience seemed exceptional in these respects. Drawing out patterns and relationships between codes, I drew up an initial thematic network (see Appendix 9).

3.7.3.4 Phase 4: Reviewing of Themes

Returning to NVIVO10, I reviewed the quotes pertaining to each candidate theme for internal homogeneity and external heterogeneity. I reflected on the following questions:
Internal homogeneity:

- Is there enough data to support this theme?
- Is this theme internally consistent: Is this really one consistent theme or many? Do the quotes form a ‘coherent pattern’ under the theme?
- Does the theme accurately describe the data within or does the theme need redefining to better represent the body of extracts?
- Do some extracts sit better in another theme?
- Are some extracts irrelevant to the theme and RQ?

External heterogeneity:

- Is this theme unique within my set of themes?
- Does it stand alone or is it better subsumed into an existing or new ‘super’ theme?
- Is this theme a ‘main theme’ or a sub-theme?

I then checked the thematic map against the full data set by reading through interviews transcripts again and asking two key questions:

- Is the thematic map comprehensive and accurate? Are these themes a fair and full reflection of what participants have said?
- Have I missed any quotes that should be coded to these themes?

I revisited this initial thematic map (Appendix 9) over a number of weeks, to pull out the key themes (Appendix 10). Braun and Clarke (2006) advise that when this process become one of fine tuning a framework that already effectively describes the data then the process has been exhausted.

3.7.3.5. Phase 5: Defining and Naming Themes

The final phase is to consider how themes explain the data and answer the research questions and inter-relate. I reflected on the following.
• Is this theme one clear thing. Can I sum it up in a few sentences?
• Do the quotes support the theme?
• How well does the theme title represent its contents?
• Are sub themes required to explain the data more clearly?
• How do themes inter-relate?
• How does this theme relate to my research questions?

Themes were reviewed, revised and shared with my peer reference group who suggested themes should be simpler, and that I should include a distinct theme of ‘support’. I reviewed my thematic map in the light of these comments, dividing the more complex themes and increasing the network from five themes to eight themes. These were shared with participants for comments. Themes were defined and the network was finalised (Figure 3).

![Map of final themes](image)

Figure 3: Map of final themes
Chapter 4: Findings

4.0 Overview
In this section I describe in detail the themes and sub themes generated by the thematic analysis and consider these with regard to the overarching research question

These findings are context specific, based on analysis of the perceptions of this group of eight NTD sisters and their parents. The data is derived from analysis of their self-reported experiences, both past and present and their reflections on these and their views about what the future might hold.

4.1 RQ: What are the experience of NTD sisters growing up with a sibling with ASD?

Eight themes were generated.

1. Continuum of Perceived Challenge: Positively and negatively perceived aspects of having a sibling with ASD.

2. Continuum of Acceptance: a range from denial and upset, through resignation, to positive acceptance. Sense of fairness, and understanding and beliefs strongly influence acceptance.


4. Continuum of Relatability: the range of feelings NTD sisters have towards their sibling, the shifting nature of sibling relationships and the development of mutuality.
5. Continuum of Cohesive Positive Identity: the perceived impact of a sibling with ASD on personality, identity and life choices and the coming together of private and public personas.

6. Social world: Threats and Friends. The perceived impact of having a sibling with ASD on peer relations and social confidence and competence; Society’s treatment of NTD siblings and experiences of sharing school placement with a sibling with ASD.

7. Social Carer: the particular role that NTD siblings adopt in supporting their sibling.

8. Support: experiences of family, peer and professional support and aspirations for future support.

For purposes of clarity, themes are discussed individually. In reality, themes are linked and inter-related. Together they describe the social, psychological and emotional experience of NTD sisters of siblings with ASD. For example, 
acceptance both promotes and is enhanced by a mutually rewarding relationship and cohesive positive identity. Similarly, social world shapes the role of social carer, and being a social carer affects one’s social world, and is linked to one’s sibling relationship. Successful adjustment is associated with positive acceptance, mutually satisfying relationship and cohesive positive identity.

The order in which themes are discussed relates to the research questions and does not indicate any relative importance.
4.2 Full Description of Themes

4.2.1 Theme 1: Continuum of Perceived Challenge

Although siblings with ASD behave in similar ways, some NTD sisters perceive behaviours negatively whilst others minimise challenges and talk primarily about their sibling’s strengths. Living with a sibling with ASD is a continuum of perceived challenge (see Figure 4). Perception can be very fluid. Some NTD sisters hold negative, mixed, and ambivalent views about their sibling; feelings of love and affection are combined with frustration, irritation and embarrassment. Other NTD sisters are generally positive about their sibling, their relationship and the impact of ASD on their own lives. Older NTD sisters perceive that they become more positive over time with older participants recalling that they felt more negatively in mid-childhood and early teens.

Positively perceived aspects are:

- Fun and humour
- Sibling is my friend
- Admirable qualities
- Talents
- Warmth and affection

Negatively perceived aspects are:
- Physical aggression
- Arguments
- Meltdowns
- Disruption to home work and exams
- Disruption to sleep
- Obsessive behaviours
- Emotional rejection
- Invades my personal space
- Reduced parental attention
- Embarrassment
- Restricts trips out
- Interrupts time with friends
- Medical emergencies

4.2.2 Theme 2: Continuum of Acceptance

![Continuum of Acceptance Diagram]

Figure 5: Continuum of Acceptance

...the child with autism is the centre of attention all the time (Grace, 11yrs; brother Asp 9yrs)

These NTD sisters respond variously to their siblings; denial and upset, tolerance and wistfulness, and positive acceptance. Understanding and beliefs about ASD
and perceptions of fairness influence acceptance (see Figure 5). Mixed, sometimes contradictory, attitudes suggest that acceptance is fluid, variable and context dependent for some NTD sisters, especially for the four primary age girls in this study. Looking back over their childhood, the four older NTD sisters in this group show an understanding that children’s needs differ and that their parents are doing the best job they can.

Subtheme: Denial and upset

There are definitely times when she doesn’t want him there, doesn’t want him around. She hates D going to watch her shows ...She goes crazy. No way does she want him there. (Jane, Grace’s mum)

Grace excludes her brother from her dance shows; they provide an opportunity to showcase her talents but the potential for public humiliation is great. By excluding him completely she also secures her parents’ full attention for an hour or two.

Infringement of personal space and ‘private’ time with friends can be very upsetting.

He comes into my room all the time, takes things... drives me crazy.

(Keira, 10yrs: brother ASP, 13yrs)

Rachel recalls similar, pre-adolescent angst. She describes being torn between loyalty to her brothers and fear of the negative judgement of peers.

There’s conflict and you’re torn and you don’t know what to do... it’s when everything tangles up into a mess. That is the most difficult time. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

This internal struggle is shared by others.

...she struggles to see any positives to be honest... the embarrassment, the disappointment, always having to give way. (Mary, Ellie’s mother)
Mary draws parallels between her daughter’s wish for a ‘normal’ sister and her own grief and loss at having a child with disability; to accept the sibling she has, Ellie must first acknowledge, and relinquish, the sibling she anticipated having.

**Subtheme: Resignation and wistfulness**

_Sometimes I just wish that everything was normal [gentle laugh]_ (Ellie, 11yrs: sister ASD and MLD, 14yrs)

At times, sisters are resigned and wistful for ‘normality’. Ellie and Keira envy the sibling relationships their friends enjoy. As sole NTD children in their families, Ellie misses a sister to hang-out with and Keira misses a ‘cool’ big brother.

_I wish we could go out more, with [brother] and family... more trips would make it loads better._ (Harriet, 10yrs: brother ASD and medical needs, 8yrs)

In addition to ASD, Harriet’s brother suffers from a life-limiting illness which perhaps makes her cherish him more. She isn’t critical of him personally, but she does wish for more shared, family fun.

_If you’ve lived with it all your life, it is normal._ (Rhiannon, 18yrs: brother, Asp, 13yrs)

Sometimes NTD sisters appear resigned to, and pragmatic about, the adjustments and restrictions associated with having a sibling with ASD. This is their ‘normal’.

_No door slamming, maybe a tut or raised eyebrow at the most. She has probably seen that if we are being stressed we are probably at our limits._ (Jack, Rhiannon’s dad)
Jack attributes Rhiannon’s tolerance, at least in part, to her implicit understanding that her parents are already doing their best.

*Subtheme: Positive acceptance*

*You are more able to accept yourself and him [her older brother, L,] too for what you are, no blame, no guilt...* (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Ellie and Keira anticipate that life will become easier as they get older, as both they and their siblings mature. Adolescent NTD sisters say that they have become desensitised to behaviours and, in retrospect, Rachel feels that the frustration and embarrassment she previously blamed her brothers for, was partly caused by her own poor self-esteem and feelings of social inadequacy. Her improved relationship with her older brother gives her hope that her relationship with her younger brother will improve.

*Subtheme: Fairness*

*She’ll say ‘You love M more than me’ and I say ‘I don’t love her more than you, but she needs me in a different way to you, and to be honest she needs me more than you do.’* (Mary, Ellie’s mum)

The perception of ‘unfair’ treatment causes resentment for some NTD sisters. Ellie and Grace believe siblings with ASD get more attention, do fewer chores, are reprimanded less often and receive more treats. They may logically understand why their parents prioritise their sibling but emotional immaturity, and their own need for parental attention, makes it hard to accept unequal treatment.

*Mum needs to concentrate on her and if I want something but I don’t get it, it just upsets me.* (Ellie, 11yrs: sister ASD and MLD, 14yrs)
All the sisters believe that they receive less parental attention than their siblings and their peers. By secondary age and beyond though, NTD sisters can, in retrospect, rationalise this inequality.

_I do have odd pangs of jealousy. When he got horse riding lessons at school I was like ‘I always wanted a horse!’ But it didn’t mean the same to him and it wasn’t his fault, it was just part of his routine. There was no point being jealous because he wasn’t gloating or feeling he was getting anything special..._ (Rhiannon, 18yrs: brother, Asp, 13yrs)

Although occasional jealousy is natural, adolescent siblings come to appreciate a distinction between ‘fair’ and ‘equal’ treatment; their sibling may need more attention to be safe or to attain a similar level of wellbeing. Rhiannon’s brother’s lack of social guile means she no longer feels in competition with him. Ironically, she now feels guilty about the preferential treatment she received from her grandparents.

_I feel guilty about the trips over, he doesn’t get the invites. I don’t think he notices to be honest... but I feel it..._ (Rhiannon, 18yrs: brother, Asp, 13yrs)

Even though she doesn’t welcome their attention and her brother is indifferent to the slight, she sees the preferential treatment she is offered as symptomatic of her extended family’s hostility towards her brother. This causes her guilt and sadness.

Subtheme: Understanding and beliefs

_The more you know about Asperger’s the easier it is to accept that you can’t do much about it._ (Rhiannon, 18yrs: brother, Asp, 13yrs)

Understanding is perceived as the bedrock of acceptance. Young girls especially have a deductive knowledge of ASD; when asked to define the condition they hesitate then give examples of their sibling’s behaviour. Some, like Grace,
generate a composite definition based on experience and snippets of information they’ve acquired from their parents.

…um someone who doesn’t understand what goes on sometimes. Someone who thinks of things in another way. Like they take things more seriously and they sometimes don’t think before they say something. So sometimes they could hurt someone but they don’t really mean it…I just made that up. (Grace, 11yrs: brother Asp 9yrs)

Most NTD sisters declared themselves satisfied with their current level of understanding, although some lacked confidence in their knowledge. At the end of our interview, Ellie asked me to explain ASD to her, in order that she could check her understanding.

Mostly, sisters learn about ASD from their parents, who disseminate information from the training courses and materials they have accessed. Rhiannon and Rachel value opportunities to swap anecdotes and share experiences during formal and informal peer support. NTD sisters describe learning how to manage their siblings’ behaviours through observation and first-hand experience, through coaching and counselling from their parents, and, occasionally, from books or pamphlets.

Families also provide a blueprint of values and beliefs that support positive acceptance. These values include accepting one’s lot, celebrating strengths, and unconditional love for family. Despite her bothers’ highly challenging behaviours, Polly maintains a predominantly positive, strengths-based attitude towards them. She celebrates their uniqueness and minimises and tolerates negative behaviours.

*Interviewer: Does it ever get you down?*
Polly: No not really...They have been given a gift haven’t they, they are clever

Interviewer: What if someone has a sibling who can’t do the things your brothers can?

Polly: Well they’ll need you more so those brothers and sisters can be closer to each other. And that’s a gift too.

Rachel’s reconciliation to her family’s religious faith has helped her accept her brothers’ challenging behaviours. She believes God wants her to use her experiences of ASD in her future career. Although she still struggles with her younger brother’s behaviour, she believes her experiences suggest a vocation to help others. Her brothers have matured over the years but it is the change in her own perception that has made the greatest difference to her wellbeing.

I have gone from seeing it [ASD] as a challenge to a gift now. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Bella feels that ASD is an intrinsic, and valued, part of family life.

I wouldn’t change anything ’cos I love them the way they are...well it’s part of them and it’s who they are so I’d kind of miss it ’cos it’s part of how I grew up. And if it just went you wouldn’t know what to do anymore. (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

4.2.3 Theme 3: Coping and Resilience

Figure 6: Coping and Resilience
These NTD sisters display a range of emotion- and problem-focussed coping strategies which are modelled and supported by their parents, primarily their mothers. Family beliefs and values are also highly influential in shaping appraisal-focussed coping strategies. A commitment to finding positive meaning in experiences, spirituality and a commitment to family support and love, help these NTD sisters cope with their situation (see Figure 6).

Caring for a child with disability causes familial stress and families adapt to meet these challenges. Supportive family relationships and networks, and the beliefs and examples provided primarily by their mothers, help NTD sisters cope with challenging events and build personal resilience. Exam time can be especially challenging for NTD sisters but there is a shared perception that NTD sisters ultimately develop strength of character and do well academically.

*Subtheme: Strategies*

**Emotion-focussed coping**

*I was into painting, drawingarty stuff and creative writing. I used to get lost in that sort of thing...it was about me and getting involved in something I could lose myself in.* (Rhiannon, 18yrs: brother, Asp, 13yrs)

Many NTD sisters enjoy ring-fenced activities away from their siblings. The perceived benefits are varied; making friends who do not associate them with their sibling, relief from the threat of embarrassment, respite from looking out for their sibling. These activities boost self-esteem and relieve stress. Younger girls, especially, appreciate having time and resources set aside just for them.

*Outdoors is my thing...but the boys don’t like that* (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs)

*I think she likes it ’cos the boys don’t do outdoors and she loves the freedom, not having to do her hair, camping and all that.* (Nicola, Polly’s mum)
Polly enjoys helping with her brothers, but she also values camping and rock-climbing with her uncle. ‘Freedom’ is manifold; from peer-group expectations about appearance, from her brothers’ challenging behaviour at home and from prioritising her brothers’ needs.

*So mum and me will put face masks on and stuff, paint nails...* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Keira actively practises Reiki with her mum to relieve stress and others indulge in pampering, again often modelled by, and in the company of, their mothers. Some NTD sisters have physical havens that they, and often their families, associate with relaxing.

*Yes it’s always calm there. It’s where we go to relax.* (Keira, 10yrs: brother ASP, 13yrs)

**Problem-focussed coping**

*And if they start an argument just tell your parents. And the parents should tell the sibling not to and try and distract them.* (Grace, 11yrs: brother Asp 9yrs)

Whilst young sisters rely heavily on their mothers to manage their sibling, mothers increasingly support their daughters to be more skilled in this respect.

*She is coming out of the stage of screaming at me to sort the problems... they do talk more now and I am trying to encourage her to talk to him.*

(Paula, Keira’s mother)

*My mum says I should tell him what I want him to do, not what I don’t want him to do.* (Keira, 10yrs: brother ASP, 13yrs)
Mothers model behaviour management strategies and coach their NTD daughters on how to talk to their siblings.

NTD sisters of all ages, commonly avoid from problem situations.

\textit{At home I try not to hang around with him [D, her twin] too much...I don’t really ask him anymore ’cos it is always the same.} (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

\textit{There are still a lot of people who don’t know about my brothers because I think ‘oh you don’t need to know’.} (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Physical separation and mental compartmentalisation are common coping strategies. Ellie and Grace avoid being seen in public with their siblings. Bella no longer asks her twin, D, why he is upset. She and Grace both protect break times for their own friends, ignoring their brothers’ fallouts with peers. Polly, Rhiannon and Harriet cautiously restrict the information they share with friends.

\textbf{Appraisal-focussed coping}

\textit{Well they have been given a gift haven’t they...I wouldn’t change them}  
(Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs)

Positive beliefs and thoughts support effective coping. Strengths-based beliefs provide a positive prism through which NTD sisters view sibling behaviour and their sibling relationship.

\textit{I don’t really worry about the future... I think I’m born positive...} 
\textit{Just don’t worry, ’cos it doesn’t help.} (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs)
This positivity stretches to one’s own situation, and future life choices; ASD has opened doors rather than restricted freedoms.

_We have a good laugh together as he [J, aged 14,] gets along with my friends as well._ (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs)

_Me and my mum have to go along with it. Once it was really funny ‘cos we drove past a train station and he got really upset ‘cos he wanted to leave the car and get on the train._ (Grace, 11yrs: brother Asp 9yrs)

Some NTD sisters show how shared humour helps their relationship with their sibling, and can even help their sibling and friends bond too. Others find humour in their sibling’s over literal understanding or fixations. Jokes are often shared between NTD sisters and their mothers to make light of obsessions, defuse difficult situations, and minimise behavioural meltdowns.

**Subtheme: Personal resilience**

_We’ve moved to suit M’s needs for a quiet home and the right school...we moved from the city to live in X, it’s up in the hills, so Rhiannon was very isolated there too ...then we moved again, straight into a Welsh medium school...looking back I think, ‘How did we do that to her?!’_ (Jack, Rhiannon’s dad)

The ‘family task’ of caring for her brother meant that Rhiannon faced domestic, social and academic upheaval. She faced these changes with minimal support from her parents, who were occupied managing her brother’s highly anxious and challenging behaviours. In retrospect, her father describes this as a period of ‘emotional neglect’ for Rhiannon.

Disrupted domestic routines and exposure to verbal, physical and emotional hostility can be stressful for NTD sisters. Other factors including a new school,
supportive friends or hostile peers, and exams also influence stress levels and coping capacity. A dip in school performance often indicates emotional upset.

_She just wasn’t doing her homework... she just had a bit of a rebellion in that way ...’cos no-one is going to ‘out meltdown’ her brother! A test to see if you’re noticing her... I think she thought ‘I’ve had it hard enough, I don’t like maths, and I’m not mithered to do it’._ (Jane, Grace’s mother)

On the surface, Grace had accepted her move to a new school, necessitated by the breakdown of her family’s relationship with the school she had attended for six years. In reality, Grace was unsettled, resentful and unhappy at having to leave her friends and a school she liked. Her protest, when it came, was a silent one. For a number of weeks she was simply unable, or unwilling, to attempt Maths homework, or to even discuss the matter. To her mother, this was her quiet way of drawing attention to an area of learning that she didn’t enjoy. Grace’s silence might also indicate that she her lacked the capacity, or confidence, to voice her disquiet.

_L’s [Rachel’s older brother] flash-times were first thing in the morning and at night – the times when she [Rachel] was here and needed peace. Home was never peaceful for her ....L used to bang his head on their adjoining wall...try and strangle himself, drown himself in the bath, ineffectual but distressing nonetheless. I wouldn’t know he was doing it but Rachel would come down and say, ‘make him stop!’...I was crying, he was crying and I could hear Rachel howling upstairs too._ (Joanne, Rachel’s mother)

For Rachel, Keira and Rhiannon their siblings’ mental health crises presented extremely challenging behaviours at home. Their brothers’ meltdowns often occurred on the edges of the day, when children with ASD can be most
unsettled. These are also times when other children are most likely to be at home, requiring parental attention. As children, the girls were particularly vulnerable to their siblings’ aggression. They were ‘captive’ at home, smaller, weaker and more likely to rely on their parents for protection and lacked the insight to manage their sibling effectively or to manage their own subsequent stress.

Exam time presents challenges for many teenagers and NTD sisters perceive that having a sibling with ASD exacerbates their stress. Keira and her mother fear she will underperform in her 11+ and Grace became so anxious that she vomited in school tests. GCSE exams were a flash point for Rachel, Rhiannon and Polly; all three report increased anxiety leading up to GCSEs, resulting in dips in academic performance.

...we had to have meetings with the school and stuff, cos she just went ‘pop’. Part of that was probably hormonal but not all ... she has been scarly calm through her ‘A’ levels which worries me a bit! (Jack, Rhiannon’s father)

They accessed counselling and found emergency respite with extended family or friends, in order to revise in peace and be well rested for their exams. Families, and the girls themselves, learn from these difficult experiences. In sixth form, they made plans ahead of time to assure peaceful study and adequate sleep. NTD sisters report being more confident and better prepared for ‘A’ levels.

She didn’t do as well in GCSE as we might have thought ...so I think it did impact on her. I actually think she’ll do Ok at Uni...maybe in the long run she has got to where she would have been attainment wise. (Joanne, Rachel’s mother)

Ultimately, Rhiannon not only recovered academic ground, she gained emotional maturity and strength of character.
How did she turn out so smashing? Maybe we sent her away for a year or two and forgot about her [laughs]. She always seemed quite self-contained … that’s the legacy of having M. It has shaped her and changed her and she is a very compassionate young woman and long may that continue. (Jack, Rhiannon’s father)

Subtheme: Family resilience

You have to change to support a child who is different – whether that is a talent, or a disability. They can’t change, they have to be changed for. A family gets stronger by changing to support their children. (Mary, Ellie’s mum)

Raising one or more children with ASD makes great demands on family resources and relationships. This ‘family task’ is stressful for most families at some time, and for some families most of the time. These challenges impact on NTD sisters too.

Sometimes I catch myself saying “your father is driving me mad”. She’s hearing that, taking it all in...You get very tense and snappy and Harriet is exposed to that. (Debbie, Harriet’s mother)

Parents are candid about the stress incurred by having a child with ASD. In four families, grandparents live with, or close to, the family, providing high levels of practical and emotional support. However, other familial relationships can become strained and distant as relatives struggle to understand and accept the demands of raising a child with ASD. The surviving family unit is smaller, more tightly drawn together, with a strong sense of being ‘in this together’. These NTD sisters understand this family narrative.

Yeah we’re a strong family, yeah. We talk things out lots (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)
4.2.4 Theme 4: Continuum of Relatability

Sibling relationships are described in terms of conflict, ambivalence and mutuality (see Figure 7). These NTD sisters share an enduring and loyal bond with their siblings. Grace and Ellie’s accounts suggest that conflict, ambivalence and jealousy can dominate, especially in mid-childhood, but mutual affection, shared fun and strengths-based beliefs help the older girls perceive the relative strengths and benefits of their sibling. Although sibling roles are often atypical, these NTD sisters perceive that their relationships become more reciprocal and mutually rewarding with age.

**Subtheme: Enduring bond**

Keira: *When I’m nearly asleep he comes into my room and gives me hugs... he loves me a lot.*

Interviewer: *And do you love him?*

Keira: *A bit.*

To varying degrees, all NTD sisters talk affectionately about their sibling. Even during periods of their lives when they find them predominantly irritating, sisters still show loyalty and care for their siblings.

*She has developed this great bond with him [L, her older brother]. I am glad they have it. They talk about things, and if he does anything for her she is completely bowled over by it and grateful to him...it’s vastly*
important to her, their relationship matters vastly to her... (Joanne, Rachel’s’ mum)

Rachel’s relationship with her older brother was previously defined by his hostility and rejection. She takes great satisfaction in their improved relationship. Rhiannon believes the effort she has invested in building her relationship with her younger brother is worthwhile.

I think he deserves it ... I wish that I’d done it sooner and a bit more because he really does care. He is trying to engage with you but he doesn’t know how. (Rhiannon, 18yrs: brother, Asp, 13yrs)

Bella feels that her relationship with her twin is closer than her relationship with her younger brother. Their mother believes the twins implicitly understand and support each other’s weaknesses.

They have a closeness that other siblings don’t have. If they come across a situation that is new to them, you will see them come together... she often stands behind him and pushes him forward, gets him to go first... that’s her insecurity and that bond transcends even the autism. He is so used to her he understands her in a way that he can’t understand anyone else. And she knows him very, very well. (Kim, Bella’s mum)

**Subtheme: Shared fun**

Shared fun is something all NTD sisters value. They share hugs and laughter with their siblings. Some NTD sisters express, almost exclusively, positive views about their relationship whilst others describe elements of fun and warmth in, generally, negative relationships. Sometimes, ASD behaviours generate humour.

She just makes me laugh... the other day, M said to mummy “Why are we driving around in circles?” Mum said “That’s a very good question” And M
said “So what’s a very good answer?” And we all laughed a lot. (Ellie, 11yrs: sister ASD and MLD, 14yrs)

Humour comes from their sibling’s fixation on a topic, misunderstanding and over-literal interpretations or the surreal-ness of a situation. This is gentle, affectionate and non-mocking, humour.

[Ellie describing her ‘dream life’]

It’s a party for one of us.

Interviewer: Is it for you?

It’s for her.

Interviewer: And would it just be you at the party? Who else would be there?

Our family. Sometimes we have really good laughs and she is so funny you just have to laugh

(Ellie, 11yrs: sister ASD and MLD, 14yrs)

Ellie and Keira both recall fun family parties. Harriet and Polly describe their own enjoyment when they see their siblings having fun. Often humour is shared with parents and family members and serves to enhance family bonds.

Subtheme: Conflict

...well when I am doing my homework he is always wanting me to play and that gets really frustrating [sic]. He is shouting at me. (Grace, 11yrs: brother Asp 9yrs)

Most NTD sisters report feeling, or having felt, irritated, annoyed and frustrated by their siblings. A common cause of frustration is homework. This is a practical problem, finding space and time to complete work without interruption.

He said ‘do you want to do it? And I said ‘no,’ and he said ‘why not?’ and I said I don’t want to. And he says ‘I don’t want to‘ is not an answer’ and
he keeps on doing that. On and on...Once I said we could make a robot out of card but he wanted to make it from metal and nothing else would do! (Keira, 10yrs: brother ASP, 13yrs)

Lack of flexibility and relentless and repetitive demands also cause frustration and irritation. Some NTD sisters recall their sibling’s subsequent aggression and to perceive it more keenly,

He will shout and get quite nasty. He is always shouting because if I say ‘no’ to him then it gets into a big argument. (Grace, 11yrs: brother Asp 9yrs)

Rachel and Polly’s brothers took particular dislike to their sisters. Talking about her older brother, L, Rachel recalls,

For a year he hated the pitch of my voice so when I spoke he would say ‘shut up, shut up,’... It would be so obvious that he didn’t care that you felt bad about that...He would just say ‘no’ and I would be ‘Please play with me’ (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Both boys were wary of people in general, possibly jealous of another child in the house and had sensory intolerances that meant that they found the pitch of their sisters’ voices particularly upsetting. Young children may be less able to adjust their own behaviours and, consequently, may inadvertently irritate their siblings with ASD. Nicola, Polly’s mum, believes that Polly’s love for her brothers and her ‘laid back’ and positive approach helped her overcome their aggression.

Subtheme: Ambivalence

It’s quite weird because although I am always shouting at him, I do feel sorry for him (Grace, 11yrs: brother Asp 9yrs)

Grace and Ellie describe becoming increasingly concerned with their standing amongst peers and sometimes find it hard to reconcile their fragile social identity
with having a sibling with ASD. Often, sisters recognise their own ambivalence, torn between love and loyalty on one hand, and embarrassment and irritation on the other,

Well I want to look after him [younger brother, H] but at the same time I want distance from him. That is just so much a conflict... I will be the one who sets him off. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

As a young adult, Rachel still struggles with her younger brother’s behaviour. Her ambivalence suggests her continued need to protect herself; she wants a closer relationship but recognises their current pattern of interaction is mutually harmful.

Subtheme: Mutuality

The social indifference and naiveté commonly associated with ASD can be viewed as a strength. Indifference to peer pressure means that brothers with ASD are perceived as more loyal playmates than other boys.

big sisters and boys are probably angry with each other lots of the time ...but we’re not like that most of the time because well we like playing with each other... he doesn’t mind me being a girl, or his sister. He would think I was just a friend and he will play with me. (Harriet, 10yrs: brother ASD and medical needs, 8yrs)

Teenage boys with ASD are perceived as less likely than NTD peers to tease their sisters. Older adolescent NTD sisters especially describe appreciating their siblings’ talents and acts of thoughtfulness; Polly’s elder brother, L, proofreads her ‘A’ level coursework whilst Rhiannon watches films with her brother.

He is a really nice person, funny and polite. We have similar interests ...We do Minecraft a lot together and he has a massive thing for Yugioh
trading games, so I learnt that as well so we could have that in common. I liked them before but when he really got into them I picked them up again and carried on with them. (Rhiannon, 18yrs: brother, Asp, 13yrs)

Rhiannon describes her enhanced sense of wellbeing from knowing she has a good relationship with her brother. Although she has ‘worked’ to build the connection their relationships is now two-way and they have shared interests they both enjoy. Rachel describes how her once hostile older brother reached out to support her when she was struggling with the fallout from her younger brother’s mental health crisis.

It’s just about being friends... When the little one was kicking off, he [older brother] would say ‘Shall we go and look at a film in my room?’ and I would say ‘Yes!’...that was when my older brother came into the picture and helped ‘cos I was really struggling. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Sibling relationships are on a continuum of mutuality. Initially NTD sisters do most of the work to build the relationship but most also appreciate their siblings’ innocence and love and can identify some relative strengths and talents. Rachel has come to see relative strengths in her atypical sibling relationship with her older brother. Rachel, Grace, and Ellie describe guilt, dissonance and discomfort about any resentment or embarrassment they feel towards their sibling. For Rachel, Polly and Keira their own wellbeing, identity and family relationships are enhanced by resolving their dissonance, acknowledging their authentic and unique bond and developing mutually satisfying sibling relationships. Sometimes, shared hobbies are also developed.
4.2.5 Theme 5: Continuum of Cohesive Positive Identity

![Continuum of Cohesive Positive Identity](image)

NTD sisters’ lives are shaped by having a sibling with ASD and the perceived impact is both positive and negative. These NTD sisters perceive themselves as more caring and emotionally mature than their peers and most aspire to be successful at school. Conversely some may lack social confidence and become introverted, or be easily swayed by peers. Many young NTD sisters describe a gap between their private and social identities; loyalty to one’s sibling in private, but embarrassment in public. Other, mostly older girls convey a more cohesive positive identity is created when girls determine to accept their sibling and their own situation and act to reconcile their social relationships to this fact. Their experiences influence choice of friends, university course, voluntary work and career path. For many NTD sisters having a sibling with ASD becomes an important and positive part of their identity (see Figure 8).

Subtheme: Precocious emotional maturity

*It’s a good thing, it means you have more sympathy for other people, you can look at people and appreciate what they are going through.*

(Rhiannon, 18yrs: brother, Asp, 13yrs)

Having a sibling with ASD is credited with making girls more empathetic, compassionate and emotionally mature. Parents generally approve but some worry that their daughters are more inhibited and socially sensitive and less carefree. They perceive the need to boost self-esteem and social confidence. Harriet, Grace and Ellie are all described as having good social skills. This is
attributed to being left to make their own friends whilst their parents cared for their sibling. Nonetheless even apparently socially confident girls are wary of trusting peers with information about their sibling. This caution can spill over into with introversion and social anxiety.

...She does tend to get friends with baggage... to fix them... I am always talking to her about a friend with anorexia, I say you can’t fix her.

(Joanne, Rachel’s mum)

Joanne worries that her daughter’s sense of self-worth is dependent on being able to ‘fix’ others. Keira needed support to prioritise her own friendships when she generalised her caring behaviour to other lone children and became increasingly isolated from her own peers.

Subtheme: Being good

I think she is an internaliser and very conscious of my feelings so she would be good so as not to make it any worse and helpful...

(Joanne, Rachel’s mother)

Rachel’s mother feels that her daughter makes an overt effort to ‘be good’ partially to protect her parents. This can mask anxiety that, her mother believes, contributed to her developing insomnia and an eating disorder.

She is consciously a very good girl... I wish she’d just go and be wild once in a while but she won’t. (Joanne, Rachel’s mum)

Rachel refers to herself as ‘not cool’ and at times wishes she could go ‘crazy’ at university but concedes “it’s just not me”. Rhiannon and her friends call themselves the ‘nerd herd’. At times, she too has struggled to make friends. This is exacerbated by having moved house numerous times.
I think doing well at school is important to her. She talks all the time about wanting to go to Uni and she is doing 6th form now... she has high hopes, expectations. (Nicola, Polly’s mum)

Most of the girls are described as ‘good’ at school. For Polly, doing well at school is an important part of her identity. She attends a girls’ grammar school, away from her brothers. Like Bella, she works hard at school and has a small, but mature and close group of friends. Conversely, Ellie’s mum worries that she might rebel as a teenager to gain attention, or to fit in with her peer group.

She could go off the rails. I think if we are not careful she will look for attention elsewhere... (Mary, Ellie’s mum)

Subtheme: Identity

Having a sibling with ASD becomes part of the girls’ positive self-image. When she was younger and struggling to cope with her brothers, Rachel preferred to emphasise other parts of her identity,

I would define myself through my music and the things I did in church... and then various things with friends that made it easier. Those were the things I would talk about if people asked me to talk about myself. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Now she is proud of her expertise and the help that she gives others. Rachel and Polly both want to study psychology “because of the ways the boys are” (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs) and to better understand human behaviour. They volunteer with ASD projects and are considering careers in caring professions. Polly wants to “give back” and use her hard-won knowledge to help others. Rachel describes her experiences as “a gift”.

When you get into older teens you are more confident and know who you are. ... So I cried at my class basically. I said ‘you mocked this and it is in
no way funny. How dare you?’ (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Adolescent and adult NTD sisters describe emotionally charged moments when they spoke publically to support their siblings.

*If a boyfriend couldn’t accept M, or thought he was weird, then he [the boyfriend] would have to go, it just wouldn’t work.* (Rhiannon, 18yrs: brother, Asp, 13yrs)

As they reconcile their public and private personas, unsympathetic friends are dropped and some NTD sisters become determinedly positive about their experiences and their identity as a sibling of someone with ASD.

*It’s really important, it is at the core. I wouldn’t be doing psychology at Uni if I didn’t have brothers with autism. I might not even be a Christian really… being an autism sibling and the sense that I should be using that experience.* (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

### 4.2.6 Theme 6: Social World: Threats and Friends

NTD sisters view their social world as one of valued friends and potential threats (see Figure 9). Friends can provide support and respite for NTD sisters but peers also threaten embarrassment, bullying and social isolation. Many NTD sisters
witness bullying and ignorance towards their siblings and, sometimes, are themselves the victims of prejudice. Having a sibling with ASD can be perceived as limiting one’s social life; practical barriers can limit the frequency and spontaneity of social opportunities and psycho emotional barriers, primarily embarrassment, lead many NTD sisters to be cautious in their choice of friends.

Some NTD sisters experience conflicted loyalty between their sibling and their peer group. Those who attend the same primary school as their sibling often experience tension between caring for their sibling and their own social inclusion. NTD sisters often describe as acting as the eyes and ears of their mothers in school and are highly sensitive to any conflict between home and school.

School staff are perceived as generally benign but unaware of the impact that living with ASD can have on NTD siblings. Better informed staff often appear uncomfortable or unwilling to raise the topic. This can promote feelings of embarrassment, isolation and even shame in NTD siblings.

Subtheme: Prejudice

*There is the stigma of having a condition a mental health problem. People think that just affects that person but it doesn’t; they live in a house with other people and those people also live with autism. People just don’t get how big a thing it is.* (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Social ignorance and intolerance of ASD extends to associated prejudice towards NTD siblings and a lack of awareness of the challenges faced by NTD siblings.

Subtheme: Embarrassment

NTD sisters are keenly aware of the negative judgments that society makes about ASD. Going into town, inviting friends home and being walked to the school bus stop are everyday events that can fill siblings with social angst
I remember being embarrassed sometimes, especially with his tantrums, he would be in a supermarket and just go into a full tantrum ... just embarrassing like, 'oh what are you doing?! I used to have this shame thing when I saw him doing something odd... people stare at him and then they stare at you...’ (Rhiannon, 18yrs: brother, Asp, 13yrs)

Grace and Ellie, are reluctant to go out locally with their siblings, for fear of being spotted by peers who might think poorly of them both. They have sympathy for their sibling and recognise ignorance and unkindness in their peers. Although they are sympathetic towards their sibling they also fear social approbation, even bullying, for being considered ‘different’.

Well I don’t want them to be mean to me either. I don’t want them to be mean to me because of her ...I said to my mum once, on holiday, nobody knows us here so I don’t mind being nice to her. If we are walking in town and somebody, like a boy in my class came up, that would be really embarrassing and I wouldn’t want them to see us. (Ellie, 11yrs: sister ASD and MLD, 14yrs)

Ellie’s embarrassment is essentially a self–preservation strategy in her fluid, fast expanding, pre-teenage social world. Her fears of social approbation are not groundless, as Keira’s experience shows,

Well sometimes he used to come over to me and he was in a mood about school and then none of my friends wanted to play with me anymore.

(Keira, 10yrs: brother ASP, 13yrs)

Embarrassment isn’t simply determined by age. Rachel is older but she is still, occasionally, embarrassed by her brother. She has greater self-confidence and her friends’ reactions are less judgemental,
...he might kick off. And I would still be horribly embarrassed if he did that. If my friend had witnessed that ...but from Year 10, Y11 and 6th Form...you start to be happy in yourself and think 'okay it doesn’t matter so much’ you know your friends aren’t going to say ‘oh your brother is a freak’ they are more likely to say ‘oh your brother is quite funny’ [laughs]. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Conversely, Harriet, aged 10, is “never embarrassed” by her brother. She is, perhaps, too embarrassed to admit this or too young to worry about social approbation or the life-limiting nature of his illness makes her more focussed on her love for him. Polly appears virtually impossible to embarrass. This is a trait her mother attributes to her “laid back” temperament, loyalty to her brothers and a well-developed sense of humour. She also attends school 20 miles away from home, which perhaps reduces the likelihood of being judged negatively by schoolmates.

Subtheme: Educating peers

**when you are with them and he’s being D you can say ’yes he is different in case you’re wondering’ or ’yes he is annoying but this is how you can deal with it’, things like that.** (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Bella believes her friends are not deliberately unkind to her twin. Perhaps because he is her twin and they share schools she takes the opportunity to talk to them about ASD and how to manage his behaviour.

*Some people have said to me, ‘oh your brother is a bit weird isn’t he? He’s a bit odd.’ They won’t say it to him but the say it to me.* (Rhiannon, 18yrs: brother, Asp, 13yrs)

Sometimes peers’ comments are malicious, and sometimes peers are simply
curious and insensitive. The girls have all witnessed their sibling being called names or bullied by other children.

*When he shouted in assembly people would laugh and I didn’t really like that...I just said ‘please can you not do that because if you were him and everybody laughed at you would you like it?’ And they were like ‘nope’.*  
(Harriet, 10yrs: brother ASD and medical needs, 8yrs)

Some, like Harriet, speak out on their sibling’s behalf. However Keira’s attempts to explain behaviours to friends and classmates failed to enhance their understanding and empathy. Her brother’s obsessions and sensory intolerances seemed implausible and her accounts of his meltdowns were met with disbelief by schoolmates, who see a much calmer child at school. Rhiannon concludes that her friends do not, and perhaps cannot, understand what it means to live with ASD.

*They still don’t understand, like ‘Autism? What’s that??’* (Rhiannon, 18yrs: brother, Asp, 13yrs)

**Subtheme: Social impact**

*R’s social life has been second to M’s needs, has had to be really... we haven’t had her friends around to the extent that others do... the way they just drop in or have sleepovers.* (Jack, Rhiannon’s father)

Some parents describe their daughters as socially skilled and good at making friends, perhaps because they are often left to their own devices. Others feel that their experiences have made their daughters introverted. Most concede that their daughter’s social life has been restricted by having a sibling with ASD. They attribute this to the lack of spontaneity with which invites can be issued and the embarrassment that prevents some girls bringing friends home. Inviting friends
to a sleepover is a staple of many girls’ social lives. Having friends to stay is problematic in a home where one or more sibling has ASD; disturbed sleep patterns, intolerance of strangers, rigid routine and hygiene and toileting issues can make sleepovers almost impossible to organise. One parent felt sleepovers were possible only in a large house and another relied on grandparents to host them. Some parents admit to only agreeing to invite their daughter’s friends who will tolerate, and be tolerated by, the child with ASD.

*I would say that because of my brothers I didn’t often meet up with people.* (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

This results in smaller social circle and a quieter social life for many girls. This is not necessarily a bad thing. To protect and support oneself and one’s sibling, NTD sisters are selective about who they tell about their sibling and the information they share.

*I try and keep it separate, so if they come over to the house and they see some leaflet or something I say ‘oh it’s nothing really’.* (Rhiannon, 18yrs: brother, Asp, 13yrs)

NTD sisters may select friends who mirror their attitudes to their siblings. For Bella, it is important to have friends she can trust, who are comfortable around her brother.

*Apparently my friends are like me very kind and caring. And they are very nice to D and they understand him and when he comes to sit with us we will all get involved with him ...We get along really well and are always telling jokes and messing around.* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Conversely, Grace and her friends “pretend he doesn’t exist”. Girls who feel confident and safe in their social circle are happier to include their siblings in
their group of friends. Rhiannon has consciously rejected friends who have been unkind to her brother. She also thinks that being significantly older than him makes it easier for her friends to tolerate him,

> Age difference helps. My friends have always been that much more mature than him and they don’t get drawn in by him so much.

(Rhiannon, 18yrs: brother, Asp, 13yrs)

**Subtheme: School life**

When NTD sisters attend different secondary schools to their sibling, peers and staff can be unaware of the home situation. GCSEs present a particular challenge although some younger girls experience anxiety and difficulty studying for earlier exams. These crises can necessitate a referral to CAMHS or counselling for the NTD sisters.

> No one has ever come and asked. It’s never been brought up really. I think people think ‘oh it’s private’ they don’t like to ask. (Rhiannon, 18yrs: brother, Asp, 13yrs)

Participants perceive that some staff lack understanding and imagination about the likely impact on NTD sisters. Ellie sees a learning mentor every week at her primary school, whilst Rachel recalls that her high school teachers merely noted that she was “nothing like” her younger brother. Staff usually respond sympathetically to requests for homework extensions but don’t appear to anticipate a need for additional emotional or pastoral support, and often maintain a well-intentioned wall of silence about ASD. Although NTD sisters believe staff know about their sibling, and some teachers even have personal experience of ASD in their own families, ASD is rarely discussed in schools. This apparent respect for privacy can be interpreted by siblings as indifference or even disapproval.
4.2.7 Theme 7: Social Carer

NTD sisters often adopt caring responsibilities towards their siblings. Social caring responsibilities include acting as play leader, minder and social mentor for their sibling (see Figure 9). This role is different to the care provided by parents and evolves as siblings mature. NTD sisters are ideally placed to understand their sibling and the socially complex world in which they both operate. This role is especially pronounced when siblings attend the same school. Most NTD sisters envisage continuing to support their siblings into adulthood.

Subtheme: Play leader and entertainer

It’s the talking to him, the way that she does that, playing games as well.

(Debbie, Harriet’s mother)

Younger girls describe acting as play leader and resident entertainer. Debbie, Harriet’s mum loves to see her children having fun together, and is grateful for the respite it affords her. Harriet sets up simple play routines to please her brother, tolerating high levels of repetition, often for hours at a time. She finds the role intrinsically rewarding,

I do it over and over... for ages he just laughs... I like to play and make him laugh, it makes me happy. (Harriet, 10yrs: brother ASD and medical needs, 8yrs)
Subtheme: Minder and sole friend

He didn’t have any friends at all... all the boys didn’t like him. (Grace, 11yrs: brother Asp 9yrs)

All of the NTD sisters in this study have shared schools with at least one of their siblings at some point in time. They have an implicit understanding of their siblings and of how schools work. They observe their sibling’s peer relations at close quarters and are keenly aware of their social world. Consequently NTD sisters can become aware of issues at school even before their parents do. Polly recalls her concern when her elder brother, J, remained in reception class for three years. It can be particularly difficult for girls who strive to be ‘good’ at school themselves to see their sibling falling foul of the school’s disciplinary code. Polly, Rachel and Rhiannon variously describe their embarrassment, worry and powerlessness when their brothers started secondary school. They witnessed their sibling seemingly upset, or in trouble.

I would see him [younger brother, H] around school and I would be wondering what he was thinking. I’d think ‘Oh what’s’ gone wrong now, has this happened or has he kicked off in class?’...In year 7 he found the transition too hard and by Christmas he was spending every lesson in the IRP [unit]. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

When siblings attend the same school, the family-school relationship can be dominated by the needs of the child with disability. Tension between home and school left Harriet and Grace constantly vigilant for their sibling’s welfare, acting as their mother’s ‘eyes and ears’ at school.

She knows things are difficult between me and school. That’s why she is looking out for him when she is in school. They probably don’t realise she is checking up all the time. (Debbie, Harriet’s mother)
NTD sisters describe being distracted school work and neglecting their own friendships. They may also come to blame teachers, potentially undermining their own learning relationships and sense of security.

*The teachers were really quite mean to him, or some of them were. And so he reacted up a lot.* (Grace, 11yrs: brother Asp 9yrs)

Most sisters have experienced being their sibling’s only playmate at school.

*He used to play with other children quite a lot but I notice now that they have been playing with their other friends ...he plays on his own now...I don’t really like that much so I always go over to him and play with him for about 10 to 15 minutes.* (Harriet, 10yrs: brother ASD and medical needs, 8yrs)

Harriet interprets her brother’s isolation through the prism of her own needs; she concedes that he usually prefers his own company, but his isolation makes her uncomfortable, so she chooses to play with him and neglect her own friends.

In difficult situations, Rhiannon put aside her irritation with her brother to protect him.

*She resented all that fuss he made but she still looked after him. She would spot other kids approaching him sometimes before even we did, and she would go and stand next to him to guard him. She really looked after him.* (Jack, Rhiannon’s father)

**Subtheme: Social mentor**

Sisters are often better placed than their parents to help siblings navigate socially complex situations.

*If he has a problem or a worry then he comes to me first and tells me. If it is a problem I go tell the parents, and if not I say, ‘don’t worry about it M, it’s no big deal.’* (Rhiannon, 18yrs: brother, Asp, 13yrs)
Rhiannon feels she has a more nuanced understanding of her brother’s social world than her parents. She shares some of his key interests and is a sensitive and engaged chaperone for visits to Comic-con and sci-fi films. They are active on the same social media. He uses her as a sounding board for problems and she can advise him, allay any unfounded anxieties and, if necessary, alert their parents.

Subtheme: Future relationship

I will always look put for D and he’ll always be my brother and S too.

(Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Older adolescent sisters, especially, imagine a future where they will continue to care for their siblings. Some already have a say in key decisions concerning their siblings; they are interested in their siblings’ welfare and will be impacted by the choices the family makes. Ellie, whose sister has a high level of need, is concerned that her responsibilities to her sister will impede her capacity to “do my own things”. The future for her is one of uncertainty,

It’s quite scary. I don’t know if it will affect the way I grow up. (Ellie, 11yrs: sister ASD and MLD, 14yrs)

Ellie’s mother, Mary is a careful to strike a balance between being realistic about her sister’s future needs whilst not overburdening or upsetting Ellie.

As long as she knows she has a choice we will try and show her how it can be in the future… this will be part of our life now and she needs to be comfortable with that. (Mary, Ellie’s mother)

Jack believes that Rhiannon has a more positive, up-to-date, view of her brother’s abilities and needs.
I bring the past into the present and I think ‘oh he won’t cope with that’ but he does. I think she is more in tune with where he is at now… there are parts of M she knows best. She would know how M would cope and react and she should have an input. (Jack, Rhiannon’s father)

Her insight and proven commitment to her brother’s wellbeing means she has a valuable contribution to make to key decisions to be made about her brother’s future. Harriet worries that he might not survive into adulthood. Polly also has concerns but adopts a determinedly positive approach to her brothers and their situation. This makes it hard for her to consider the future in any detail.

I don’t really think about the future… I think I’m born positive, my mum is like that too… (Harriet, 10yrs: brother ASD and medical needs, 8yrs)

Rachel envisages a positive and mutually satisfying relationship with her older brother, L, without any caring responsibility towards him. However, her relationship with her younger brother is more problematic. Level of burden and relationship quality impact on the nature and quality of their perceived future relationship.

I think I will definitely always be in contact with them both, but as it stands at the moment, I will be in contact more with the older one… (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Parents are keen not to over burden their NTD children, but hope their children remain close as adults. Many acknowledge their NTD children will have some caring responsibility towards their sibling, in adulthood.
She has asked if she would have to look after M when she is older and I have said no we have lots of years to make sure that M is taken care of but I did say ‘I hope you will always be friends’ and there will be times in her life when she needs you. (Mary, Ellie’s mum)

4.2.8 Theme 8: Support

Figure 11: Support

NTD sisters are primarily supported by their family or ‘virtual family’, especially their mothers. Peer support is also valued but can be problematic. Professional support is described as sparse and professional systems are perceived as lacking. NTD sisters would like more responsive and holistic professional support (see Figure 11).

Subtheme: Family

Always have quality time with your other child, (Grace, 11yrs: brother Asp 9yrs)

NTD sisters value parental attention. Parents feel guilty that the needs of their NTD child takes second place, and young NTD sisters especially wish for more parental attention. One-on-one time with parents builds strong relationships and
a sense of being special. Just knowing that their parents spend the time they can with them reassures NTD sisters.

*I’ve always had my mum there for me...she does a lot of things with me when she get the time...* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

The mother-daughter relationship is described by most NTD sisters as a central pillar of support, modelling behaviour management strategies, managing stress and imparting values and beliefs about ASD and life in general. This relationship is perceived as key, even in Rhiannon’s family where her father is the primary, at-home, carer.

*My mum has a strong sense of self belief ...it’s really a waste of time to worry about what other people think.* (Rhiannon, 18yrs: brother, Asp, 13yrs)

These daughters receive most initial and subsequent information about ASD from their mothers and their mothers are the primary and preferred source of explanations, information and support.

*Interviewer: Would you have liked more information?*

*Polly: Not really, I heard all about it from my mum*

They are also most likely to approach their mothers with any subsequent questions. Knowledge and understanding about ASD appears often to be deductive. NTD sisters like to ‘check out’ their understanding of what is happening around their siblings.

*She gets her coping strategies from her mum....she has told a friend that the top of her heroes list is her mum... There are a couple of things that Rhiannon has probably picked up from me but most of it has been from her mum and I think that has been enough.* (Jack, Rhiannon’s dad)
They all variously describe their mothers as on-hand counsellors and sounding boards, supporting their emotional needs,

*I share things with my mum 'cos we are quite close. If I was going to tell someone something, I would probably tell her.* (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs)

Some NTD sisters become more hesitant to talk to their mothers when they perceive their mother is overwhelmed or if a topic is sensitive. Such topics include asking if it's possible to ‘catch’ ASD or if their own children will inherit it.

*My friends say that my mum is really good, she does a lot of things that other mums wouldn’t, like get your ears pierced or your hair dyed and she lets me do things, like she’ll say ‘oh do you want to get your hair done’ or do you want to get your ears pierced, stuff like that.* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Mothers are often credited with providing ‘compensatory’ treats for their NTD daughters, including allocating her the biggest bedroom, ring-fencing clubs and activities away from their sibling and making an effort to schedule time when she can socialise with friends.

*Mum and me will go there and put face masks on and stuff, paint nails and stuff... she will come into me and lie on my bed and talk.* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

Many describe sharing brief, but quality, mother-daughter time, or even a trip away. Other mothers model emotion-focussed coping strategies such as having pamper time, using reiki, physical exercise and listening to music. Sometimes mothers are conscious of teaching strategies but in many cases daughters simply copy their mothers’ example.
Some extended family members, especially grandmothers and maternal family, provide practical and emotional support. Bella lives with her mum and grandma and Harriet's grandmother transports her to, and from, school every day. Supportive relatives also promote positive familistic values.

...baking with my gran and going on walks and just being with them.

Because they, my grandparents, put us and me first. So I've learnt to put M first too. (Ellie, 11yrs: sister ASD and MLD, 14yrs)

Close adult family friends can also become 'virtual family' providing practical support, extra attention and a sympathetic ear.

Subtheme: Peers

You can tell your best friend everything and you have permission to do that, and time. I have one friend from my old school and I can explain everything to her. (Grace, 11yrs: brother Asp 9yrs)

Many girls have one or two sympathetic friends with whom they are happy to discuss their sibling. These friends provide sympathy and distraction. Grace and Ellie are reluctant to share too much, too soon, with too many people; they are concerned that they might be judged negatively or gossiped about by unkind peers.

I have shared with one friend more closely, as she has a sister with Asperger's...So we could say 'oh my brother does that' or 'oh my sister does this' and we'd both understand. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

Sometimes friends too have a sibling with ASD and provide informal peer support, validation and even advice. For Rachel, friends with personal experience of a sibling with ASD have credibility and can be trusted too.
The idea of formalised peer support is popular with NTD sisters and their families. Some are lucky enough to have has access to either an ASD support group, or young carers group.

...because I know how people feel and that my brother is not the only one like that. (Keira, 10yrs: brother ASP, 13yrs)

Ellie and Harriet both attend formal peer support activities and enjoy these, not least for the time spent away from home and apart from their siblings. However, others found practical barriers to accessing peer support; finding and getting to a support group can be difficult and it can be hard to build rapport with the other siblings there.

Everyone was younger than me so I didn’t really connect with them...It would have been nice but just no opportunity really. (Rhiannon, 18yrs: brother, Asp, 13yrs)

Peer support is most valued when girls feel that they have been able to connect and build a genuine friendship with other young people. Some, mostly adolescent NTD sisters, describe enjoyment from ‘giving back’ to support groups. By helping other NTD siblings they feel their experience is validated and they realise how much they have learned. They are comfortable around ASD and enjoy making a positive difference for others.

Subtheme: Professionals

I had counselling when it got hard for me around my GCSEs. I think counselling is useful if things are hard at home to help you deal with it. (Rhiannon, 18yrs: brother, Asp, 13yrs)

At times of familial stress, outside support or intervention can be beneficial. These NTD sisters’ experiences of specialist psychological support is mixed.
They hadn’t experienced living with someone with autism so they really had no idea where I was coming from but my church youth worker was my best counsellor, although he knew nothing about autism really.

(Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

The describe how specialist support can fall short of expectations; a sleep counsellor who recommended sleep hygiene but disregarded the fact of the screaming child in the adjacent bedroom, or the CAMHS worker who never enquires about the wellbeing of other children in the family.

My primary school knew, yes, the one we attended together, but they never mentioned it. At High school, my head of house found out when I was in Y10 …I don’t think they knew before. (Rhiannon, 18yrs: brother, Asp, 13yrs)

Some NTD sisters who go to a different school than their sibling perceive staff are unaware that they have a sibling with ASD. Parents sometimes perceive school don’t want, or need, to know, or that the information is confidential to the child with ASD. When information is shared with school it is not always communicated effectively within schools and staff can appear wary or reluctant to raise the needs of NTD children with their parents. Sometimes NTD siblings are subject to insensitive comments, or unwelcome questions from staff. NTD sisters can be left unsure of who knows what about them, or knowing that staff are aware but not willing or able to support them.

Subtheme: Aspirations

In schools, all of the NTD sisters feel that awareness raising about ASD amongst staff and pupils would improve their own situation. Staff and peers would learn how to behave more appropriately around children with ASD, thus reducing a major source of stress for NTD sisters and freeing them to focus on their own
learning and friendships.

*They can help me by helping him, not letting me worry too much and just focussing on my work, and my friends, instead of worrying.* (Keira, 10yrs: brother ASP, 13yrs)

The need for enhanced awareness isn’t limited to schools. Rachel believes more public and positive examples of people with ASD would help dispel broader ignorance and stigma.

*You don’t see autism in TV programmes... you might see someone in a wheelchair as the ‘person with disability’...it would be good to have it open. Maybe if Coronation Street had a well written character with autism that would help.*

NTD sisters is this study want professional support that is,

- **Convenient and timely**: *school would have been a good place for me*  
  (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

- **Informed and informative**: *It would have been good to have someone who totally got it.* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)

- **Sensitive**: *There are questions you don’t want to ask your parents.*  
  ((Rhiannon, 18yrs: brother, Asp, 13yrs)

- **Cathartic**: *Sometimes it get really annoying and you just want to express that.* (Grace, 11yrs: brother Asp 9yrs)

- **Accepting**: *You could go in and be accepted and understood.* (Bella, 12yrs; twin brother D Asp; brother S, ASD 9yrs)
• **Inclusive:** ...like if someone came and helped her and then came and helped me. (Ellie, 11yrs: sister ASD and MLD, 14yrs)

• **Face-to-face** ...in a group maybe...I prefer face to face. (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs). *I’m pretty anti anything online for the children* (Kim, Bella’s mum). Online support is unfamiliar and treated with suspicion by NTD sisters and their parents. Parents recognise the utility of social media and the internet in their own support network but are wary of their daughters joining ‘virtual’ support groups.

  *what I probably would have valued the most, is groups where you could just go and be happy with other people who go where you were coming from...it would have been nice not to have been alone, to have known other people were going through it...* (Rachel 19yrs: brother L, Asp, 21yrs; brother H, ASD, 13yrs)

‘Real world’ empathy and connection is deemed as important and peer and group interventions are viewed positively.

One type of support does not fit all. Many suggest that personalised assessments of need should taking into account sibling, family and social context, personal preferences and temperament.

  *Every child with ASD is different and every family is too. What you might need will change too.* (Kim, Bella’s mum)
Chapter 5: Discussion

5.0 Overview

In this section I relate my findings back to those of existing research and to my detailed research questions. Appropriate psychological models are introduced to help understand and explain the experiences of these NTD sisters. Implications for practice and future research are also considered.

5.1 Introduction

The findings of this research are best understood in the context of a relatively small participant pool and participant demographics; sibling participants are female and aged 10-19 years old. They are the sole NTD sibling in their families, and have one or two siblings with ASD. Sibling pairs are close in age and all have experienced sharing school placement with a brother or sister with ASD. All but one of the siblings with ASD are male. Most have a diagnosis of Asperger’s or HFA. Participants were interviewed at different age and stages of their lives and some perceptions are of current events, some are retrospective and some are future projections. This analysis treats all of these perspective equally. The views of the primary, at-home parent, all mothers except in one case, are also reflected in this study.

Furthermore, this analysis is mine alone. Although my interpretations have been discussed in supervision, with colleagues, and also cross-referenced with the literature, this analysis is influenced by my personal, professional and educational background and worldview.

In this chapter I will discuss the similarities and differences between my findings and those of other recent qualitative studies; the theoretical implications of my research; indicated support and future research; and finally, the contribution to knowledge made by this research. This chapter is organised with reference to
my research questions (shown below). My research themes are identified in italics.

What are the experiences and perceptions of NTD sisters growing up with siblings with ASD?

- What do NTD sisters perceive are the positive and negative aspects of growing up with a CYP with ASD?
- What are NTD sisters’ experiences of family life, school life, and relationships with friends and the wider peer group?
- How do NTD sisters perceive their relationships with siblings with ASD?
- How do NTD sisters cope with, and adjust to, having a sibling with ASD?
- What supports, or could support, the wellbeing of sisters growing up with a sibling with ASD?

5.1.1 Summary of findings

Analysis suggests eight themes of experience: Continuum of Perceived Challenge; Continuum of Acceptance; Coping and Resilience; Continuum of Relatability; Continuum of Positive Identity; Social world: Threats and Friends; Social Carer; Support.

Continuum of Perceived Challenge

Although siblings with ASD behave in similar ways to each other, some NTD sisters perceive behaviours negatively whilst others minimise challenges and talk primarily about their sibling’s strengths. Living with a sibling with ASD is a
continuum of perceived challenge, with NTD sisters viewing their experience as generally positive or generally negative.

Less accepting NTD sisters hold negative, mixed, and ambivalent views about their sibling; feelings of love and affection are combined with frustration, irritation and embarrassment. Other NTD sisters are generally positive about their sibling, their relationship and the impact of ASD on their own lives. Views are perceived as becoming more positive over time, with the four older NTD sisters recalling that they felt more negatively in mid-childhood and early teens.

Negatively perceived aspects include arguments and meltdowns, social embarrassment, frustration about the compromises placed on social life, and ceding priority to one’s sibling. Positive perceptions include love and affection, sharing fun and being friends.

Continuum of Acceptance

NTD sisters respond variously to their siblings; denial and upset, tolerance and wistfulness, and positive acceptance. Mixed, sometimes contradictory, attitudes suggest that for younger girls especially acceptance is fluid, variable and context dependent. Understanding and beliefs about the nature of ASD and perceptions of fairness also influence acceptance. NTD sisters in mid-childhood sometimes complain of unfairness and missing out on parental attention. Older girls are more likely to appreciate that needs differ and that their parents have done the best they can.

Coping and Resilience

These NTD sisters display a range of emotion- and problem- focussed coping strategies. These are modelled and supported by their parents, primarily their mothers. Family beliefs and values are also highly influential in shaping appraisal-focussed strengths -based coping strategies. A commitment to finding
positive meaning in experiences, spirituality and a commitment to family support and love, help NTD sisters cope with their situation.

Caring for a child with disability causes familial stress and families often adapt to meet these challenges. Supportive family relationships and networks, and the beliefs and examples provided primarily by their mothers, help NTD sisters cope with challenging events and build personal resilience. Exam time can be especially challenging for NTD sisters but there is a shared perception that NTD sisters ultimately develop strength of character and do well academically.

**Continuum of Relatability**

These NTD sisters share an enduring and loyal bond with their siblings. Conflict and ambivalence feature significantly in the accounts of three out of four girls in mid-childhood but mutual affection, shared fun and strengths-based beliefs help sisters come to appreciate the relative strengths and benefits of their sibling and their sibling relationship. Although sibling roles are often atypical, sibling relationships are described as becoming more reciprocal and mutually rewarding with age. Some adolescent sisters also invite their sibling to socialise with their friends.

**Continuum of Positive Identity**

Having a sibling with ASD is perceived as shaping the lives of NTD sisters. The perceived influence is both positive and negative. Most NTD sisters describe themselves as more caring and emotionally mature than their peers and aspire to be ‘good’. Conversely, they may lack social confidence and become introverted. Some girls perceive a gap between their private and social identities; loyalty to one’s sibling in private but embarrassment in public. Ultimately a *cohesive positive identity* is created when girls determine to accept their sibling and their own situation and act to reconcile their own social relationships to this fact. Their experiences influence choice of friends, university
course, voluntary work and career path. For many NTD sisters, having a sibling with ASD becomes an important and positive part of their identity.

**Social world: Friends and Threats**

These NTD sisters view their social world as one of valued friends and potential threats. Friends provide support and respite for NTD sisters but peers also threaten embarrassment, bullying and social isolation. All of these NTD sisters have witnessed bullying and ignorance towards their siblings and, sometimes, are themselves the victims of prejudice. Having a sibling with ASD is perceived as limiting one’s social life; practical barriers limit the frequency and spontaneity of social opportunities and psycho emotional barriers, primarily embarrassment, lead many NTD sisters to be cautious in their choice of friends. Those who attend the same school as their sibling often experience a conflict of loyalty between their sibling and their own social inclusion. NTD sisters act as the eyes and ears of their mothers in school and are highly sensitive to any conflict between home and school.

School staff are perceived as generally benign but unaware of the potential impact of living with ASD on NTD siblings. Those who are better informed often appear uncomfortable or unwilling to raise the matter. This can promote feelings of embarrassment, isolation and even shame in NTD siblings.

**Social Carer**

NTD sisters often adopt a caring responsibility towards their siblings. Social caring responsibilities include acting as play leader, minder and social mentor for their sibling. This role is described differently to the care provided by parents and evolves as siblings mature. NTD sisters uniquely understand their sibling and their needs and the socially complex world in which they and their siblings operate. This role appears to be especially pronounced when siblings attend the
same school. These NTD sisters envisage continuing to support their siblings into adulthood.

Support

These NTD sisters are primarily supported by family, ‘virtual family’ and close friends. Peer support is often enjoyable and valuable but can be difficult to organise and access. Online support is viewed with some suspicion by all of the participants. Professional support for NTD siblings is perceived as sparse and of variable quality. These NTD sisters would value more responsive and holistic professional support, especially at times of family crisis and during exams. Addressing the needs of their sibling with ASD and reducing parental stress also benefits NTD sisters. Support should be tailored to the needs of each young person, their perceptions and their familial and social context.

My findings offer further support for the multifactorial and mixed nature of NTD sibling experience (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012), the complex nature of the sibling relationship and the influence of family values and relationships in shaping the sibling experience (Angell et al., 2012).

My research also validates findings that suggests NTD siblings experience a common range of behaviours and events. However, the multidimensional nature of ASD and family contexts means that no two experiences are identical. Experience is influenced by age, attitudes and beliefs, temperament, family context and perceived and actual support. (Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Importantly, attributed meaning and strengths-based views are also influential in shaping perception and perceived impact (Angell et al., 2012; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012).
5.2 What do NTD sisters perceive are the positive and negative aspects of growing up with a CYP with ASD?

A Continuum of Perceived Challenge is supported by earlier research that found NTD siblings identify both negative and positive aspects to having a sibling with ASD (e.g. Angell et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012).

Positively perceived aspects that tally with other research, are being friends and sharing fun and mutual activities (Angell et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012); enjoying a closer, kinder, more innocent relationship than that which ‘normal’ sibling pairs experience (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012); admiring and benefitting from one’s sibling’s talents and relative strengths (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012); enhanced maturity and caring nature (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012).

I also found that two adolescent NTD sisters perceive having a sibling with ASD as a ‘gift’ and perceive that their experience and knowledge of ASD shapes their personal and professional identity and influences voluntary work, academic study and career.

In line with previous studies (e.g. Benderix & Sivberg, 2007; Mascha & Boucher, 2006), I identify a larger range of negatively perceived aspects than positive ones. My unique focus on school life means that NTD sisters also identified disruption to academic study and interference in school relationships as negative aspects.

I find NTD sisters complain of irritating obsessive behaviours (Angell et al., 2012; Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2009;
Petalas, Hastings, Nash, Reilly, et al., 2012); verbal aggression and arguments (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2009) and domestic disruption, including difficulty sleeping (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2009).

Significantly, I also find that NTD sisters were unhappy when their siblings’ behaviour made it difficult for them to complete homework and exam revision. Doing well in school is important to many of the girls in this study and any threats to this are apparently felt keenly.

Some NTD sisters complain of being socially embarrassed by their sibling (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009; Mascha & Boucher, 2006; Petalas, Hastings, Nash, Reilly, et al., 2012). Two were wary of being seen by peers in the company of their sibling whilst others report that their sibling interferes with their social lives. In my study this interference was both when friends were invited home and in the playground at school. I found that this was a particular problem for some NTD sisters who share a primary school playground with their sibling, especially when that sibling has unhappy peer relations and relies heavily on their NTD sister for support and company.

Like others (Cridland et al., 2015; Petalas et al., 2009; Sage & Jegatheesan, 2010), I found that some NTD sisters complain of perceived unfairness. I found this to be primarily a concern for girls in mid-childhood. Most NTD sisters feel that they cede to their siblings’ needs and wishes (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2009). Interestingly, however, I found that NTD sisters vary in the resentment they feel at this apparent reality.

Similarly, I found that having a sibling with ASD means that NTD sisters perceive that they receive less parental attention than their sibling or their peers with NTD developing siblings and have more restricted leisure, social and family activities (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Petalas et al.,
2009; Sage & Jegatheesan, 2010). Again, whilst some complained of this, other, again generally older, NTD sisters were more relaxed about the situation. This may be explained by a combination of increased independence, access to more support from others outside of the home, or a shift in personal perception to see relative strengths in their familial relationships and ways in which their experiences have positively shaped them.

I found that although their siblings’ extreme behaviours are often challenging for NTD sisters (Hastings, 2003; Meyer, 2011), personal perception of such behaviours is paramount (Petalas et al., 2009). Some NTD sisters appear sanguine, downplaying negatives and emphasising positive behaviours, whilst others grudgingly concede positives and fixate on negative relationship history (Petalas, Hastings, Nash, Reilly, et al., 2012). I concur that positive attributions about one’s sibling are associated with more effective coping (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Conversely, negative perceptions about one’s sibling are associated with reduced satisfaction (McHale et al., 1986).

The retrospective accounts of the four oldest NTD sisters in my research, and the contemporary views of the group as a whole offer some support for the assertion that NTD siblings in mid-childhood hold mixed and ambivalent views (Petalas et al., 2009). Similarly, I found that the three NTD sisters in their mid-to-late teens perceive that their views have become more positive with age, whilst the primary-age girls perceive that their situation will become more positive as they near adulthood. My findings are congruent with previous findings that getting older does not guarantee positivity (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012).
5.3 What are NTD sisters’ experiences of family life, school life, and relationships with friends and the wider peer group?

5.3.1 Family life

I found that some NTD sisters express a degree of disappointment when they compare their relationship to ‘normal’ sibling relationships (Petalas, Hastings, Nash, Reilly, et al., 2012). This was most likely in those of primary-age or when the sibling relationship had been particularly negative. I found that some older NTD sisters see their caring role as an extension of their typical ‘big sister’ role, especially if their sibling with ASD has additional health needs. This may be because older NTD sisters enjoy full parental attention in early childhood. Later on, they are older and more able to rationalise their siblings’ behaviour and their friends and contemporaries are more mature and understanding, thus reducing the likelihood of embarrassment or social disapprobation. Problems do arise, however, if the younger sibling with ASD rejects the care that their sister offers. NTD sisters feel resentful, undervalued (Cridland et al., 2015) and without an identifiable role, causing dissatisfaction and upset. My findings therefore support research with the general population that mutually satisfying roles are important for sibling cohesion (Stoneman, Brody, & MacKinnon, 1984).

I found even relatively young NTD sisters keenly anticipate family activities even though, in reality, activities are often compromised or abandoned. They enjoy activities, in part, because they are enjoyed by other family members. The value placed on ‘shared family fun’ is further evidence of familistic values and family focus (Dellve et al., 2000; Updegraaff et al., 2002). In this, my findings are congruent with those of earlier studies (Cridland et al., 2015; Dellve et al., 2000; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012),
5.3.2 Friends

The dichotomy of *Social World: Threats and Friends* is consistent with the consensus of existing research. Petalas et al. (2009) found NTD siblings distinguish between trusted friends and potentially unkind peers and my findings suggest that trusted friends provide distraction and solace, and sharing experiences with peers provides emotional support and validation. Angell et al. (2012) found NTD siblings are anxious about peers’ acceptance of their sibling. I also found NTD sisters value friends who are kind and tolerant towards their siblings, for example, including them in conversations at lunchtime. Like Petalas, Hastings, Nash, Reilly, et al. (2012), I found sisters often had a relatively small group of trusted and close friends. Some felt that they had chosen their friends wisely and well, whilst others perceived that they had been excluded from ‘cooler’ groups.

Benderix and Sivberg (2007) suggest that NTD siblings have a poor social life and are wary about who they invite home, whilst Angell et al. found that NTD siblings range from “social butterfly to those who said they had no friends” (Angell et al., 2012, p. 3). NTD sisters in my research show a similar range of sociability to participants in Angell et al.’s study. Some are wary about who they invite home, whilst others cite practical barriers to inviting friends home. Some are more likely to invite friends home as their parents prefer to monitor their friendships or find it easier than transporting them elsewhere. I also found mixed views on the impact of any restrictions on sibling sociability. Some see enhanced sociability and social skills as a pleasant side-effect of their sibling and parents being less available to them, whilst others attribute their introversion to limited social opportunities, and fear of being embarrassed by their sibling in formative years.
5.3.3 Wider peer group

Some NTD sisters in my study experience embarrassment about their siblings with ASD but embarrassment varies greatly in extent and frequency. (Angell et al., 2012; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Embarrassment is a social phenomenon, a manifestation of social confidence in a given social context (Tracy & Robins, 2007). Underlying asocial characteristics (Piven & Palmer, 1999) or impeded sociability (Benderix & Sivberg, 2007) might account for the heightened social discomfort of some NTD sisters. I found that even NTD sisters in mid-childhood, who are considered skilled and successful social networkers, experience considerable embarrassment, suggesting support for Roeyers and Mycke (1995) finding that siblings of children with ASD experience greater social discomfort than siblings of children with other disabilities.

Petalas, Hastings, Nash, Reilly, et al. (2012, p. 307) found that adolescents experience “emotional discord” between loyalty to their sibling and concern for their own social acceptance. The embarrassment that Petalas, Hastings, Nash, Reilly, et al. (2012) describe in 14-17 year olds, I found in 10 year old girls. By mid to late-teens, the girls in my study report reduced embarrassment, describing this emotion as a feature of their earlier childhoods. Embarrassment is a self-imposed psycho-emotional barrier “sustained through imagery, cultural representations and interactions with others” (Reeve, 2004, p. 3). The more one perceives the need for social acceptance, the more vulnerable one is to embarrassment. Research suggests that girls perceive peer pressure more keenly, and at a younger age than boys (Darlington, Margo, & Sternberg, 2011). Transfer to high school and onset of puberty is a time of social flux and shifting sense of self when fragile social identity is especially important (McGee, Ward, Gibbons, & Harlow, 2004). Siblings’ loud, inappropriate behaviours risk the disapprobation of peers and socially aware and skilled girls are especially
concerned with their own standing within the peer group. When peer pressure is reduced, such as at family parties or on foreign holidays, embarrassment dissipates.

I found that the invisible nature of ASD exacerbates social prejudice and that NTD siblings are exposed to this hostility (Petalas et al., 2009). When peers notice something "weird" ((Rhiannon, 18yrs: brother, Asp, 13yrs) about children with ASD they direct insensitive questions and comments to the NTD sibling causing social anxiety, embarrassment and anger (Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Reeve (2004) defines disablistism as being stared at and asked personal questions that one would not normally be asked. Using this definition, my findings suggest that these NTD sisters experience disablistism in relation to their sibling.

The NTD sisters in my study generally perceive that peers are ignorant about ASD and how they should behave around people with ASD (Opperman & Alant, 2003; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). They perceive that peers do not fully believe or appreciate the challenges that they face at home and this can be upsetting and isolating. Some try to explain or educate their peers whilst others socially withdraw (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012).

I found that NTD sisters become increasingly intolerant of ignorant and unkind peers (Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012) and increasingly accepting of their siblings. They socialise more publically with their siblings and begin volunteering, studying and working in areas associated with ASD. By adulthood, NTD sisters overcome embarrassment and social anxiety to develop a cohesive positive identity; they are proud of their sibling and of themselves and adopt a peer group consistent with this. They identify
strengths and knowledge that come from having a sibling with ASD and hold ambitions that are consistent with their sibling’s needs.

5.3.4 School life

Research suggests that NTD siblings are negatively affected by parental stress caused by the process of gaining additional support for the child with ASD (e.g. Petalas, Hastings, Nash, Reilly, et al., 2012). Dyson (2010) found that parents of children with Learning Difficulties (LD) report increased family stress generated by everyday negative interactions with school. I found that on-going issues relating to behaviour management and the deployment of resources can cause daily tension between parents and school. Consequently, NTD sisters who attend the same school as their sibling can become hyper-vigilant around their sibling. Primary age girls are especially vulnerable in this respect. Previous research suggests that tense and mistrusting parent-school relations can threaten the academic achievement of NTD children (e.g. Adams & Christenson, 2000; Hughes & Kwok, 2007). My findings suggest that poor home-school relations distract NTD sisters from their learning and social relationships. Conversely, I found that NTD siblings thrive when they know that their siblings’ needs are met, a suggestion borne out by previous research (Moyson & Roeyers, 2011).

I found support for the assertion that NTD siblings set high academic and behavioural expectations for themselves (Angell et al., 2012; Moyson & Roeyers, 2011; Sage & Jegatheesan, 2010). Again, my findings suggest that the factors behind this are varied and complex. Some suggest that the motivation to ‘be good’ variously comes from a desire to please parents, to avoid causing parental stress, and to become socially ‘invisible’. NTD sisters may find escape in academic study or be drawn to trustworthy, mature peers who, co-incidentally,
work hard at school. Many come to positively identify themselves in terms of their academic focus and their relatively small, conscientious friendship group.

Parental relationships with professionals can be marred by ineffectual information sharing processes (Hodge & Runswick-Cole, 2008) and professional indifference to the emotional dimension of raising a child with disability (Woodcock & Tregaskis, 2006). I found that these barriers also negatively impact NTD siblings. At secondary school, especially, staff are often unaware of the existence of a sibling with ASD and the challenges this might bring. Even well-informed staff appear wary of asking questions, and unsure of how to best support NTD siblings. Consequently, NTD sisters can be unsure as to whom they should turn at times of crisis and feel unsupported.

Cridland et al. (2015) found that teenage NTD sisters mediate and advocate for their brothers with teachers. Conversely, I found that NTD sisters rarely spoke to their teachers about ASD or their siblings and never to discuss their siblings’ needs. This difference may indicate cultural differences between Australian and UK schools or reflect that, in my study, by secondary phase, NTD sisters report reduced daily contact with their sibling in school, or attend a different school altogether.

5.4 How do NTD sisters cope with, and adjust to, having a sibling with ASD?

5.4.1 Coping

Although emotion-focussed coping is considered less effective than problem focussed coping, child siblings are more likely than adults to adopt an emotion-focussed coping style (Angell et al., 2012; Orsmond, Kuo, & Seltzer, 2009; Petalas et al., 2009; Won et al., 2003) and have limited power and opportunity
to address their sibling’s disruptive behaviours. I found effective emotion-focussed coping strategies include playing sports, Reiki, pampering and listening to music. Less effective emotion-focussed coping strategies include crying, and disordered eating. In reality, NTD sisters benefit from addressing their stress and emotional upset with the most practical and positive strategies available.

I found further evidence that NTD siblings use problem-focussed coping strategies including moderating their siblings’ behaviour and distraction (Petalas et al., 2009). Some younger NTD sisters often respond to their siblings’ unwanted behaviours by shouting, arguing with their siblings and referring to their parents. Interestingly, I found that, in school, the same NTD sisters perceive themselves as more likely to take direct action, attempting to manage their sibling personally, or effectively removing themselves from situations. This supports previous findings that context is influential in determining the use of coping strategies (Frydenberg, 2004).

Others suggest that NTD siblings commonly compartmentalise their lives to reduce the unwelcome curiosity of peers and subsequent social disapproval (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that some NTD sisters restrict the time spent with their siblings, restrict their sibling’s access to certain places or activities and are wary with whom they share information, and whom they invite home.

Compartmentalising is a coping strategy designed to avoid cognitive dissonance but Thomas warns of “the negative psycho-emotional aspects of concealment” (Thomas 1999: 55). Even apparently confident and popular siblings fear either themselves, or their sibling, being ‘found out’ by peers. Hence the reticence reported by Ellie, Grace, and Rachel to be seen with their sibling in some social contexts. Others have a small, close group of friends that they trust or attend a
different school to the one attended by their sibling, thus reducing the potential for embarrassment in front of peers. Rhiannon, Polly, Bella, Harriet and Rachel also describe how holding positive cognitions about their siblings helps them face up to any negative judgements of peers.

My findings support those of Petalas et al. (2009) who found that inferred meaning is key in determining how well siblings cope with events. Appraisal-focussed coping strategies such as humour, acceptance and positive reframing are associated with effective coping (Stoeber & Janssen, 2011) and promote acceptance. I also found evidence that shared humour supports relationships and family cohesion (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012) and defuses tension.

Moyson and Roeyers (2011) found that acceptance is one of nine elements that determine sibling quality of life. Reflecting on their current situation and earlier lives, the adolescent NTD sisters in my study suggest that acceptance is central in enabling them to reframe negative elements and adopt a strengths’ based approach to their sibling and their own situation.

My findings are also supportive of acceptance being fluid, partial and context dependent, especially in mid-childhood (Petalas et al., 2009). The four youngest participants in my study tend to equate ‘fairness’ with ‘parity’ (Petalas et al., 2009; Sage & Jegatheesan, 2010). The five adolescent sisters are more understanding as to why they receive less attention and practical support than either their siblings or their peers (Dellve et al., 2000; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that the all of the adolescent NTD sisters in this study feel that their parents are doing the best they can. This suggests sisters are content if they believe themselves fairly supported and listened to by their parents. Even if this awareness comes only in retrospect, it is important in helping older NTD siblings reframe difficult times in
their childhood and overcome residual resentment or regret. This underlines the value of family-focussed thinking in promoting sibling wellbeing (Dellve et al., 2000) and of positive meaning in promoting acceptance (Moyson & Roeyers, 2011; Petalas et al., 2009).

Other appraisal focussed coping strategies evidenced in my findings include rationalising feelings of embarrassment and shame (Moyson & Roeyers, 2011; Petalas et al., 2009), positive reframing and identifying and celebrating ‘daily uplifts’ (Giallo & Gavidia-Payne, 2006) and using deterministic religious faith to think positively about experiences (Taunt & Hastings, 2002; Turnbull et al., 2006). When religious faith is shared by other family members it can also strengthen family cohesion (Walsh, 2006).

The three NTD sisters in mid-to-late teens perceive that they have become more positive over time and have developed more effective appraisal-focussed coping strategies. However, I found that two NTD sisters in mid-childhood also hold relatively positive views, whilst the oldest sister in this study still harbours some negative views about one of her siblings and the impact of her experience on her own development. Petalas, Hastings, Nash, Reilly, et al. (2012) found that adolescent siblings perceive that their situation has improved over time. I also found that even Rachel, who continues to experience considerable challenge, feels that her situation has improved from mid-childhood. This sense of being on an upward trajectory emboldens siblings to approach new challenges positively. Interestingly the four primary-age girls in my study also believe their situation will improve, suggesting they take wise counsel from older peers or their parents.

I found that significant negativity about one’s own sibling and life situation is uncomfortable for many NTD sisters as is maintaining apparent conflict between their own needs and those of their sibling. Cognitive Dissonance Theory
(Festing er, 1957) suggests that, having understood the lifelong nature of ASD, NTD siblings will seek to resolve psychological conflict by changing the ways they perceive their sibling and their own life situation. In support of this I found that some siblings normalise their sibling’s behaviour and their relationship (Angell et al., 2012; Cridland et al., 2015; Petalas, Hastings, Nash, Reilly, et al., 2012). Ambivalence also affords emotional distance from one’s sibling whilst appraising the implications for one’s own wellbeing (Opperman & Alant, 2003). Normalising of behaviours may also reduce cognitive dissonance and promote inclusion and acceptance (Culham & Nind, 2003). I found that some sisters ‘talk the talk’ of acceptance whilst struggling to fully accept their siblings. Bella and Polly boast of their siblings’ strengths and gloss over challenges. Although their mothers recount intense upsets, the girls themselves were only willing to share with me their positive cognitions, to identify and celebrate strengths. Although my study generally illustrates the benefits of positive thought as a coping strategy (Taunt & Hastings, 2002), I also found that strengths-based views can encourage the denial of unpalatable truths, including problems one’s sibling is likely to face in adulthood.

Risk appraisals, depending on context and informed by experience (Lazarus & Folkman, 1984) are clearly evident in my findings; Ellie can only enjoy her sister’s company safely away from peers. However, equally socially ‘popular’ Harriet, who fears for her brother’s very survival, is able to face down the ignorance of her peers. Meanwhile, Rachel, a young adult who in childhood suffered significant emotional hurt and distress as a result of her brothers’ behaviour struggles to trust her volatile younger brother.
5.4.2 Personal resilience

My findings generally support the assertion that NTD siblings develop personal resilience (Rossiter & Sharpe, 2001). Turnbull and Turnbull (1990) found that parents of children with disability describe the ‘gift’ their child’s exceptionality has conferred on their family. Similarly, I found that the three oldest teenage NTD sisters consider having a sibling with ASD as a ‘gift’, which they credit with making them more knowledgeable about ASD and indicating a particular career or path of study. The four oldest NTD sisters perceive that they are more caring and understanding of others and more emotionally mature and sensitive than their peers (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012; Stalker & Connors, 2004; Taunt & Hastings, 2002), as well as being closer to their siblings, and their mothers than they would otherwise be (Walsh, 2006). My findings are further evidence of personal and relational transformations (Scorgie & Sobsey, 2000) afforded by having a sibling with ASD. I found that by the time they reach ‘A’ level study and university, NTD sisters perceive that they have overcome the severe exam anxiety they experienced at GCSE. The practical and emotional networks of support spontaneously generated in response to exam crises are reminiscent of ‘hardiness zones’ (Debold, Brown, Weseen, & Brookins, 1999). These are relational support networks that have been shown to be instrumental in developing emotional and psychological resilience in adolescent girls.

Seeking social support is associated with enhanced resilience (McCubbin, McCubbin, Thompson, Sae-Young, & Allen, 1997). In line with previous research, I found that adolescent sisters report themselves as more likely to seek social support than when they were younger children (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that even teenage NTD sisters who dislike confiding in their peers look to them for instrumental support, perhaps
arranging to stay with friends when home life becomes difficult or co-opting them to co-supervise their sibling on trips.

5.4.3. Family resilience

My findings suggest that the concept of family resilience may be useful in understanding how family processes and beliefs support the adjustment of NTD sisters (Angell et al., 2012; Bayat, 2007; Walsh, 2006). NTD sisters perceive their coping capacity is enhanced by attributes previously associated with resilient families (Walsh, 2006, p. 131).

1. A shared, socially-constructed family belief system that:
   i. makes meaning of adversity;
   ii. affirms strength and maintains a positive outlook.

I found that sisters talk proudly of their close, strong family unit and the challenges that they have overcome. They acquire ‘learned optimism’ (Walsh, 2006) from their families. They value their mothers’ positive outlook and strength of character, and, by adulthood, adopt strengths-based views, embracing the ‘gift’ of a sibling with ASD. Positive beliefs are generalizable to their own situation and not restricted to ASD and the child with disability. The families in my study display familistic behaviours and values (Updegraff et al., 2002) and they advocate family loyalty and are supportive of all their children. I also agree with previous findings (Dellve et al., 2000) that a balanced focus on the welfare of the whole family appears to promote adjustment.

2. Positive organisational features including flexibility, connectedness and social and economic resources.

I found that NTD sisters appreciate the efforts that their parents, and supportive relatives make for them. They feel close to their mothers and other key adults and appreciate the support they provide- hosting sleepovers, facilitating hobbies and providing respite and trips away.
Effective communication that ensures clarity, open emotional expression and collaborative problem solving.

NTD sisters appreciate knowing that they can “talk about anything” (Polly 16yrs: brother J, ASD and MLD, 14yrs; brother L, ASD, 8yrs) to their mothers and often confide in her. Many describe their mothers as their best friend.

I found that NTD sisters consider parental behaviours, beliefs and values as highly influential in shaping coping, acceptance and adjustment (Angell et al., 2012; Benderix & Sivberg, 2007; Dellve et al., 2000; Updegraff et al., 2002) and sibling relationships (Sage & Jegatheesan, 2010). NTD sisters are keenly aware of their mothers’ views on disability, their sibling and associated topics. As they get older they increasingly talk of shared ‘familistic’ values; strong, enduring commitment to family, family love and the family task of supporting the child with ASD.

Having a large family has been found to dilute the negative effects of having a sibling with ASD and provide alternative sources of support (Angell et al., 2012; Kaminsky & Dewey, 2001). One might therefore assume that sole NTD siblings experience increased difficulty adjusting to their sibling with ASD. However, the accounts of the four older NTD sisters in this study suggest that the relatively intense nature of the relationship with one’s only sibling and other family members including a strong mother-daughter bond means that they have also experienced an intense, truncated adjustment. Cognitive dissonance theory (Festinger, 1957) would also suggest that strong familistic values and cognitions also reduces sibling dissonance. Such beliefs in my study include ‘we look after each other’, ‘we adapt’, ‘we are strong’, ‘we work it out’, ‘we cannot be treated equally but we can be treated fairly’, ‘my mother is my best friend’. The families in my study also work creatively to support their NTD daughters, often relying
on extended family to do so. Addressing NTD sisters’ needs in this way also reduces cognitive dissonance and would be harder to achieve in larger families.

5.4.4 Mother-daughter bond

My study provides further evidence that siblings primarily learn about ASD, and managing ASD, from watching and talking to their mothers (Angell et al., 2012; Dellve et al., 2000). They credit her as their most useful and trusted source of information and advice. Although age tends to be the biggest factor in determining current coping style, (Lade, Frydenberg, & Poole, 1998), I found girls openly admired their mothers’ coping style and professed a desire to emulate her.

In this, my findings offer tentative support for the suggestion that the mother-daughter bond is enhanced, rather than impeded by having a sibling with ASD (Dellve et al., 2000) suggest that and my findings support this. In families with multiple NTD siblings, the siblings support each other (Angell et al., 2012). My findings suggest that sole NTD sisters look to their mothers for support and, in turn, attempt to comfort and support their mothers. Mothers in my study make a conscious effort to make time for their NTD daughters.

5.4.5 Adjustment

My findings support the three stage model of adjustment proposed by Dellve et al. (2000):

- Involvement: NTD siblings are involved with their siblings but see their needs and desires as mostly separate and often competing. I found evidence of irritation, frustration and embarrassment characteristic of this stage.

- Integration: NTD siblings seek to harmonise experiences, emotions, family beliefs and formally acquired knowledge of ASD, whilst balancing their own needs. I found that the four adolescent
and adult NTD sisters perceived that they had increased empathy and reduced resentment towards their sibling and parents.

- **Reconciliation:** mature and confident understanding and acceptance of what ASD means to their family, their sibling and themselves.

I found that as they mature, NTD sisters positively accept their sibling, celebrating rather than tolerating their situation. They develop a *cohesive positive identity* reconciling home and social worlds. Verté et al. (2003) found that positive self-image is vitally important in positive adjustment. I found NTD sisters enjoy ‘giving back’ to the ASD community and supporting their family and see these behaviours as being of their own choice. They celebrate mutuality in their sibling relationship and the benefits of close family ties. This final stage of adjustment includes personal and relational transformations (Scorgie & Sobsey, 2000)

Adjustment can be understood with reference to cognitive dissonance theory (Festinger, 1957). Mid-childhood sees highest levels of dissonance between familial and sibling loyalty and a heightened desire for acceptance by an ill-informed and unpredictable peer group. Living with dissonance is psychologically uncomfortable. Emotion-, problem,- and appraisal-focussed coping strategies help NTD sisters manage dissonance in the short-term, but in the longer term cognitions, about sibling, family, and the social world need to be brought into line. NTD siblings, sometimes consciously, work to reduce dissonance by finding ways to accept and admire their sibling, enjoying intrinsic satisfaction in their sibling relationships and synchronising their home and social lives. The continua of relatability, acceptance and cohesive positive identity reflect this process.

It can be hypothesised that particularly strong family-focussed cognitions, such as a fear their sibling may die, religious beliefs or being twins, may promote consonance and subsequent adjustment. Conversely, heightened dissonance,
caused by poor relationship history or a yearning to belong to a particularly ‘cool’ peer group, may impede the adjustment process. However, the present data cannot inform us about the relationship between these variables.

5.5 How do NTD siblings perceive their relationships with brothers and sisters with ASD? What do they value? What future relationships do they anticipate?

My findings are consistent with those of recent qualitative studies. NTD sisters hold mixed, sometimes contradictory views about their sibling relationship (Angell et al., 2012; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Sisters express love and warmth even in the face of considerable challenge (Angell et al., 2012; Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). Moreover, sisters believe that their sibling loves them and they value this love. Feelings of sympathy and empathy (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009) and tolerance and forbearance (Moyson & Roeyers, 2011; Petalas et al., 2009) are also evident in my findings. NTD sisters also report feeling negative emotions of anger, irritation and frustration (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012) especially in mid-childhood.

As the sole NTD siblings in their families, the NTD sisters in my study had no personal experience of ‘normal’ sibling relationships, but still, variously considered their sibling relationship as normal (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012), worse than normal (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012) and better than normal (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012). NTD sisters perceive their siblings with ASD as being kinder, more open to a
relationship and less likely to tease them than NTD boys of that age (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012) and their siblings’ relative social innocence means that they bicker less than ‘normal’ sibling pairs. NTD sisters also increasingly perceive themselves as benefitting from their siblings’ talents including their willingness to proof read coursework and their excellent IT skills.

Petalas, Hastings, Nash, Reilly, et al. (2012) found that adolescents sometimes feel that they have lost the closeness they enjoyed with their sibling in earlier childhood. However, the retrospective accounts of adolescent NTD sisters in my study suggest that, for them, mid-childhood is a time of greater estrangement. Mothers recall young childhood as a time when their NTD daughters were unencumbered by embarrassment and happy and accepting of their siblings. Similarly, adolescent NTD sisters increasingly devise and share hobbies with their sibling. The difference in findings may reflect the nature of ASD in my study, or gender differences including increased fear of social disapprobation for girls in mid-childhood and the emphasis girls place on maintaining relationships (Dellve et al., 2000; Orsmond & Seltzer, 2000).

5.5.1 Continuum of Relatability

Although NTD sisters sometimes complain that their siblings disregard personal boundaries and can pester them relentlessly, too little interaction is equally disappointing to them (Petalas, Hastings, Nash, Reilly, et al., 2012). My findings provide further evidence of the value girls place on their sibling relationships (Dellve et al., 2000) and suggest that positive interactions and shared fun are highly valued (Angell et al., 2012; Benderix & Sivberg, 2007; Diener et al., 2015; Mascha & Boucher, 2006; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). NTD sisters increasingly consider their sibling to be their friend (Angell et al., 2012; Petalas et al., 2009), working to develop shared interests. In line with previous findings, I found shared interests include movie
watching, gaming and climbing (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that NTD sisters enjoy shared activities partly for the increased closeness that they bring (Angell et al., 2012; Diener et al., 2015). Diener et al. (2015) found that the artificial introduction of activities that showcase the relative strengths of children with ASD changes the dynamic of sibling relationships, making roles more equal and reciprocal. Given evidence that close sibling relationships result in better mental health for NTD siblings (Gass et al., 2007), working to build a *mutually satisfying relationship* is an effective coping strategy and supports longer term adjustment.

Research suggests that the severity of ASD negatively affects sibling relationships (Angell et al., 2012; Benderix & Sivberg, 2007; Benson & Karlof, 2008; Dellve et al., 2000; Dodd, 2004; Petalas, Hastings, Nash, Reilly, et al., 2012). However, I found that is the NTD sister has a clear and valued role in supporting her sibling she can appear highly motivated and to gain satisfaction from their relationship. The threat posed to sibling relationships by *maladaptive behaviours* (Meyer et al., 2011) is more evident in my findings. Irrespective of severity of diagnoses, siblings with ASD can experience mental health crises. The extreme behaviours associated with these crises strain relationships. My findings also support the importance of relationship history. (Petalas, Hastings, Nash, Hall, et al., 2012) As well as generating a certain emotional caution and mistrust NTD sisters sometimes find it difficult to ‘let go’ of residual resentment.

Brody, Stoneman, and MacKinnon (1982) suggest mutually acceptable roles are pivotal in developing satisfying sibling relationships and my findings underline the importance of acceptable roles and reciprocity. Although relationships are more asymmetrical than normal, when one sibling has ASD (Stoneman, 2005), I found that sibling relationships are not completely one-way. This suggestion is supported by other recent research with children with ASD (Petalas et al., 2015).
I found that some siblings with ASD have a sense of family cohesion, show affection, regret the distress that they cause and reach out to their sisters when perceiving that support is needed.

Stoneman, Brody, Davis, and Crapps (1989) suggest that such sibling relationships become more asymmetrical over time, yet Diener et al. (2015) show how providing contexts in which the sibling with ASD can excel, makes roles and relationships more balanced. My research suggests that sibling pairs that include young adults with HFA and Asperger’s, become increasingly reciprocal. The siblings with ASD in my study experience significant anxiety at secondary school but go onto courses of study and careers that make them happier, less anxious and more able to engage with their sibling. Additionally, the parents in my study are able to provide ongoing emotional, practical and financial support, reducing the burden of care on NTD siblings. If circumstance’s change, the balance in sibling relationships may change again.

5.5.2 Carer role

My findings suggest that NTD sisters perceive a heightened caring responsibility towards their sibling, a finding supported by the literature (Angell et al., 2012; Benderix & Sivberg, 2007; Cridland et al., 2015; Dellve et al., 2000; Diener et al., 2015; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). The responsibilities identified by Angell et al (2012) are evident in my findings "...responsible caregivers, siblings’ helpers, entertainers when their siblings needed to be redirected or occupied, “rescuers” when their siblings were aggressive, and parents’ helpers” (p. 4).

Research with the families of children with LD found that daughters as young as three years old copied their mothers’ behaviours towards their sibling (Dyson, 2010). Harriet adopts extensive caring responsibilities despite being the
youngest participant in my study. Her brother has additional health and mobility needs and is non-verbal; she provides personal and nursing care, helps both her mum and her brother, entertains him for hours on end and describes a range of behaviours management strategies to ‘rescue’ his behaviours. Subscribing to the ‘familistic’ values of loyalty and family support as well as acknowledging that her brother has different and greater needs appears to support her adjustment. My findings therefore demonstrate the link between adopting a carer role and positive sibling adjustment (Midlarsky et al., 2008).

Although caring responsibilities increase with age (Cridland et al., 2015), Benderix and Sivberg (2007) suggest that siblings in mid-childhood are most likely to find additional responsibilities burdensome. Cridland et al. (2015) also found that feeling valued enhances satisfaction about one’s caring responsibilities. I also found that motivation and perceived capacity play an important part in shaping the views of the carer role. Rachel, aged 19, feels unsure of, and unrewarded by, her younger brother and is wary of taking responsibility for him in case she fails. Harriet, aged 10, feels valued by her brother and her mother and relishes her responsibility.

In contrast to research in Israel (Barak-Levy et al., 2010), I found that parents are more concerned than their NTD daughters that caring responsibilities will prove onerous. Cultural differences and severity of ASD might explain this apparent difference in findings. Higher socio-economic status has also been linked to lower levels of sibling responsibility in families of children with LD (Damiani, 1999). All of the families in my research have at least one parent in paid employment and own their own homes. Choosing, rather than feeling compelled, to take on caring responsibilities, may be an important factor in determining relationship satisfaction.
5.5.2.1 Social carer role

Most of the NTD siblings in my research have Asperger’s or HFA and, consequently their sisters provide high levels of social support and mentoring. Using Angell et. al.’s (2012) dichotomy they are ‘sibling helpers’. I found evidence to support the roles of sole friend, and play leader and entertainer (Petalas et al., 2009) and social mentor and minder, mediating between their siblings and peers (Angell et al., 2012; Cridland et al., 2015; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). Stalker and Connors (2004) find NTD siblings of children with LD are uniquely placed as social carers, mediating between their sibling and “the World of normals” (p.227). My findings suggest that this is an important role when one’s sibling experiences impaired social understanding and communication. I found that NTD sisters frequently act as coach and confidante to their siblings. They are ideally placed to understand and interpret their sibling’s needs and intentions and the nuanced, shifting social worlds that they both inhabit. I also agree that NTD sisters protect their siblings from bullying (Benderix & Sivberg, 2007; Cridland et al., 2015; Diener et al., 2015; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). They maintain a protective yet unobtrusive watch, embedded as they are in the school-yard or social media site, far more effectively than any parent. They provide wise counsel, second guess parental wishes, debrief anxiety-inducing situations and brief for future challenges. They ease their siblings’ social path, supporting friends in how best to interact with their sibling and fielding insensitive queries from peers.

As with previous research, (Dellve et al., 2000; Petalas et al., 2009) I found NTD sisters sometimes prioritise their sibling’s needs to the detriment of their own. I find this is most often a school-based problem, and specifically a feature of the primary phase when siblings share a school playground. In the absence of parents, NTD sisters assume greater responsibility for their siblings. Neglecting
one’s own social networks at such an age threatens future relationships and resilience (McCubbin et al., 1997). This suggests that, at times, NTD sisters’ own wellbeing could potentially be compromised by their caring responsibilities (The Children’s Society, 2013).

5.5.3 Future relationship

My research supports previous findings that NTD siblings have concerns about the future (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Reilly, et al., 2012). They worry about their sibling’s health, independent living arrangements and social inclusion. Unlike other groups of NTD siblings (Petalas, Hastings, Nash, Reilly, et al., 2012), the NTD sisters in my study all anticipate maintaining their sibling relationships into adulthood, although the extent and nature of the anticipated relationship varies (Angell et al., 2012; Dellve et al., 2000). They also hope to fulfil any caring responsibility and pursue their own ambitions (Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012) including university study in distant cities and foreign travel.

Benderix and Sivberg (2007) and Petalas, Hastings, Nash, Reilly, et al. (2012) suggest that negative relationship history inhibits close adult relationships. The NTD sisters in my study seem able to ‘forgive and forget’ difficulties in early teens, mid-childhood and before. However, sibling relationships that are strained by the time one or the other sibling leaves home seem more likely to remain problematic in adulthood.

My analysis is also congruent with previous findings that show that attitudes to future caring responsibility is influenced by the perceived availability of alternative sources of support (Benderix & Sivberg, 2007; Dellve et al., 2000; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that in families of children with Asperger’s or HFA, where parents can continue to provide practical care, the primary anticipated caring responsibility is that of social guardian and
mentor and NTD sister’s perceive that the nature and degree of the responsibility will remain as current.

5.6 What supports, or could support, the wellbeing of sisters growing up with a sibling with ASD?

My study also supports recommendations from existing research that NTD siblings can be further supported by a raft of well-planned and judiciously executed direct and indirect interventions. However, it is important to note that outside interventions implemented to bolster wellbeing, are less effectual in families with poor internal cohesion (Rivers & Stoneman, 2003). Adolescents may also be resistant to receiving professional support (Cridland et al., 2015). Appropriate and comprehensive assessment of context, need and desired outcome is indicated to ensure support is effectual and resources are used wisely.

5.6.1 Family matters

My findings are congruent with those of previous research suggesting that parents, primarily mothers, are NTD siblings’ primary source of information and support (Angell et al., 2012; Benderix & Sivberg, 2007; Moyson & Roeyers, 2011). NTD sisters also feel supported by being able to talk through questions or concerns with their mothers (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011) reinforcing the suggestion that effective communication with parents supports NTD siblings’ psychological adjustment (Petalas et al., 2009). Parents, primarily mothers also convey key values and beliefs that are powerful in promoting wellbeing and resilience (Angell et al., 2012; Bayat, 2007). An emphasis on building strong family cohesion, adaptability and solidarity (Angell et al., 2012; Bayat, 2007; Dellve et al., 2000) appears to bolster wellbeing and resilience. Mothers are also instrumental in modelling strengths-based views,
positively reframing experiences and facilitating their daughters’ effective emotion and problem-focussed coping strategies. My findings underline the importance of supportive extended family and friends, who also validate beliefs and values and provide emotional and practical assistance (Moyson & Roeyers, 2011; Opperman & Alant, 2003; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that NTD siblings are predominantly supported by female members of their maternal extended family members and maternal friends; grandmothers, aunties and friends of their mothers. Other research (e.g. Boyd, 2002) shows that mothers with children with ASD are successfully supported by informal social support networks. My findings suggest these networks also support their NTD daughters.

My findings echo those of previous research with families of children with generic, ‘invisible’ LD. Dyson (2010) found that extended family members can fail to understand the nature of the challenge of raising a child with disability and unsympathetic relatives are a net source of stress irrespective of any practical support they offer. I found that NTD sisters also feel uncomfortable and disloyal when receiving support from extended family who seem to favour them above their sibling or who criticise their parents. Conversely, close friends who share and support key family values, commitments and beliefs, become ‘virtual family’ members, providing much-valued support.

I found further evidence of the benefits of family-focussed coping in supporting the adjustment of NTD children (Dellve et al., 2000). Parents are conscious of the need to support their NTD daughters’ social inclusion and, for example, were more concerned than their daughters about restrictions on sleepovers and reduced spontaneity in inviting friends home. Supportive, extended families play an important part in supplementing NTD siblings’ social lives.
My findings also support previous research that suggests that NTD siblings are sensitive to parental stress (Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Hall, et al., 2012). Some NTD sisters are wary of sharing negative emotions with their parents (Benderix & Sivberg, 2007). Crises for the child with ASD can stretch practical and emotional resources to breaking point. I found that parents do not always realise how sensitive their NTD daughter is to their stress. I found that NTD sisters can become very concerned with the welfare of other family members (Dellve et al., 2000). Domestic disturbances often occur at times of the day when NTD sisters are at home or most need parental support in dealing with their sibling and their own emotional response (Petalas et al., 2009).

Conversely, resilient and well—supported parents are more practically and emotionally available to their NTD child (Orsmond & Seltzer, 2009; Petalas, Hastings, Nash, Hall, et al., 2012).

5.6.2 Knowledge and understanding

My findings underline the positive function of knowledge and understanding in sibling adjustment (Dellve et al., 2000; Frydenberg, 2008; Petalas et al., 2009; Sage & Jegatheesan, 2010). NTD sisters perceive that they learn most from observing and talking to their mothers, and from their own trial and error with their siblings. However, my findings also support suggestions that formal instruction about ASD (Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012) and enhanced behaviour management strategies to supplement their observational and deductive learning would prove welcome and useful(Angell et al., 2012; Benderix & Sivberg, 2007; Dellve et al., 2000; Miller, 2001; Petalas et al., 2009).

Frydenberg (2008) found that teaching adolescents effective, problem-focussed coping strategies works best in families where they can express concerns and feel valued by their parents. I found that adolescent NTD sisters attribute living in families where adults talking openly on a range of topics with encouraging
them to share their own concerns and ask questions. My findings suggest that open discussions about family pressures, and, very importantly, family resilience might be useful in reassuring NTD sisters about the family's capacity to survive crises.

I found that NTD sisters are highly motivated to understand and support their siblings' behaviours (Benderix & Sivberg, 2007; Dellve et al., 2000). Parental, peer, and professional support is advocated to develop new coping strategies when existing ones become ineffectual or self-defeating (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012).

I found that older NTD sisters believe that their understanding of ASD has increased with age and personal experience (Angell et al., 2012; Cridland et al., 2015; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). They also underline the importance of relevant information, responsive to NTD sibling’s life-stage and current needs (Petalas et al., 2009). Girls in mid-childhood and early teens felt that they would especially benefit from creative ideas to facilitate problem-focused coping; developing scripts to share with peers; opportunities to safely share negative emotions and manage stress; support to positively reframe experiences and identify strengths (Diener et al., 2015). Teenage girls and young women have legitimate questions about their own personality traits, the heritability of ASD, and the lives of adults with ASD. My research supports earlier findings (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011; Petalas et al., 2009) that adolescents and young women sometimes avoid discussing sensitive topics with their parents for fear of upsetting them. This includes information about what is happening to, and for, their sibling. NTD sisters in this study suggest that information of this nature has helped reduce their anxiety and support their emotional wellbeing. However,
some raised concerns about confidentiality of information pertaining to the person with ASD.

5.6.3 Peer support

Previous research has established that NTD siblings enjoy and value peer support (Angell et al., 2012; Benderix & Sivberg, 2007; Cridland et al., 2015; Dodd, 2004; Moysen & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). I found that NTD sisters perceive that organised peer support enables them to learn from others and find friends who implicitly understand their situation and in whom they can more freely confide. Peer support groups are also credited with helping NTD sisters feel less isolated, finding humour in their situations, and appreciating that, usually, situations improve. I found that children in mid-childhood enjoy social activities and days out with peers. Older teens appreciate being able to talk with like-minded friends with similar experiences. My findings support those of Petalas, Hastings, Nash, Reilly, et al. (2012) who found that some NTD siblings are wary of talking to ‘normal’ friends about their siblings. Children in mid-childhood are less likely than teenagers to seek social support (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012), suggesting that groups for children in mid-childhood are especially valuable.

Peer support can, however, be problematic. It is difficult to organise sessions at times and in venues to suit everyone. The gender, age and personality mix of the groups means that some NTD siblings simply do not ‘gel’ with others. They may have limited social skills, lack confidence or have atypical interests that set them apart from other siblings. At times of particular crisis, peer support can fall short. Rachel describes a time when she was so angry, and believed her life situation so uniquely difficult, that she felt even other siblings of ASD would not be able to understand or support her.
Petalas, Hastings, Nash, Reilly, et al. (2012) suggest online forums could address the need for flexible peer support. Angell et al. (2012) found NTD siblings in the US value online peer support groups. There are some online groups for siblings of children with additional needs in the UK. (e.g. www.siblingsupport.org) but the NTD sisters and parents participating in my research are not familiar with these and all professed themselves wary of online and social media contact with unknown and untrusted peers. Online support remains a flexible and potentially valuable means of support but parents and children would need to be reassured of its safety, perhaps through the brokerage of trusted organisations, or by restricting online support to a local network of siblings who also meet in person.

I found that NTD sisters enjoy using their experiences to volunteer and support others (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012). In doing so, they are reminded of their own knowledge and resilience. ‘Giving back’ to the community contributes to positive acceptance and to a cohesive positive identity. Supporting other siblings and children with ASD validates experience and generates a sense of importance and value (Angell et al., 2012). Angell et al. (2012) describe how US siblings write books and give public talks about their experiences. They celebrate their ‘journey’ to well-adjusted adulthood and champion the therapeutic benefits of sharing experiences. Although the NTD sisters in my research gain enjoyment and satisfaction from supporting their peers, theirs is a quieter, more private competence. Some NTD siblings in the UK might also benefit from more public celebration of their successful adjustment, affirming to younger siblings that ‘things really do get better’.

NTD daughters appear to benefit from informal social support just as their mothers do (Boyd, 2002). Research with the normal population suggests peer group is especially important to adolescent girls (e.g. Newman, Lohman, & Newman, 2007). Any assessment of need and support should therefore include
social context and current informal social support. Socio-grams (Banerjee, 2012) might prove a useful complement to assessments of family context and support advocated by existing research (Aldridge & Becker, 1999; Angell et al., 2012; Turnbull et al., 1984).

5.6.4 Professional support: applied psychologists

In the UK, the foci and role of educational and clinical psychologists have converged in recent years (Farrell et al., 2006). Applied Child and Educational Psychologists (CEPs) should use appropriate psychological theories and research to better understand and support the wellbeing of children and young people in general, and to provide focussed interventions for identified groups and individuals in crisis. Professional focus might appropriately be with individuals, with systems, including family and school, and at community and societal level:

“...applied psychologists are required to ...provide an integrated and coherent perspective of complex environments (e.g., school, homes...etc.), the complex problems and situations which occur in such environments ...and the complex needs of people which results from such problems”

(Cameron, 2006, p. 292)

The complex nature of this particular phenomenon has been underlined by this research and any professional response should be appropriate and measured. This section is not therefore intended to provide a prescriptive menu of interventions, appropriate in all situations. Rather, it assumes prior and ongoing assessment of personal, familial and social factors, and discussion of desired outcomes. Family–centric approaches, such as Team around the Family (Limbrick, 2004) help ensure both the needs of the child with ASD, and those of other family members, are considered. Using examples from my findings I will
illustrate how the “innovative and creative application of psychology” might promote the wellbeing of NTD siblings (Cameron & Monsen, 2005, p. 286).

Research in this field has previously adopted a family systems approach (Angell et al., 2012; Cridland et al., 2015). The important interplay between home and school systems in understanding children’s behaviour is clearly established in child and educational psychology practice (Dowling & Osborne, 1994) and is evident in my findings. My study shows that NTD sisters variously present with profound distress, exam anxiety, refusal to speak or eating disorders that appear symptomatic of shortcomings by school and home to communicate effectively, or to appropriately address the young person’s needs. In addition to any short-term therapeutic intervention for the young person, the role of the CEP would be to help adults in both systems understand how they might be contributing to the situation and how they might support the young person’s needs by affecting systemic changes.

My study upholds previous findings that skilled and sensitive professional intervention has a place in supporting NTD siblings (Angell et al., 2012; Benderix & Sivberg, 2007; Petalas, Hastings, Nash, Reilly, et al., 2012). Talking therapies are especially indicated to help manage anxiety around exams and times of crisis for the child with ASD, when NTD sisters feel that they have no-one else to talk to (Petalas et al., 2009). My findings suggest pre-teenage girls might benefit from learning to manage rejection and hostility from their sibling and maintaining a healthy and balanced focus on their own needs. Rachel says she does not blame her parents or siblings for earlier difficulties but still lacks confidence and trust in her sibling relationship, and fears over-burdening her mother. Help to address unhelpful thoughts and opportunities to work through historic resentment and concerns in a safe manner, are also indicated.
I found that positive reframing promotes acceptance and adjustment (Angell et al., 2012; Moyson & Roeyers, 2011). However, I suggest there may be a need to redefine ‘strengths’ for adolescents who confuse realism with negativity. At sixteen, Polly was unable, or unwilling, to discuss the future because of the very real challenges it presents her family. Some NTD siblings might choose not to think about the future as this is frightening and negative. For Polly, positivity borders on denial. Focussing on strengths at the expense of open and frank communication undermines effective coping (Frydenberg, 2008).

Although NTD sisters and their parents say that they want more professional psychological support, some, who had accessed talking therapies through CAMHS, were left feeling that support was ineffectual or ‘too little, too late’. Better assessments to ascertain the level and nature of need, and timely and preventative interventions, are required to ensure more appropriate and timely interventions. Psychological interventions, including cognitive behaviour therapy (NICE, 2010, 2014) and mindfulness (e.g. Hofmann, Sawyer, Witt, & Oh, 2010), can reduce anxiety. Parents and sisters in my study are comfortable with the concept of group-based interventions. These require fewer resources and have been shown to be useful in promoting knowledge and positive self-image (Smith & Perry, 2005), preventing the development of longer term mental health issues (Gillham et al., 2006) and facilitating positive reframing (Garland, Gaylord, & Park, 2009). Online therapeutic interventions can be both efficacious and easy to access (Spence et al., 2011) which might prove especially useful for this population, if families can be assured of the confidentiality and security of e-interventions.

Most NTD sisters in my study anticipate enjoying an adult relationship with relatively independent siblings. However, some parents doubt their child with ASD has the capacity to live independently but are wary of discussing ‘private
matters’ about their child with ASD with their NTD child. This discrepancy may be explained by previous research that found NTD siblings of children with HFA or Asperger’s may underestimate their sibling’s future support needs, whilst parents may be overly pessimistic (Rivers & Stoneman, 2003). Parents often need support to discuss ASD with their normally developing children (Crotzer, 2008). Families might benefit from tools, including person-centred planning (e.g. Sanderson, Goodwin, & Kinsella, 2014), that allow families and friends to make workable plans for the future.

I also agree that effective support and behaviour management of children with ASD is fundamental to the wellbeing of NTD siblings (Benderix & Sivberg, 2007; Dellve et al., 2000). Benderix and Sivberg (2007) suggest that home-based behavioural interventions exacerbate family stress and argue for short-term placements for children with ASD to address behavioural concerns. Those parents in my study who have been offered respite are reluctant to send away their children with ASD. One solution proposed by a mother in my study, might be to offer short-term residential interventions with the option for families to stay on-site.

There is a clear role for applied psychologists in devising and delivering, or training others to deliver, programmes of information about ASD and behaviour management for siblings and others; family-focussed approaches, such as Team around the Family to assess and support family needs; person-centred planning to support children and families; socio-grams to capture NTD children’s social contexts.

5.6.6 Young carers

My research confirms that NTD sisters adopt caring responsibilities and found that some NTD sisters identify themselves as young carers (Aldridge & Becker, 1999). I suggest this is a helpful association, as it acknowledges their additional
caring responsibilities and the potential impact on educational and emotional development. There are also additional local peer-support opportunities for young carers (http://www.carersuk.org). Research suggests that young carers are best supported by a combination of formal and informal support. Gray and Robinson (2009) found that young carers benefit from peer groups, forums and opportunities for socialisation with peers, a key worker to advocate for their needs and provide emotional and psychological support and the raising of awareness of young carers in schools. Gray and Robinson (2009) suggest that online and DVD training is especially useful for staff training to mitigate for fluid staffing in schools and any reluctance to release staff during the school day. These recommendations are fully compatible with my own research.

I found some NTD sisters live constantly with the knowledge of their brother’s or sister’s critical health issues and, subsequently, experience additional worry for sustained periods of time. This can have negative long term psychological consequences (e.g. Fleary & Heffer, 2013). Parents and professionals should consider ways of supporting NTD siblings to come to manage these concerns. Some children with ASD are likely to need high levels of support into adulthood. In such cases, some NTD sisters worry that their future caring responsibilities might limit their own life choices and opportunities. In one such family, parents have been pro-active in identifying future residential placements, openly sharing the details of this plan with their NTD daughter. In line with previous research (Petelas, Hastings, Nash, Reilly, et al., 2012), my findings suggest open discussion helps siblings prepare for the future.

5.6.5 Professional support: schools

My findings suggest effective communication between home and school is important to assure the wellbeing of NTD siblings. In the first instance, school
staff should be made aware that pupils have siblings with ASD, and informed of any crises at home. There is need to clarify ethical considerations and protocols for communicating sensitive family information between home and school. Where is the line between privacy of the child with ASD and informed pastoral care for the NTD sibling who lives in a challenging family context? What is the process by which relevant information is updated and shared with key staff? My study suggests this may be of particular issue at secondary phase due to the larger number of staff and reduced direct contact between parents and staff. There is an increased risk of physical or verbal aggression at home (Benderix & Sivberg, 2007) and increased likelihood of bullying from peers (Petalas, Hastings, Nash, Reilly, et al., 2012) and school staff should be vigilant for apparent unhappiness, anxiety or distress in NTD siblings especially at times of domestic crisis or during the exam period. My findings reinforce the call for awareness raising amongst school staff and pupils about ASD and the potential impact of ASD on siblings (Petalas et al., 2009).

NTD sisters envisage a role for schools in providing readily accessible pastoral support, facilitating peer groups, and providing counselling and informed advice at times of crisis. Some NTD siblings would benefit from support to manage and respond to classmates’ and peers’ reactions to ASD. (Angell et al., 2012; Petalas, Hastings, Nash, Reilly, et al., 2012; Sage & Jegatheesan, 2010) Some of the youngest girls in my research asked for formal explanations of ASD or struggled to find terms to discuss their experiences. Language to explain ones’ experiences and needs is useful to access peer support and counselling. My findings suggest that NTD sisters in the last 18 months of primary education might benefit from programmes to enhance their transition to high school, devising ‘scripts’ for their new friends’ queries and preparing them for any unkind and ill-informed comments from others.
I found that NTD sisters face emotional and practical challenges when revising for, and sitting, exams. These challenges can trigger considerable anxiety and GCSE exams can be a time of particular crisis. Identifying and moderating exam stress is important for pupil wellbeing (e.g. Putwain, 2008) and school staff are ideally placed to assess and support needs in this respect.

Some NTD sisters strive to be behaviourally and academically ‘good’ (Angell et al., 2012; Moyson & Roeyers, 2011; Sage & Jegatheesan, 2010). For many this is a positively perceived attribute but it can become another source of anxiety. In extreme cases, perfectionism masks underlying feelings of low worth. Perfectionism is significantly more prevalent in girls, can precede eating disorders and poses a threat to longer-term mental health (Flett, Hewitt, Oliver, & Macdonald, 2002). Girls who set unrealistically high expectations for themselves can be supported with help to set realistic and attainable goals; break down overwhelming tasks; focus on one activity or task at a time; understand everyone makes mistakes; view mistakes as learning opportunities; be realistic about possible outcomes (Stoeber & Janssen, 2011).

5.7 Future research

This is a case study and it would be highly appropriate to replicate this research with other groups of sole female NTD sisters of similar ages in the UK or internationally. This would indicate which themes and findings might be generalisable to wider populations. Similarly, replicating this research with other groups, including NTD brothers and mixed gender groups, would indicate the findings that are influenced by gender of NTD sibling.

Almost all siblings with ASD in my study are male and research should be mindful of the gender mix of sibling pairs (Orsmond & Seltzer, 2000; Stoneman, 2005). Further exploratory research with NTD brothers, and same sex sibling pairs is therefore indicated.
NTD sisters’ experiences and perceptions change over the course of childhood and adolescence and adjustment is a gradual process. Retrospective accounts are useful but can be unreliable. Longitudinal studies with NTD siblings are indicated in their own right and would help check the reliability of existing retrospection-based findings.

My findings suggest that the experiences of sole NTD sisters are particularly intense and adjustment may be easier for older NTD sisters. Further research is indicated into family factors, including NTD sisters with multiple NTD siblings, and more focused research on the influence of birth order. Further research to illuminate the cultural and social context of NTD sibling experience is also indicated. A systems approach that explicitly references family, school and other social influences may be particularly useful in separating the phenomenon from the contexts in which NTD siblings live.

This research suggests that NTD sisters primarily learn from, and are supported by, their mothers even when their father is the primary at-home carer. Female relatives and friends supplement this support. The importance of extended family and wider support networks is evident in my study. Future research is needed to understand support networks, perhaps gathering perspectives from other members of the support network, and exploring the support relationships of NTD brothers. Research might usefully explore the experiences of NTD siblings with limited support networks or reduced choice about the caring responsibilities that they adopt.

My own findings and those of recent research (Diener et al., 2015) show how NTD sisters’ perceptions of the relative strengths of children with HFA and Asperger’s helps build more reciprocal sibling relationships in adolescence. Pilowsky et al. (2004) found siblings of nonverbal children experience greater adjustment difficulties. Further research is indicated with NTD sisters of less
able, non-verbal children with ASD to explore their perceptions and the utility of a strengths-based approach in such cases.

My findings suggest that talking therapies, group and peer interventions might prove efficacious. Others suggest the need for intervention studies to ascertain the relative benefits of different support for NTD siblings (Angell et al., 2012; Smith & Elder, 2010). Further research is needed to refine and test recommended interventions and to clarify which groups are most likely to benefit from interventions.

Further research is indicated to ascertain professionals’ awareness of the needs of NTD siblings and other barriers that may impede professionals’ understanding and support of NTD siblings.
Chapter 6: Conclusion

6.0 Overview

In this section I summarise my findings and reflect on the research process. Finally, I reiterate the contribution of this research to theoretical, empirical and applied practice. I reflect on the limitations of this research and summarise the contribution to knowledge.

6.1 Summary of findings: What are the experiences and perceptions of NTD sisters growing up with siblings with ASD?

What do NTD sisters perceive are the positive and negative aspects of growing up with a CYP with ASD?

Girls in mid-childhood have ambivalent, mixed and sometimes contradictory views. Negatively perceived aspects include aggressive, obsessive and irritating behaviours, impaired social life and disruption to homework and exams. More accepting NTD sisters adopt predominantly positive views of their siblings and life situation. All NTD sisters in this study perceive that the situation improves as they get older. Positively perceived aspects include enhanced maturity and sensitivity, benefitting from specific talents, including IT and proof reading skills, and close sibling relationship.

What are NTD sisters’ experiences of family life, school life, and relationships with friends and the wider peer group?

Domestic challenges and conflict cause upset and frustration but these NTD sisters also enjoy and cherish shared family time. Mother-daughter bonds are especially important and valued. Despite jealousy and resentment in mid-childhood these NTD sisters adopt caring responsibilities towards their sibling.
This group of NTD sisters are conscious when there is tension in home-school relations and this tension can negatively impact on their own wellbeing and performance. The girls often set high behavioural and academic standards for themselves in school which can exacerbate their anxiety and stress when domestic crises occur. Ineffectual information sharing, lack of awareness amongst staff and a benign reluctance to pry mean that NTD sisters can feel isolated and unsupported in school.

These NTD sisters view their social world as one of potential threats and valued friends. Friends are a source of support and respite but peers often lack awareness and empathy. These NTD sisters try to educate their peers with limited success. The younger girls, especially, experience high levels of embarrassment. All of the NTD sisters in this study have witnessed peer hostility to their siblings and can themselves experience prejudice. Their own social lives are impacted by having a sibling with ASD. Some attribute their limited social confidence to lack of social opportunities whilst others feel that they are more socially independent and confident. Most of the NTD sisters perceive that they have a closer, smaller, group of trusted friends as a result of having a sibling with ASD.

How do NTD sisters perceive their relationships with their siblings with ASD?

Sibling relationships change over time. Relationships in mid-childhood are often marked by conflict, resentment and irritation. Nonetheless these sibling pairs share an enduring bond and love their sibling and know they are loved in return. They share fun times and activities. Ambivalence is replaced by more pride and loyalty and an increasingly strengths-based view of their sibling and sibling
relationship. The older NTD sisters in this study come to see their relationships as mutually beneficial.

These NTD sisters adopt a caring role towards their sibling. This is, primarily, demonstrated by social carer responsibilities which are different to the responsibilities adopted by their parents. The social carer role comprises play leader and entertainer, social minder and social mentor. Responsibilities can be onerous, especially for those who share primary school with their sibling. All of the NTD sisters in this study envisage a future caring responsibility for their sibling, and this can cause concern. Some also support their siblings’ medical needs and worry about their health concerns.

How do NTD sisters cope with, and adjust to, having a sibling with ASD?

NTD sisters deploy a range of emotion-focussed, problem-focussed and appraisal-focussed coping strategies. They attribute their mothers, and other family members, with modelling and supporting these. Acceptance is on a continuum. Maturity, an understanding of the pervasive and permanent nature of ASD, adopting a strengths-based approach to one’s sibling and one’s situation and the perception that one is treated fairly, if not equitably, by one’s parents also promote positive acceptance.

Adjustment can be understood as the reduction of cognitive dissonance manifesting in positive acceptance, relationship mutuality and cohesive positive identity. Dissonance between family and sibling loyalty on one hand and challenging domestic behaviours and desire for peer acceptance on the other, cause psychological discomfort, especially in mid-childhood. NTD sisters resolve dissonance by finding positive meaning in their experiences, adopting strengths-based views and finding satisfaction in their relationship. Family and peer-group
personas are reconciled and one’s own needs are balanced with those of one’s sibling. Familistic values and behaviours also reduce cognitive dissonance. Birth order appears influential; Older NTD sisters adjust more easily than younger NTD sisters. My findings suggest that NTD sisters may adjust sooner than groups in other research.

NTD sisters show great personal resilience. GCSEs and school-based exams can be difficult but by ‘A’ levels most NTD sisters have recovered their equilibrium. Families adapt to meet the needs of all their children and share strong familistic values. Extended family members, and friends who share familistic focus and values, also provide emotional and practical help creating a support network.

What supports, or could support, the wellbeing of sisters growing up with a sibling with ASD?

NTD sisters are primarily supported by their mothers. They appreciate having their own needs recognised and met, even for brief periods of time. Peer support is valuable but can be difficult to access. Professional support is limited and perceived as reactive and often ineffectual.

Applied psychologists could support school staff and directly support NTD sisters with talking therapies at times of crises. Professional assessment should consider all family members and be sensitive to social context and desired outcomes. Systems’ approaches can promote an understanding of ways in which family, school and peer factors impact on NTD sisters and may also indicate potential sources of support.

TD sisters benefit indirectly from interventions that address the behavioural and mental health needs of their siblings and support their parents. Enhanced peer and societal awareness of ASD, and increased professional awareness of the needs of NTD siblings, are indicated.
6.2 Limitations of Research

6.2.1 Limitations of literature review

Research in this field is international and, consequently, themes common to a number of studies might reasonably be considered to transcend, at least some, cultural and social differences. However, social and cultural factors influence the sibling experience, and one relative weakness of my literature review is that it minimises these factors. Given the resonance of my findings with the experiences of NTD siblings of children with LD and with young carers (Dyson, 2010; Gray & Robinson, 2009), my original literature review could have included a focus on UK qualitative studies of these groups.

6.2.2 Limitations of methodology

This study is unequivocally qualitative and interpretive and clearly focussed on the personal experiences of siblings. Its findings will therefore be viewed sceptically by some, primarily for issues of internal validity and interpretation bias. The inherent limitation of case study research is that the number of participants and nature of methodology means that the generalisation of findings to other populations is limited.

The trustworthiness of this research relies on the rigour of design, data collection and analysis. Triangulation of data from multiple siblings and the checking of analysis by others are primary examples of robust research practice. Research rationale, methods of data collection and analysis are described in detail and the interview schedule and protocol are comprehensive. These allow the reader to scrutinise the research process and determine for themselves the veracity of conclusions drawn. I believe that the clarity with which I have presented my research and analysis methods, and the ways in which I have linked my analysis to existing research and psychological theory, shows these findings have some relevance beyond this group of NTD sisters.
Initially, I considered including quantitative measures as part of this case study. The rationale for not doing so is presented in Chapter 3. I decided to focus on producing robust, qualitative research and was concerned that, in a study of this size, numeric data would overshadow qualitative research. The lack of self-reported numeric data made it imperative that I engage in rigorous qualitative research and analysis. It would have been difficult to do justice to even more data in this study, but I can see that an expanded study might usefully include self-rating items. These would enable the researcher to weight strength of perceptions and feelings. Ironically, having completed this substantial piece of qualitative research, I believe I am now better placed to balance both types of data and maintain a phenomenological focus. The siblings in this study provide frequent retrospective accounts of challenges from their childhood. Retrospective accounts are likely to be more positive (Hardt & Rutter, 2004). One potential risk of interview methods is of participants “faking good” (Cridland et al., 2015, p. 9) or minimising problems. It is possible that participants view events more positively in retrospect, or that knowing I would also be interviewing their parents, presented more positive views. The consistency of findings across the participant group would suggest that this is unlikely. However, I would like to have interviewed NTD sisters more than once, over a period of time.

A number of researchers argue for more precise and focussed studies, to explore factors of gender and age with homogenous groups (Hodapp et al., 2005; Moyson & Roeyers, 2011; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). If I had been successful in recruiting a larger number of volunteers, I would like to have focussed on a narrower age group, perhaps young adults to explore their emerging adult identities, or girls transferring to high school, or primary age girls who share school placement with their sibling.

Despite a wide-ranging recruitment strategy, the families in this study are all associated with ASD support groups. Similarly, all families who participated
learnt of the study via email or e-newsletter, a popular means of contact and support for families of children with disability (McCoyd & Kerson, 2006). Family characteristics and family coping behaviours, including accessing social support, influence the experience of NTD siblings. NTD sisters in families that are not associated with support groups and without internet access, may have a qualitatively different experience.

My study confirms the utility of open-ended questions (e.g. Barak-Levy et al., 2010) and confirms that research designed to capture individual perception of experience is vital, if one is to understand the impact of ASD and plan meaningful support for NTD siblings. (Angell et al., 2012; Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, et al., 2012). NTD siblings alone are able to describe the personal and individual impact that experiences have on their wellbeing. Parental perspectives can be more negative than those of NTD siblings (Dew et al., 2008; Rivers & Stoneman, 2003). I found parents more concerned than their NTD children about the restrictive burden of caring responsibilities. They harbour more concerns and regrets about their NTD child’s upbringing and worry about impact on personality and self-confidence. However, parents are more dismissive of short-term concerns than their children; siblings were very irritated and frustrated by obstructive behaviours which parents put down to typical bickering. These differences between parental and sibling perspectives underline the importance of gathering views of young people themselves and of reflecting these differences in subsequent analysis.

Previous research in this field asked seven year old siblings to draw and talk about their experiences. Sage and Jegatheesan (2010) use drawing to complement spoken or written responses to encourage children to communicate in ways that feel most natural to them. I found that girls up to the end of primary education, age 11, happily elected to draw and talk about their experiences. The activity seemed natural to them and often they began drawing
before I had finished my introduction. Their drawings contain detail that they did not initially mention in their verbal answers and reduced the need for me to ask further potentially leading questions. Conversely, girls at secondary school elected not to draw, suggesting this is the cut-off age for this type of activity. Some simply declined the offer to draw, perhaps viewing it as ‘too young’ for them, whilst others picked up the pencil but began talking in such detail that they felt they had nothing left to add.

6.2.3 Personal reflections on research

The interview, transcription and coding processes were lengthy and allowed me to immerse myself in the accounts of siblings, and the accounts of those who might be expected to know them best, their parents. I found this immersive process to be both illuminating and thought provoking. I could see at close quarters the common emotions that run through the accounts, the complex nature of people’s lives and the unique ways that individuals respond to challenges. The differences in circumstance and personalities made commonalities more profound. Working closely with families also emphasised the importance of future relevance and application of my findings.

I first became aware of draw and tell techniques through a seminar led by Child and Educational Psychologists inspired by the work of Heather Moran (1996). Since undertaking these interviews, I have increasingly used draw and tell techniques in my professional interviews with primary age children. Children usually enjoy the activity and their pictures can be very powerful in discussions with key adults who may have become indifferent to the communicative effect of a child’s behaviour but are struck by a simple sketch. On reflection, I suggest that looking through paper or digital photo albums might similarly support a child or young person’s recall of experiences and perceptions and sharing Instagram or Facebook pages may improve the engagement of older NTD sisters.
The process of thematic analysis and writing up one’s analysis involves condensing individual experience. I often found it difficult to choose between equally powerful, but slightly different, quotes and examples. The focus of this study means that parental experiences of raising a child with ASD are marginal to this research. I was privileged to hear these powerful accounts but regret I have not been able to use them further.

I have considerable personal and professional experience of children and young people. I have worked with children and their families, as a teacher and psychologist, for 25 years. I have three daughters of my own, who are now the same age as the sisters in this study. These factors shaped my decision making from inception of the research to the write-up of this thesis. It was a pleasure and privilege to listen to these girls and young women. At times, I was deeply disappointed by the ways some professionals responded to their requests for support. I resolved, not for the first time, to always try to look a little more closely at the bigger picture.

I had taken steps to ensure young participants felt safe and happy to take part. Although I enjoyed the interview process and felt privileged to hear their stories, interviews with parents were at times, very emotionally charged. More than once, a parent told me that this was the first time they had spoken of a particular event or emotion, or that the process of talking through experiences helped them make sense of previously confusing thoughts and feelings. On reflection, these interviews afforded parents a rare debrief for the challenges associated with raising a child with ASD, and the all-too-common struggles with diagnosis and support. In retrospect, I should perhaps have anticipated that parents would need to talk through their experiences, and process any feelings of anger, guilt and loss, before they could focus on their NTD child’s experiences. Perhaps the fact that parental interviews took place in their homes made parents less guarded in their responses.
Although I have had no other professional involvement with the families in this research, I was conscious that they might perceive participation in this study could materially benefit their family. I was keen to make clear that I had no access to, or influence regarding, support and resources for children and their families. Although not professionally involved with these cases, I acknowledge that my status as a professional and Local Authority Officer may have influenced parents in their decision to contribute. During the interview stage, I became aware that some NTD sisters had joined the study, in part, because they were contemplating courses and careers in psychology. On reflection, I am more than happy if their involvement came from a broader interest in the human condition or if taking part in this research has illuminated their career choices. I wish them the very best in their chosen paths.

6.3 Contribution to knowledge

6.3.1 Contribution to empirical and theoretical knowledge

This study contributes to the very small, international body of exploratory and descriptive research regarding the first-hand accounts of child and adolescent NTD siblings of ASD. It uniquely describes the experiences and perceptions of a group of UK-based NTD sisters of siblings with ASD.

This study is the first to explore the school-based experiences and caring responsibilities of primary-age NTD sisters, and the first to look at NTD sisters’ experiences of secondary school, in the UK. It is unique in exploring the perceived impact on NTD sisters’ learning and psycho-emotional welfare and complements recently published research about the school-based caring responsibilities of Australian NTD sisters (Cridland et al., 2015).

This study maintains a uniquely broad focus on NTD sisters’ experiences, looking at perceptions of home and family life, sibling relationships (including carer
responsibilities and sharing schools), friends and peer relations. It gathers contemporary and retrospective accounts from mid-childhood through to young adulthood. It thus provides a unique and holistic view of home, school and social domains, the multi-faceted nature of NTD sisters’ caring responsibilities towards their siblings with ASD and the adjustment process as NTD sisters seek to reduce dissonance between family and social loyalties, and balance their own needs with those of their sibling. For sole NTD daughters, the mother-daughter relationship is the key conduit for familistic beliefs, values and information about ASD, and short- and longer-term coping strategies. Other female relationships, often with maternal relatives and friends, supplement this support. This is the case even when their father is the primary at-home carer.

Along with other recently published research in this field (Cridland et. al., 2015; Diener et. al., 2015), this study begins to explore the role and impact of gender, by describing the detailed experiences and reflections of a group of NTD sisters. These accounts suggest that there are ‘pinch points’ or times of particular psychological challenge, shared by a number of NTD sisters. The primary age girls in this study often describe themselves as acting as their mothers’ ‘eyes and ears’ in school. This vigilance can cause particular stress can especially at times of their sibling’s behavioural crises or when home-school relations are strained. For NTD sisters who share a primary school placement with their sibling with ASD, their own relative immaturity, and the closer proximity to, and involvement with, their siblings afforded by the primary school context, appears to make them especially vulnerable to any friction between home and school.

Retrospective and contemporaneous accounts suggest that many NTD sisters of late primary age develop a heightened sense of their peer group and can feel acutely embarrassed by their siblings. They may find it hard to reconcile their social aspirations and their loyalty to their sibling and family. Retrospective
accounts indicate that this sense of conflict dissipates as girls identify trusted friendship networks at secondary school. For some, however, this conflict may continue into early teens.

Similarly, retrospective accounts from the older NTD sisters suggest that GCSE exams also present particular challenges. For many girls it is important to revise for exams and achieve academically but their siblings’ behaviour at home can make this very difficult. These ‘pinch points’ suggest times when support from both within and outside of the family may be especially useful.

My findings suggest that NTD sisters who are also the sole NTD sibling in their family may experience foreshortened and more intensive adjustment than reported in mixed-gender, mixed-family size groups in other studies (e.g. Petalas, Hastings, Nash, Reilly, et al., 2012). This study highlights the utility of strengths-based beliefs in coping and adjustment and makes links to cognitive dissonance theory to explain the motivation of NTD sisters who spontaneously adopt a strengths-based approach to their sibling and their own situation. My findings suggest that Moyson and Roeyers (2011) model of acceptance could usefully be extended to include a stage of ‘positive acceptance’. The older NTD sisters in this study perceive that being a sibling of a child with ASD can be viewed, by some, as ‘a gift’ that shapes personal and professional identity.

This study describes the unique social caring role that NTD sisters fulfil towards their siblings with ASD and explores the perceived impact of this social caring role on psycho-emotional wellbeing, academic motivation and longer term identity. Cridland et al. (2015) explore the impact of family systems on the caring role adopted by NTD sisters in school. I suggest that the relationship is multi-directional and that NTD sisters’ behaviour, perceptions and caring responsibilities can best be understood with reference to home, school and peer systems.
Studies that gather the unique perspectives of child and adolescent siblings are relatively rare. One of the aims of my research was to give a voice to NTD siblings who are routinely ignored in ASD research, and, perhaps even more importantly, in professional assessments of family need. This, and other research (Dew et al., 2008; Rivers & Stoneman, 2003), suggests that the young person’s perspective is quite different from that of their parents.

This research generated a comprehensive interview schedule and clear, detailed protocols for research with other groups of NTD siblings across the 10-19 age range. It supports the usefulness of ‘draw and talk’ approaches to facilitate interviews with children up to the end of primary phase. This research also offers an interview schedule for use with parents, or other family members, such as grandparents.

My experience of piloting and conducting the interviews, indicate a number of pointers to good practice. Firstly, with regard to interviews with children and young people, I suggest it is important to allow the young person to select an environment in which they feel safe and to take steps to build and maintain rapport. During the interview it is important to ensure that language is appropriate to the age of the young person and techniques such as ‘draw and tell’ can prove useful in providing some younger children with thinking time, and in allowing their ideas to direct the discussion even before they start to speak.

Although it is important to plan one’s interview questions carefully, it is equally important to allow time for an effective debrief. The interviewer should be conscious of the social context in which interviews take place and facilitate, or even provide, the child or young person with a script to explain their absence to their, often curious, peers. Similarly the interviewer should themselves be prepared with a script of their own to explain the purpose of the research, what happens next and the more complex terms and ideas raised in the interview. Of
course, these should use language appropriate to the levels of the children concerned and, if possible, be supported by leaflets and other such materials for them to refer to afterwards.

6.3.2 Contribution to applied practice

My findings suggest that there is a perceived need for timely and appropriate professional support for NTD sisters and their families, at times of crisis. There is also a need for professional support to inform and facilitate discussions on sensitive subjects such as heritability and future care and in developing scripts for use with hostile peers. Support in planning for exams, and in dealing with anxiety and crises during exams, is also indicated. Concerns about the safety of online support may be a barrier to its apparent utility.

My research emphasises the unique position that NTD sisters play in mediating between home and school and suggests the utility of a shared systems approach to understand how tension in home-school relations, and dissonance between familial loyalty and peer group pressure can be problematic for NTD sisters. Primary-aged girls who share school placement with their sibling with ASD are particularly vulnerable.

NTD sisters are driven to perform well academically and behaviourally yet having a sibling with ASD often interrupts homework and exam preparation. This can result in heightened levels of anxiety, unhealthy perfectionist tendencies and, even, self-harm. This study identifies exams, especially GCSEs, as times of particular difficulty and highlights the need for families and schools to plan to support NTD sisters at these times. My findings underline the need for more effective and child-focused information sharing protocols, for assessments of family needs to include those of NTD siblings and for enhanced awareness of the needs of NTD siblings amongst professionals. Social context and available social
support should be included in any assessment of current need and when planning a potential intervention.
References


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Appendices

Appendix 1: Participant Information Sheets and Consents

Appendix 1a: Participant Information Letter (Parents/Carer)

Participant Information Sheet

Dear Parent or carer

You and your child are being invited to take part in a study. My name is Linda Callaghan. I am an educational psychologist working for Flintshire County Council and studying for a doctorate with the University of Manchester.

As part of my course, I am carrying out some research with children who have a sibling with a diagnosis of autism. My research also involves the views of their parents. I am especially interested in the experiences of children and young people who have a sibling with autism, understanding ways to enhance their psychological wellbeing and collating views on additional support that may benefit this group of children and young people. Psychological wellbeing is defined as being the state when ‘an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’ (WHO, 2005). These ideas will contribute to training and self-help materials that will support children, families and schools in the future and may also be used to inform decisions about how children and young people are supported in the future.

Before you decide whether or not to take part, it is important for you to understand why the study is being done and what it will involve. Please take
time to read the following information carefully and discuss it with others if you wish.

Please contact me on linda.callaghan@postgrad.manchester.ac.uk if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the study?

The study will be run by me, in my capacity as a student on the D.Ed.Psy course, School of Education, University of Manchester and as an Educational Psychologist.

Title of the study

What are the experiences of children and young people of having a sibling with Autistic Spectrum Disorder?

What is the aim of the study?

The aims of this study are

- To explore children and young people’s experience of having a sibling with ASD
- To explore the psychological well-being of the non-autistic siblings
- To identify support that is valuable to this group other and their families

Findings will be used to inform training materials for use by Children and Young People with a sibling who has ASD, their parents and schools.

Why has my child been chosen?

Your child has important information about growing up alongside a sibling with autism. Their experiences and views will help understanding of the needs of this group of children and young people.

Why have I been chosen?

As the parent of both a child with autism and of neurologically typical children, you have valuable views on your children’s experiences, well-being and support needs.

What is the next step?

If you would like to volunteer to take part in this study please contact me, either by
You will be asked to provide some preliminary information to ensure you match the criteria for inclusion in this study. You and your child will then be asked to sign written consent forms. A copy of the consent form is attached for your information. You do not need to sign it now.

**What would my child be asked to do if they took part?**

Your child will be asked to meet with me for a session lasting approximately 30 minutes. In this session, I will ask them to draw two pictures: the first to show their life growing up with a sibling with autism and the second to show any support or improvements that could be made. As they draw I will ask them about

- their experiences
- their understanding of autism
- their relationship with their sibling
- the impact of having a sibling with autism on their lives
- the strategies for dealing with difficult times

This meeting will take place in your child’s school unless you prefer it to take place in your home. The interviews with your child will be recorded on audio tape.

**What would I be asked to do if I took part?**

You will be asked to take part in one interview lasting approximately 45 minutes. The interview will cover similar topics to those in your child’s interview

- your views on your child’s experiences
- Your views on what if any support might be beneficial to your child

The interview can take place in your home or over the telephone if you prefer. The interview will be recorded and transcribed at a later date.

**What happens to the data collected?**

Pictures, tape transcripts and emailed responses will be analysed to look for general themes and experiences.

**How is confidentiality maintained?**
You and your child’s views and experiences will be made anonymous by me and you and your child will not be identified or identifiable in the write up of the research, or in any other way, to the school, the local authority, the University or any other third party. These anonymised responses will be kept on a University of Manchester server accessed by me via an encrypted laptop.

Your contact details will be kept on record by me, on a secure University of Manchester server, accessed by an encrypted laptop, only until this study is complete in summer 2014. Your details will not be available to anybody other than me.

Audio tapes will be destroyed, in line with the University’s policy for the disposal of confidential waste, again at the end of summer 2014.

The anonymous transcripts of the discussion may be used by me and other researchers in the future.

This research will be conducted within the safeguarding policies of both University of Manchester and the Local Authority. The only reason I may need to break a confidence is if I think that your child is being seriously hurt in some way, or at risk of being hurt or of harming someone else. This will be discussed with your child before making any disclosure, and unless a law has been broken it will also be discussed with you.

**What happens if I do not want to take part or if I change my mind?**

It is up to you and your child to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you or your child are still free to withdraw at any time without giving a reason, and without detriment to yourself or your child.

**What is the duration of the study?**

The sessions with your child will last 30 minutes. The emailed survey will take you approximately 45 minutes to complete.

**Where will the study be conducted?**

The interviews will be held during the school day, in your child’s school at a time agreed with the head teacher unless you prefer the interview to take place in your home.

**Will the outcomes of the study be published?**
The study will be submitted as part of my degree and may be made available to other students for training purposes. It may, at a later date, be submitted in an edited form for publication.

**Contact for further information**

If you would like to discuss this research further please contact me on

Linda.Callaghan@postgrad.manchester.ac.uk or 07827355949

**What if I find the topic upsetting?**

I am available to offer telephone or email support throughout the study. Support is also available via your school’s family support worker, Parent Partnership or the National Autistic Society

*If a participant wants to make a formal complaint about the conduct of the study they should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.*

**How can I take part in this study?**

If you would like to volunteer to take part in this study please contact me, either by

- Email: Linda.Callaghan@postgrad.manchester.ac.uk
- Phone: 07827355949

You will then be asked to provide some preliminary information. If selected, you and your child will be asked to sign a written consent form. A copy of the consent form is attached for your information. You do not need to sign it now.
Hello

You are being invited to take part in a study. My name is Linda Callaghan. I work for Flintshire County Council and am also a student at the University of Manchester.

I am doing a project with children who have a brother or sister who has autism. I would like to know what having a brother or sister with autism is like and anything you think that could make things better.

This project may help decide how children are helped in the future.

You do not have to take part in this project – the choice is yours. Please take time to read this letter carefully and discuss it with others, including your parents, if you want to.

Please contact me on linda.callaghan@postgrad.manchester.ac.uk (or ask your parents to do so) if there is anything you want to know about the project.

Thank you for reading this.

Who will carry out the study?

The study will be run by me.

Title of the study

What are the experiences of children and young people of having a sibling with Autistic Spectrum Disorder?
**What is this study trying to do?**

This study will

- Ask children what it is like to have a brother or sister with autism
- Ask the children what could be done to make things better
- Give some ideas to put in a pack to help other children in the future

I will also ask your parent some questions.

**Why have I been chosen?**

You have been chosen because you have a brother or sister with autism

**What would I be asked to do if I took part?**

You will be asked to meet with me. I will ask you to draw two pictures. One picture will show me what it is like growing up with a brother or sister with autism. The second picture will show me what you would like your life to be like. We will talk about what you would need to get your ideal life.

This meeting will take place in your school unless you prefer it to take place in your home. The talk will be recorded on a tape recorder.

**What will happen with the pictures?**

Pictures, the write-ups of the tape recordings and your parents' answers will be looked at by me. I will write about the ideas I get from them.

**Will you write about me?**

I will only write about your ideas. I will not write about your name or give any other details that would make it possible for people to know you had taken part in the study.

**What happens if I do not want to take part or if I change my mind?**

You can stop being in the study at any time - just tell your parents or teacher. You can stop being in the study even when we have started talking. Just tell me you want to stop.

**How long does the study last?**

The talks with you will last about 30 minutes
Where will the study take place?

The talks will take place in your school between unless you want to have the interview at home.

Where will the write up of the project be?

I will give it to the University and people can read it there. In the future it may be written up for a magazine read by people who are interested in this topic.

What happens if talking in the project upsets me?

Please tell me, your parents or your teacher and we will talk to you and make a plan to help you feel better. Every adult who comes into your school should try and keep you safe. The only reason I may need to tell other adults about what you say is if I think that you are being seriously hurt in some way, or if someone is trying to hurt you or if you are about to hurt someone else. If this happens, I may talk to your parents, your Head teacher, social workers and the police. I will talk to you before I do this.

Next Steps

If you would like to talk about this project or want to take part, please ask your parents to contact me on

Linda.Callaghan@postgrad.manchester.ac.uk or 07827355949

If you are chosen to be in the project, I will ask you and your parents to sign a form.

If a participant wants to make a formal complaint about the conduct of the study they should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.
Appendix 1c) Participant Information Sheet (Older CYP)

Participant Information Sheet – for Child or Young Person

Hello

You are being invited to take part in a study. My name is Linda Callaghan. I am an educational psychologist working for Flintshire County Council and studying for a doctorate with the University of Manchester.

As part of my course, I am carrying out some research with children who have a brother or sister (known as a ‘sibling’) who has autism. My research also involves the views of your parents. I am especially interested your experiences of having a sibling with autism, your happiness and ‘psychological well-being’ and anything you think that could make things better. ‘Psychological wellbeing’ is when somebody ‘realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’ (WHO, 2005).

This study may help decide how children and young people are supported in the future. Your ideas will also help me create some training materials for children, young people, their families and schools to use in the future.

Before you decide whether or not to take part, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others, including your parents, if you wish.

Please contact me on linda.callaghan@postgrad.manchester.ac.uk (or ask your parents to do so) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the study?

The study will be run by me.
Title of the study

What are the experiences of children and young people of having a sibling with Autistic Spectrum Disorder?

What is the aim of the study?

The aims of this study are

- To look at children and young people’s experience of having a sibling with ASD
- To look at the well-being of children and young people who have a sibling with autism
- To identify support that is valuable to this group other and their families

Findings will be used to create training materials for use by children and young people, their parents and schools.

What is the next step?

If you and your parents would like to volunteer to take part in this study please contact me, either by

- Email: Linda.Callaghan@postgrad.machester.ac.uk
- Phone: 07827355949

Your parent will then be asked to provide some more information to make sure you match the criteria for taking part in this study. You and your parent will then be asked to sign a written consent form. A copy of the consent forms is attached for your information. You do not need to sign it now.

Why have I been chosen?

As somebody who has a sibling with autism, you have valuable experiences and views.

What would I be asked to do if I took part?

You will be asked to meet with me. I will ask you to draw two pictures:

1. to show your life growing up with your sibling and
2. to show an ideal life with your sibling, with any improvements that could be made.

As you draw I will ask you about

- what you think autism is
- your experiences and relationship with your sibling
- the difference you think having a sibling with autism makes to your life
- the ways you deal with any difficult times

This meeting will take place in your school unless you prefer it to take place in your home. The interviews will be recorded on audio tape.

What would my parent/carer be asked to do if they took part?

Your parent will be asked to meet me for an interview. These will be tape recorded.

What happens to the data collected?

Pictures, the transcripts (write-ups of the tape recordings) of you and your parents’ answers will be looked at for themes and ideas.

How is confidentiality maintained?

All of your views and experiences will be made anonymous by me and you will not be identified or identifiable in the write up of the research, or in any other way, to the school, the local authority, the University or anyone else.

Your name and email and phone number will be kept safely by me and destroyed as soon as the University tells me that I am allowed to. Your details will not be available to anybody other than me.

The tape recording will also be kept safely and destroyed at the end of the study, when I am allowed to do this.

The anonymous transcripts of the discussion may be used by myself and other researchers in the future.

This research will be conducted within the safeguarding policies of both University of Manchester and the Local Authority. The only reason I may need to tell other adults about what you have told me is if I think that you are being seriously hurt in some way, or at risk of being hurt or of harming someone else. Depending on the seriousness of what you tell me, I may talk to your parents, your Head teacher, social workers and the police. I will discuss this with you before making any disclosure.
What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to pull out of the study at any time without giving a reason and nobody will mind.

How long does the study last?

The interviews with you will last about 30 minutes.

Where will the study take place?

The interviews will be held in your school unless you want to have the interview at home.

Will the outcomes of the study be published?

The study will be submitted as part of my degree and may be made available to other students for training purposes. It may, in the future, be written up to be published.

What if I find the topic upsetting?

Please tell me, your parents or your teacher and we will talk to you and make a plan to help you feel better.

If a participant wants to make a formal complaint about the conduct of the study they should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

How can I take part in this study?

If you would like discuss this study or to volunteer to take part please discuss it with your parents and contact me on

- Phone: 07827355949
- Email: Linda.Callaghan@postgrad.manchester.ac.uk

You will then be asked to provide some information. If selected, you and your parent will be asked to sign a written consent form. A copy of the consent form is attached for your information. You do not need to sign it now.
Appendix 1d) Participant Consent Form

What are the experiences of children and young people of having a sibling with Autistic Spectrum Disorder?

CONSENT FORM

If you are happy to participate in this study, please sign the form below

1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that my child’s participation in the study is voluntary and that I am free to withdraw them at any time without giving a reason.

4. I understand that the interviews will be audio recorded

Please Initial Box

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5. I agree to the use of anonymous quotes

6. I agree that any data collected may be passed to other researchers

7. I agree that any data collected may be published in anonymous form in academic books or journals.

8. I understand that the researcher may need to break a confidence if during this research they learn of something that suggests a child is being seriously hurt in some way, or at risk of being hurt or of harming someone else, or that a law has been broken.

I agree to take part in the above project

Name of participant ___________________________ Date ______________ Signature ______________

Name of person taking consent ___________________________ Date ______________ Signature ______________
Appendix 1e): Head teacher information and consent

Dear Head teacher

Request to carry out research interview in your school

My name is Linda Callaghan. I am an educational psychologist working for Flintshire County Council and studying for a doctorate with the University of Manchester. and their parent have agreed to take part in a research study on the perceptions and support needs of children who have a sibling with autism. This includes one 30 minute interview with

In order to minimise disruption to the school day and to carry out the interviews in a setting in which young people feel safe, I would like to carry out this with in school. Full written consent for this interview has been given by parents.

The day and time of interview will be at your convenience. In order to carry out the interview we would need the use of a quiet room, where we can work without interruption, for 30 minutes.

As part of my research and in my current employment, I have full enhanced CRB clearance and will bring my CRB certificate and identification badge to school on the day of interview.

If you wish to discuss this matter further please contact me on 07827355949 or by email at linda.callaghan@machester.postgrad.ac.uk

If you consent to the interview taking place on school site and are happy for me to contact you to arrange a time to carry out the interview, please indicate on the attached sheet and return to me linda.callaghan@machester.postgrad.ac.uk

Yours faithfully,

Linda Callaghan

Chartered Educational Psychologist
Appendix 2a): SSI schedule and verbal prompts for use during sessions with CYPs

Written consent from parent and CYP will have been received prior to arranging session. Ensure verbal consent for continuing with session is sought and received from CYP at start of session.

WARM UP – Tell me about you and about your family (2-3 minutes)

- Who lives at home? Ages, schools, jobs, pets etc.
- What do you all enjoy doing?

‘I understand from your mum/dad that you have a sibling with autism. Can you answer a few questions/ draw a picture or a few pictures that shows me what it is like to live with X’ (10 minutes)

Prompt during conversation/ drawing with:

- Tell me about your relationship with X(name of brother/sister with ASD)
- Does [sibling with autism] behave differently to other children – if so how? Is that a problem?
- Do you do activities / go on trips with [sibling with autism]. If so tell me about one or two?
- Do you know what autism is? What makes X different from other children? What would I see X doing? What would I hear X saying?
- How would you describe autism to someone who had never heard of it?

Strengths

- What is the best part of having X as your brother/sister?
- Can you describe a good time you’ve had together, or something you really like about them?

Negatives

- What are some difficult parts of being a sibling to X)?
- Can you tell me about a problem/ thing you would definitely want to change?

Peer relations

- What do your friends think about X? Is that Ok with you?
• Do your friends make it easier for you in some ways?
Talk about the picture ‘It looks to me like... is that right?’ ‘Can you tell me what this is?’ ‘Can you tell me something about this?’

Can you now draw a second picture that shows me the best that life could be with Y' (10 minutes) / Can I ask you some questions about what your ideal life with your sibling would look like?

Prompt with
• What would your ideal life with X be like?
• What is the one/ first thing you would change?

*Peer relations*

• What would your friends be doing in this picture
• Is there anything you would change about the way your friends think/behave?

*Support*

• What helps you when you are feeling fed up?
• Can you think of other things that you don’t have at the moment that may help you?
• What would other people grown-ups be doing in this ‘ideal’ picture?
• Do you think other children like you living with a [sibling with autism] should have some help? What would it be?

*Conclusion/ Summing up*

• What piece of advice would you give to other children who were just finding out that their sibling has autism?

What is different is this picture to the first one? ‘It looks to me like... etc.

Finally, is there anything you want to ask me or anything that you want to talk about that we haven’t talked about yet?

*Thank You. If you want to talk about this topic again you can talk to your mum or dad or your teachers and they can get in touch with me if you want them to or Give email address to older participants.*
### Appendix 2b): Prompts for Parent/ carer interviews referencing influence of SDQ items

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Reference to SDQ item</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Tell me about your family: What do you think is important for me to know or understand about your family?</td>
<td></td>
</tr>
<tr>
<td>(b) Describe the relationships between X [name of sibling without autism] and Y [name of sibling with autism]</td>
<td>Pro-social item: Considerate of other people, volunteers to help others,</td>
</tr>
<tr>
<td>(c) What do you think X enjoys about being Y’s sibling? Can you give me any examples?</td>
<td></td>
</tr>
<tr>
<td>(d) What (if anything) do you think X finds difficult about being Y’s sibling? Can you give me any examples? How do you know they find this difficult?</td>
<td>Internalising and externalising behaviours, hot temper, lying, worrying complains of aches, solitary,</td>
</tr>
<tr>
<td>(e) What helps X deal with these difficult things? People, activities, ways of thinking</td>
<td></td>
</tr>
<tr>
<td>(f) Do you think X’s friendships and social life are affected by having a sibling with autism? Please give examples if possible</td>
<td>Pro-social – has at least one good friend, , picked on or bullied, solitary, considerate of other people, volunteers to help others, kind to younger children</td>
</tr>
<tr>
<td>(g) On a scale of 1-5 how would you describe Y’s behaviour at home</td>
<td></td>
</tr>
<tr>
<td>1 2 3 4 5</td>
<td>Not challenging v challenging</td>
</tr>
</tbody>
</table>
(h) Do you think children and young people living with a sibling with autism should be offered additional support? What should that support be?
Can you put these in priority order?

(i) What advice would you give to other families of a child with autism to help them support their other children? How do you manage any issues?
One ‘wish’ for any family in a similar position

(k) Are there any other comments you wish to make on this topic?

Thank you.

Goodman (1997)
## Appendix 3: Pen Portraits

<table>
<thead>
<tr>
<th>Family #1</th>
<th>Pen Portrait</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NTD sister:</strong> Grace</td>
<td>Grace is an 11 year old girl in Y6 of a small village primary school. Her brother D is 8 years old and in Y3 at the same school. D received a formal diagnosis of Asperger’s two years ago. Grace and D live at home with their parents in a small village. Their father, P, is self-employed and spends periods of time working away from home. Their mother, Jane, works in the home and is active in local ASD support network. Both children moved to their current school 18 months ago. They moved from their previous school because of their parents’ dissatisfaction with the school’s response to D’s special educational needs. The family report themselves as much more satisfied with their new school. Both children are currently expected to move up to the local mainstream High School, although parents hope D will be in receipt of a Statement of SEN by the time he transfers. Jane has recently attended a number of courses aimed at raising parental awareness of autism and in developing her skills in managing D’s behaviour. Jane finds these groups supportive and has made a number of friends through attendance at these groups. The family have limited contact with extended family, and some family members continue to see D’s Asperger’s as ‘naughtiness’ and the consequence of parenting style. Jane describes her friends as her support network. Jane rates D’s behavioural challenge between 3 and 5 on a scale of 0-5 when 5 is the most challenging.</td>
</tr>
<tr>
<td><strong>Parent:</strong> Jane (mother)</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family #2</th>
<th>Pen Portrait</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NTD sister:</strong> Ellie</td>
<td>Ellie is a ten year old girl in Y5 of a church primary school. Ellie lives with her mum, Mary, her dad, B, and 14 year old sister M. M received a diagnosis of autism when she was 7. M also has significant learning difficulties. M attended the same primary school as Ellie until the end of Y6 and she is still remembered by staff. M now goes to a special school in the town. The family have begun to visit residential colleges as they start to plan for M’s adult life. The family live close to the centre of town and have close family nearby. Ellie’s maternal grandparents regularly help with childcare and Mary’s sister is also a source of moral and practical support. B works full time. He suffered a stroke two years ago and he has felt the need to ‘slow down’ a little since then. Mary works part time as a teaching assistant. She is an active member of local ASD and school support groups. The family are members of a local church. Mary rates M’s behavioural challenge as 4 on a scale of 0-5 when 5 is the most challenging.</td>
</tr>
<tr>
<td><strong>Parent:</strong> Mary (mother)</td>
<td></td>
</tr>
<tr>
<td>Family #3</td>
<td>Harriet is a ten year old girl currently in Y5 at a local primary school. She lives with her mum, Debbie, and dad, J, and brother X who is 8 years old. X has a joint diagnosis of autism and Dravet syndrome. Dravet syndrome is a rare and catastrophic form of intractable epilepsy that begins in infancy. It is life limiting with associated learning and developmental delay. X’s condition requires a high level of support. At times, X requires constant monitoring and nursing by his mother and periods of hospitalisation. The family live in a semi-rural setting outside a larger village. Harriet’s dad, J, works away from home and Debbie, works in the home, and is X’s carer. She is also an active member of local support groups. Harriet’s maternal grandmother lives nearby and supports the family by taking Harriet to and from school and providing other childcare and moral support. Debbie describes her mother as her ‘rock’. X attends the same mainstream school as his sister for 2 days a week and is on roll at a special school in a nearby town for the rest of the week. His parents keenly hope that he maintains some mainstream placement until the end of primary school, but this plan has been under some pressure recently from professionals who have concerns that the mainstream school cannot adequately support his needs. Dawn rates X’s behavioural challenge as 4 on a scale of 0-5 when 5 is the most challenging.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>NTD sister: Harriet</td>
<td>Parent Debbie (mother)</td>
</tr>
<tr>
<td>NTD sister: Bella</td>
<td>Parent: Kim (mother)</td>
</tr>
<tr>
<td>Bella is a 12 year old girl who has just completed Y7 at High school. She has a twin brother, D and a younger brother S who is aged 9. D has a diagnosis of Asperger’s and S has diagnoses of autism. D has co-diagnoses of ADHD, OCD, Tourette’s and Irlam’s syndromes. All three children attended the same mainstream primary school, and Bella and D now attend a mainstream high school a few miles away from their rural home. Kim chose the school for its academic</td>
<td></td>
</tr>
<tr>
<td>Keira is a 10 year old girl in Y 5 of primary school. Her brother B is 13 and has had a diagnosis of Asperger’s since he was 8. B went to the same primary school as Keira until secondary transfer and now attends a local mainstream High School. The family live in a borough that maintains Local Authority Grammar schools and Keira is working hard for her 11 plus. She hopes to gain a place at the local girls’ grammar school. Paula has some concerns about the additional stress that the selection process puts on her daughter, and whether an overly academic school would best suit Keira. However, her parents feel that it would be beneficial to Keira to attend a different high school to her brother. The family moved in recent years to a house with a larger garden. They also have a caravan on the coast which they describe as their ‘haven’ where they can relax. B is Paula’s son from a previous relationship. B considers M to be his dad and has no contact with his biological father. Paula works part time and J is in full time employment. Paula rates X’s behavioural challenge as 3 on a scale of 0-5 when 5 is the most challenging.</td>
<td></td>
</tr>
<tr>
<td>NTD sister: Keira</td>
<td>Parent: Paula (mother)</td>
</tr>
</tbody>
</table>
reputation and Bella and D were two of only three children from their primary class of 30 who transferred there. Kim is estranged from her husband who, after being absent from the family for a period of time, now lives locally. His contact with his children is described by Kim as erratic. Kim’s mother has played an increasingly supportive role in her daughter’s and grandchildren’s lives. She has always lived close by and the children treat her house and large garden as a home from home. She has recently asked Kim and the children to move in with her and the living accommodation is being adapted and extended to enable this. This will enable the boys to have their own bedrooms and will mean their grandmother is very close-by to support the family at all times. Kim describes her mother as being part of the core family unit and feels they are a very open family who ‘can talk about anything’. Since the boys’ diagnoses and becoming a single parent, Kim has changed jobs from teaching to what she describes as a less demanding job in education in order to be available to her children in the evenings and weekends. Kim rates D’s behavioural challenge as 3, and S behavioural challenge as 4-5 on a scale of 0-5, when 5 is the most challenging.

**Family #6**

<table>
<thead>
<tr>
<th>NTD sister:</th>
<th>Rhiannon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent :</td>
<td>Jack (Father)</td>
</tr>
</tbody>
</table>

Rhiannon is an 18 year old female. She has just completed her A levels and is planning to leave the family’s home in a small town for University in a city 200 miles away. She lives her brother M, who is 13 and her parents. Rhiannon’s mother works full time and her father Jack is a stay at home parent and carer. Jack has three older children from his previous marriage, with whom he has limited contact. The family have experienced a number of house moves, from city, to rural isolation to small town in an endeavour to find the combination of home location and schooling for M. They have a tentative plan to buy the small adjacent property and refurbish it as an annexe for M when he reaches adulthood. Rhiannon and M attended the same primary school. M’s behaviour was described as ‘challenging from day one’ by his father. He was educated for some time in a language resource attached to his primary school. M received a diagnosis of Asperger’s at the age of 10 and transferred to a Special Education High School in Y7. Jack rates M’s behavioural challenge as 3-5 on a scale of 0-5 when 5 is the most challenging.

**Family #7**

<table>
<thead>
<tr>
<th>NTD sister:</th>
<th>Rachel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent:</td>
<td>Joanne (mother)</td>
</tr>
</tbody>
</table>

Rachel is a 19 year old female student who has just completed her first year living away from home at university. She has chosen to study psychology. Rachel has two brothers, both of whom have diagnoses on the autistic spectrum disorder. L has had a diagnosis of Asperger’s since he was six years old. He is now 21 and work in IT. He still lives at home but has recently become engaged to his girlfriend and is talking of moving into a flat with her away. All three children attended the same local mainstream primary school. L attended a different mainstream High School to Rachel. Rachel’s younger brother, H is 13 years old and was diagnosed with autism when he was 11. H now attends the same High School.
attended by Rachel, starting there in Y7 just as Rachel was entering 6th Form. 
Rachel’s mother, Joanne works part time as a teacher. Joanne is also active in local autism support network. Her husband, J, is in full-time employment. 
The family are members of a local church and, for both Rachel and Joanne, their Christian faith is an important part of their lives. The family are looking to move house to a more private location that will better suit H’s levels of anxiety. 

Joanne rates H’s behavioural challenge as ‘4 but has been 5’ on a scale of 0-5 when 5 is the most challenging. L no longer lives at home but Joanne would rate his behavioural challenge as 3.  

| Family #8 | Polly is a 16 year old girl who has just completed her GCSEs. She has two brothers, J who is 14 and L who is 8. Both have diagnoses of autism, although doctors have told the family that L’s diagnosis may be revised to Asperger’s when he gets older. Polly attends a girls’ only grammar school, a number of miles from the family home. J attends a special school for children with MLD and additional needs including autism. J and Polly attended the same mainstream primary school for a couple of years when J first started school. J remained in reception class for the 3 years he was in school and moved to a special school when he was diagnosed with autism. L attends a local mainstream primary school. 
Polly lives at home with her mum and dad in an urban area. Polly’s maternal grandmother and her partner live close by and support the family. Polly’s maternal uncle also takes Polly out on trips. Polly is interested in studying psychology at university and currently plans a career working with people with autism. 

Nicola rates J’s behavioural challenge as 4, and L’s behavioural challenge as 3, on a scale of 0-5 when 5 is the most challenging. |
Appendix 4: Examples of NTD sisters’ drawings of current and ideal life
Appendix 5: Interview transcript extract

Can you tell me what you think I need to know about your family?

There’s M, he has anxieties, he’s 13, nearly 14, in a special school now, he moved into Special Ed for Y7. He’s not as anxious as used to be but flares up from really insignificant things. I am 5 years older. He got his diagnosis when I was about 10 or 11, I knew there was something different but I didn’t know it was autism. He went to the Sunshine Room at our primary school and that’s for children with problems so I knew then there was something wrong. It was when he started school, when I realised ‘yeah there is something about the way he speaks to his friends and the way he is with other people, there is an issue there.’

Is anxiety one of the things you most notice about your brother in comparison to other children?

Yes. I mean recently he was coming into my room and telling me he couldn’t cope as he will have to change in the swimming pool change rooms, he is worried they are too big. I said well don’t get changed, and he’s a really good swimmer so the swim will be fine there and he says ‘no I am trapped in this thing now’ and you try to talk him round but you can’t, he just gets really, really worked up about it.

He has very good verbal skills

yes, too verbal sometimes, he can go on for 20 minutes without stopping sometimes,

Is he good at identifying what is making him anxious?

Mostly yes, but if he has had an argument with someone he can just end up saying what he thinks the other person meant, but it’s very much from his point of view so getting to the bottom of that can be impossible.

As a younger child how was it?

I remember being embarrassed sometimes, especially with his tantrums, he would be in a supermarket and just go into a full tantrum and I would have to sit with him on the floor whilst a parent paid for the shopping or something, and if you were walking he would just go down onto all fours for a bit and then pop up again, just embarrassing like, ‘oh what are you doing’ and people stare at him and then they stare at you... and now I know that’s Asperger’s it’s not him being difficult, but yeah I remember thinking is he weird... the more you know about Asperger’s the easier it is to accept that you can’t do much about it

Do you remember life before M was born?

A short while yeah, we lived in Manchester in a city then, but it’s quite a faint memory [laughs]

Were you ever at the same school together?

Yeah, I was in Y5 I think it was, when he was in Y1. Something like that

How was that?

I had one friend who took the mick for a bit but he is no longer a friend. My other friends just accept him, I don’t think they really know quite what is wrong but they know he is
different and just accept that and they don’t stand back or anything. Some people have said to me, ‘oh your brother is a bit weird isn’t he? He’s a bit odd.’ They won’t say it to him but the say it to me. The thing is M always tries to engage with my friends as well so when we are in my room he will come and say ‘Hi’ and if he finds out they have a hobby he likes he just takes over.

*Do you think the four or five year age group helps you get on with each other?*

Yes it does… my friends have always been that much mature than him and they don’t get drawn in by him so much

*Do you share any hobbies even though there’s an age gap?*

We do Minecraft a lot together and he has a massive thing for the Yugi trading games, well I learnt that as well so we could have that in common, I liked them before but when he really got into them I picked them up again and carried on with them. We have quite similar interests we are both into gaming like batman and things like that together. He has quite mature tastes in those kind of games and because he sticks at things she gets to be good at them… when he is interested in something he has to know everything about it. We he was interested in fish he had to buy all these books on aquariums and he’d have to research everything about it, and the same with astronomy he had to buy all the DVDs and know everything about it. Right now he is interested in gaming so he has to buy all these books about concept design and stuff so he knows all about it and you just think wow...

*The age gap is that a good or bad thing?*

Yes, If I was younger than him for example I might not be into all that to the same extent I am now. It works I think, probably. He has never been deliberately mean to hurt me, he’s never come out and said anything mean about me personally like a little 13 year old brother might, usually the other way around, he’s never tried to wind me up deliberately, he just does not get that. He comes home and he’s seen a girl at school do that to someone else and says why would you do that? He is learning to do so now, it think, ‘cos he has learnt that from his friends and he does it a bit with his friends, but he has never done that to me.

He’s too polite to me, I think with other friends he is a bit different, but with us it’s just me and him and to be honest it was me teasing him if anything. Trips and activities when you were younger that worked for you both?

We used to do swing ball quite a bit when we lived in a really remote area. We had a field in the back garden. He was quite locked in and distant at that time but he had a trampoline and we used that a bit and we both had rabbits we looked after them together but I don’t have that many memories of properly being able [to do things together]. We used to go swimming together but he wouldn’t be able to get into the water, he would just sit by the water. He was afraid of going in… we are getting closer now I think

*So you have sought out ways to deliberately try and connect with M?*

I have tried yes, I tried trading cards, top trumps as well, it’s kind of difficult to explain because yes at first it was difficult to know where to go with it but as we get older he is getting more relaxed

*So you were conscious of deliberately wanting to build a relationship with M*
Yes, and as he is getting a lot more verbal I feel better, and I feel happier for him too because he is much happier, he has his days still, but he is much happier at school now and at home.

*Is there anything else you do to build that relationship?*
### Appendix 6: List of initial codes

<table>
<thead>
<tr>
<th>Aspirations</th>
<th>Feeling mean guilty</th>
<th>Meltdowns</th>
<th>Familiar with disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>For TD sibling to thrive</td>
<td>Family cohesion</td>
<td>Negative impact on friendships</td>
<td>House moves</td>
</tr>
<tr>
<td>Future relationship</td>
<td>Positive family activities</td>
<td>Not going out</td>
<td>Loss of opportunity or spontaneity</td>
</tr>
<tr>
<td>Mixed impact</td>
<td>Feeling things get better</td>
<td>Obsessions</td>
<td>Minimise problems with peers</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Knowledge and understanding of ASD</td>
<td>One way relationship</td>
<td>Negative impact on social life</td>
</tr>
<tr>
<td>CYP’s experiences of having a sibling with ASD</td>
<td>Bottom up understanding deductive</td>
<td>Personal space</td>
<td>Negative reaction of peers</td>
</tr>
<tr>
<td>Being second or ceding priority</td>
<td>Aggression</td>
<td>Sibling’s over reliance on me</td>
<td>Negative impact on sociability confidence</td>
</tr>
<tr>
<td>Divided family</td>
<td>Arguments</td>
<td>Volatility</td>
<td>Not being believed by peers</td>
</tr>
<tr>
<td>Missing out</td>
<td>Experiencing conflict parent and sib</td>
<td>Playmate for sib</td>
<td>Peers ignorance</td>
</tr>
<tr>
<td>Carer takes feels responsibility for</td>
<td>Sib getting own way</td>
<td>Recognises own ambivalence</td>
<td>Sense of differentness</td>
</tr>
<tr>
<td>Advocate for (carer)</td>
<td>Irritating behaviours</td>
<td>Disability benefits</td>
<td>Sib is a barrier to friends</td>
</tr>
<tr>
<td>Aware of sib’s social life</td>
<td>Lack of sleep</td>
<td>Funny times</td>
<td>Sociable</td>
</tr>
<tr>
<td>Fix it gene</td>
<td>Alienation feeling different</td>
<td>Innocence of sib kindness frankness</td>
<td>Socially skilled and confidence</td>
</tr>
<tr>
<td>Protector of sib from peers</td>
<td>Asd sib enhances my social life</td>
<td>Sib is my friend</td>
<td>Teenage years</td>
</tr>
<tr>
<td>Social mentor advisor sib</td>
<td>Associated negatively with asd sib/ prejudice</td>
<td>Seeing strengths and admiring sib</td>
<td>Trust issues</td>
</tr>
<tr>
<td>Understanding sib</td>
<td>Impact on sib</td>
<td>Stronger relationship than normal</td>
<td>Trying to educate peers</td>
</tr>
<tr>
<td>Current life</td>
<td>Parental guilt</td>
<td>The dream</td>
<td>Two worlds</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>Sort ASD we all benefit</td>
<td>Warmth towards</td>
<td>Witnessing hostility to sib</td>
</tr>
<tr>
<td>Threat to mental health</td>
<td>Psychological impact</td>
<td>Impact on TD academic progress</td>
<td>Society’s response</td>
</tr>
<tr>
<td>Anger with sib</td>
<td>Acceptance</td>
<td>School’s response pastoral support</td>
<td>Public models of asd</td>
</tr>
<tr>
<td>Anxiety caused by asd sib</td>
<td>Acting out</td>
<td>Sharing school with sib</td>
<td>Society’s ignorance</td>
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<tr>
<td>Feeling patronised by professionals</td>
<td>Affection for sib</td>
<td>Self-knowledge</td>
<td>Wishing for normality</td>
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<tr>
<td>Frustration with others</td>
<td>Anxiety mental health</td>
<td>Shapes my identity</td>
<td>Impact on family of disability</td>
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<tr>
<td>Negative impact on self confidence</td>
<td>Associates with mother</td>
<td>Exaggerates my introverted cautious side</td>
<td>Benefit of diagnosis</td>
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<tr>
<td>social life of TD sib</td>
<td>attention needing</td>
<td>'mature' and caring for others</td>
<td>impact on adults</td>
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<td>----------------------</td>
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<td>-----------------</td>
</tr>
<tr>
<td>fix it gene</td>
<td>being second priority</td>
<td>resilience</td>
<td>difficult behaviours of asd sib</td>
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<tr>
<td>caring nature</td>
<td>carer - expected to be</td>
<td>shapes career</td>
<td>dislike of asd sib</td>
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<td>deep thinker</td>
<td>carer - future</td>
<td>worries about asd and me</td>
<td>empathy for sibling</td>
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<tr>
<td>emotional response</td>
<td>carer - volunteers for</td>
<td>shared interests</td>
<td>place to relax</td>
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<td>envy of normal</td>
<td>advocate for (carer)</td>
<td>parent compensating</td>
<td>frustration and resentment to sib</td>
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<td>expectations good girl</td>
<td>information</td>
<td>parent support for sib - inform and explain</td>
<td>ambitions</td>
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<tr>
<td>exposed to issues with school</td>
<td>outside agencies</td>
<td>parent support for sib - providing a buffer</td>
<td>personal attributes temperament</td>
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<tr>
<td>family systems</td>
<td>seeing strengths in sibling</td>
<td>parent support for sib - attention</td>
<td>humour</td>
</tr>
<tr>
<td>focused driven</td>
<td>Unfair treatment</td>
<td>parental acknowledgment of different needs</td>
<td>positive relationship between sibs</td>
</tr>
<tr>
<td>maturity</td>
<td>Mother as confidante</td>
<td>parental support for sib - modelling</td>
<td>extended family and friends support network</td>
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<tr>
<td>Nature/nurture</td>
<td>considered parenting</td>
<td>protective</td>
<td>annoyed by sib</td>
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<tr>
<td>negative impact on educational attainment</td>
<td>problems with friends</td>
<td>social impact</td>
<td>argue with sib</td>
</tr>
<tr>
<td>parental stress</td>
<td>right kind of friends</td>
<td>alienation feeling different</td>
<td>peer support groups</td>
</tr>
<tr>
<td>sibs need to talk</td>
<td>socially skilled and confident</td>
<td>familiar with disability</td>
<td>ideal role of school</td>
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<tr>
<td>self-esteem high</td>
<td>teaches friends</td>
<td>Life stage issues</td>
<td>wants own quality time</td>
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<tr>
<td>self-esteem low</td>
<td>teenage years</td>
<td>house moves</td>
<td>negative impact on social life – opportunities/practical</td>
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<tr>
<td>shapes identity</td>
<td>trust</td>
<td>loss of opportunity or spontaneity</td>
<td>Coping strategies</td>
</tr>
</tbody>
</table>
Appendix 7: Quotes to Support Codes

**Code: ASD is a gift**

<Internals\case 4 cyp KP> - § 1 reference coded [0.38% Coverage]

Reference 1 - 0.38% Coverage

I wouldn’t change nothing except not arguing

<Internals\case 5 CYP BL> - § 1 reference coded [1.73% Coverage]

Reference 1 - 1.73% Coverage

well it’s part of them and it’s who they are so I’d kind of miss it ‘cos it’s part of how I grew up. And if it just went you wouldn’t know what to do anymore.

Int maybe D wouldn’t be as open to you at lunchtimes

B no, I know. He is always really joking and lively

<Internals\case 5 parent KL> - § 1 reference coded [0.24% Coverage]

Reference 1 - 0.24% Coverage

I think she loves the quirkiness of them

<Internals\Case 7 CYP RN> - § 2 references coded [1.21% Coverage]

Reference 1 - 0.14% Coverage

I have gone from [seeing it as ] a challenge to a gift now

Reference 2 - 1.07% Coverage

When you get beyond into older teens and adulthood then you are more confident and know who you are. Then you are more able to accept yourself and him too for what you are, no blame, and no guilt. In teenage years you are trying to sort out who you are and who you want to hang out with and there’s conflict and you’re torn and you don’t know what to do and it’s when everything tangles up into a mess. That is the most difficult time.

<Internals\case 8 CYP PL> - § 3 references coded [4.79% Coverage]

Reference 1 - 0.55% Coverage

Does it ever get you down?

No not really. I wouldn’t change anything ‘cos I love them the way they are

Reference 3 - 3.44% Coverage
they’ve been given a gift haven’t they, they are clever

So it’s a strength

Yes

And if someone has a sibling with ASD that wasn’t as able as your brothers

Well they’ll need them more so they can be closer to each other and that’s a gift in itself

yes
Appendix 8: Generating Candidate Themes from Codes
Appendix 9: Initial Thematic Network
Appendix 10: Deciding final themes and sub themes
Appendix 11: Researcher Positionality

**Theoretical influences**

**Social interactionist perspective**

**Joint systems approaches**

**Social model of disability**

**Schools have pastoral responsibilities**

**Academic success is a refuge from domestic challenges**

**Beliefs & assumptions**

**Peer group is powerful**

**Girls internalise problems**

**Grey literature and reading out with of literature review**

**Comments and anecdotes from peers with whom I had discussed this study**

**Narratives of parents and carers in the local ASD Support Group**

**Personal factors**

**Three daughters**

**Influences**

**White female middle class**

**Three daughters**

**25 years teacher and psychologist**