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**'I consider them to be extraordinary but not in a bad way': Growing up
with a sibling with Autism Spectrum Disorder.**

Jasmine Mason

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the
degree of Masters by Research.

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Abstract

The aim of this study is to understand what it is like to grow up with a sibling with Autism Spectrum Disorder (ASD) from the Typically Developing (TD) sibling's own perspective and how they access and utilise knowledge of ASD. The data were gathered from semi-structured email interviews with seven 16-18-years-olds who have a sibling with ASD. Template Analysis (TA) was used from an interpretive phenomenologically informed stance to thematically analyse the data. The findings highlight the importance of social care funding for services such as Short Breaks and a need for meaningful public awareness of ASD. In terms of knowledge, some participants accessed knowledge of ASD from the Internet, listening to other people's experiences and professionals and they utilised this knowledge to understand how ASD affects their sibling with ASD. Some participants spoke proudly of the distinct and unique ways that sets their sibling apart from other people, suggesting that it is possible for TD siblings to share a positive relationship with their sibling with ASD.

Glossary of terms

ASD Autism Spectrum Disorder

TD Typically Developing

PDD Pervasive Developmental Disorder

PECS Picture Exchange Communication Systems

ABA Applied Behaviour Analysis

PDA Pathological Demand Avoidance

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Chapter one: Introduction and literature review

This study aims to understand what it is like to grow up with a sibling with Autism Spectrum Disorder (ASD) from the Typically Developing (TD) sibling's own perspective and how they access and utilise knowledge of ASD. The literature was reviewed to understand what is already known about this experience and inform the study. This chapter will summarise the qualitative research identified by the review on the experiences of those who have a sibling with ASD.

1.1 Introduction

ASD is a lifelong neuro-developmental disability and is classified as a Pervasive Developmental Disorder (PDD) (American Psychiatric Association (APA), 2013). ASD affects each person differently, however, in order for a diagnosis to be made, a child will be assessed as having difficulties with social communication and interactions, fixed interests and inflexible thinking (APA, 2013). When the first UK prevalence study (Lotter, 1966) was conducted, they reported one in 2500 people with an ASD diagnosis. More recently, Baird et al. (2006) reported a prevalence rate of 166.1 per 10,000 children with an ASD diagnosis in the UK. According to Bent, Barbaro and Dissanayake (2017), among the most common reasons cited for the seemingly increase in prevalence rates is the change in diagnostic criteria and Matson and Kozlowski (2011) suggest that the increase may be due to a better awareness of ASD.

Children with ASD experience challenges on a day to day basis (APA, 2013). Some may have limited verbal speech (and some with no speech at all) and consequently, may not be able to communicate their needs and wants and others may not understand social rules such as how to begin or carry on a conversation. Children with ASD may be hypersensitive to specific sounds, lights and tastes and some may be hyposensitive and have limited (or no) attention to people and objects. As a result of those challenges compounded by inability to effectively communicate their needs and wants children with ASD may experience distress and may express this distress by screaming, crying, running away or throwing self to the floor to gain access to, or avoid items, activities, people or places. Those behavioural responses may not make sense to another person (especially someone who does not understand ASD and how it can affect children) and the child may not have the ability to appropriately communicate their reasons for their response. However, ASD affects each child differently and each child has their own abilities and needs, thus, each child will experience those challenges in a unique way or may not experience them at all. In terms of the impact of those challenges on the wider family, parents and siblings may find it difficult to communicate or interact with their child or sibling, experience disruptive behaviours and experience negative attitudes from people who do not understand ASD and how it can affect children.

Our understanding of what it is like to have a sibling with ASD for TD siblings is nested within wider research on families with children with disabilities. Intellectual disability (learning disability in the UK) is sometimes described as developmental disability. I will use the term developmental disability throughout this thesis. When I am writing about a research study that focuses on siblings of children with ASD, I will be clear about this. Three main areas of research on siblings of children with developmental disability have been carried out: (a) the impact on the psychological and social well-being of those who have a sibling with developmental disability, (b) the impact on the quality of the relationship between siblings and (c) the experiences of those who have a sibling with developmental disability (Hastings, 2013). Much of the sibling literature has examined whether TD siblings of children with developmental disability are at risk of increased problems and there is a small literature that has explored what it is like to have a sibling with developmental disability from the TD sibling's own perspective (Hastings, 2013).

Families of children with developmental disability face both direct (e.g. the increased risk of mental health difficulties and care demands) and indirect (e.g. social policies and poverty) challenges (Hastings, 2013). The Families Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) (2012) reported that parents, particularly mothers, of children with developmental disabilities have greater caring demands, increased stress levels and poorer physical and mental health compared to parents of non-disabled children. In terms of siblings, the IASSID (2012) suggested that the negative impact outcomes for TD siblings are minimal.

A limitation of the literature on TD siblings who have a sibling with developmental disability is that it has grouped together different disabilities. To give an example, Kao, Romero-Bosch, Plante and Lobato (2012) explored the experiences of siblings of children with developmental disability. Disabilities included, intellectual disability, developmental delay, cerebral palsy and various neurological disorders. Children with developmental disabilities include those who use wheel chairs and those who use Picture Exchange Communication Systems (PECS) to communicate their basic needs and wants. The needs of children with different disabilities are unique to each disability, thus, the impact on and the experiences of TD siblings, are also unique to each disability (Stoneman, 2005). To give an example, contrary to other developmental disabilities (e.g. down syndrome and cerebral palsy), ASD is an 'invisible disability' because there is no visible indicator (e.g. wheel chair) to say that someone with ASD has a disability. The term "invisible disability" (Mullins & Preyde, 2013) is an umbrella term used by disability rights advocates and disability scholars (Davis, 2005) that refers to disabilities that do not

have a physical manifestation (Mullins & Preyde, 2013). This means that TD siblings of children with ASD may experience negative attitudes from people who do not understand ASD and how it can affect children because the behaviour of a child with ASD can be misinterpreted as 'bad behaviour'. TD siblings of children with ASD have reported experiencing aggressive behaviour from their sibling with ASD and negative attitudes from the public (Mascha & Boucher, 2006; Benderix & Sivberg, 2007; Petalas et al., 2009; Petalas et al., 2012). However, not all TD siblings of children with ASD may experience aggressive behaviour and negative attitudes, and a common theme across the literature is positive experiences of having a sibling with ASD (Mascha and Boucher, 2006; Petalas et al., 2009; Petalas et al., 2012; Ward et al., 2016). Conflicting research findings have been reported, thus, to understand what is already known about what it is like to grow up with a sibling with ASD I reviewed the existing literature.

1.2 Literature review

The aim of this literature review was to understand what is already known about what it is like to grow up with a sibling with ASD from the TD sibling's own perspective.

1.2.1 Search strategy

Three databases were searched: (a) PsychINFO, (b) CINAHL and (c) Scopus and the search terms used were (famil* OR "sibling" OR "brother" OR "sister") + (disab* OR "autism" OR "additional needs" OR "special needs" OR "intellectual disability" OR "developmental disability"). These search terms were searched as abstract, title and keywords.

1.2.2 Inclusion criteria

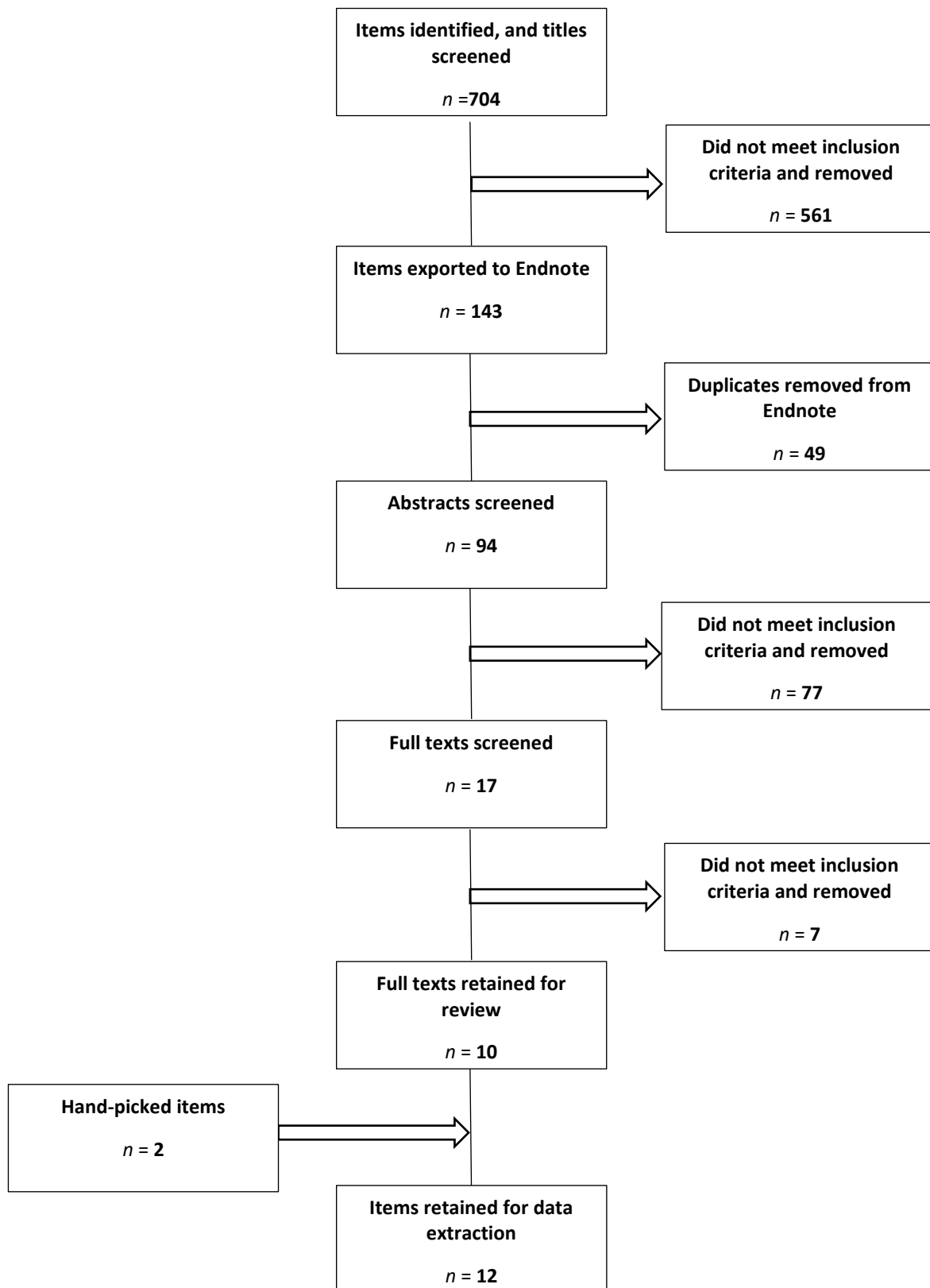
The inclusion criteria were that relevant articles should: (a) be published in English, (b) be peer reviewed, (c) be published after 2005, (d) use qualitative methods and (e) relate to TD siblings experience of growing up with a sibling with ASD. I chose to limit my search to 2005 because according to Stoneman's (2005) literature review on siblings of children with disabilities, prior to 2005, studies focused on sibling outcomes (e.g. self-concept, behaviour problems, depression, loneliness, locus of control and self-efficacy) not the experiences of TD siblings, and the aim of this literature review was to understand what is already known about what it is like to grow up with a sibling with ASD from the TD sibling's own perspective.

1.2.3 Study selection

A total of 704 items were identified. The titles were screened ($n = 704$) and titles meeting the criteria were exported to Endnote ($n = 143$). The duplicates were removed ($n = 49$) from Endnote and the abstracts of the remaining items in Endnote were screened ($n = 94$). A total of 17 full texts were

screened and ten full texts met the criteria and were retained for data extraction. A further two items were handpicked from the reference lists of identified relevant literature and also retained for data extraction. This led to the identification of 12 relevant articles - see Figure 1. Flow chart of the systematic process. Reasons for exclusion included not being related to TD siblings of children with ASD and not using qualitative research methods. Studies that did not collect data from TD siblings' own perspective were excluded because the aim of this literature review was to understand what is already known about what it is like to grow up with a sibling with ASD from the TD sibling's own perspective.

Figure 1. Flow chart of the systematic process.



1.2.4 Study characteristics

A summary of the selected literature is presented in table 1. Of 12 included studies, a total of three were conducted in the UK, three were conducted in the US, two were conducted in Australia and others were conducted in Sweden, Korea, Cyprus and Belgium. Participant sample size ranged from two (Sage & Jegatheesan, 2010) to 22 (Ward et al., 2016). The age of TD siblings ranged from 4.4 years (Bachraz & Grace, 2009) to 29.0 years (Benderix & Sivberg, 2007) and the age of siblings with ASD ranged from 3.0 years (Latta et al., 2014) to 23 years (Ward et al., 2016). In terms of methods, seven studies used interviews (semi-structured and phenomenological), three used a case study design, one used visual ethnography and one used photo elicitation methods.

Table 1. Summary of study characteristics.

Author(s)(Date) Country	Aim(s)	Number of participants Mean age SD Range	Methodological approach Method(s) of data collection	Key findings
Mascha and Boucher (2006) UK	To pilot a method designed to encourage participants to talk about their experiences of having a sibling with ASD	14 TD siblings Mean: 14.73 years SD: 2.25 Range: 11.0 to 18.0	Semi-structured interviews	Positive experiences were related to the good nature of sibling with ASD and difficult experiences were related to the aggression and bad temper of sibling with ASD.
Benderix and Sivberg (2007) Sweden	To describe the experiences of individuals who have a sibling with ASD and who were moving into a residential home	14 TD siblings Range: 5.0 to 29.0 years	Qualitative research approach Semi-structured interviews	Participants experienced frightening behaviours and feelings of empathy for their sibling with ASD. Relationships with peers were affected.
Petalas, Hastings, Nash, Dowey and Reilly (2009) UK	To explore the experiences of TD siblings who have a brother with ASD	8 TD siblings Mean = 11.19 years SD = 1.32 Range = 9.0 to 12.0	Interpretative Phenomenological Analysis Semi-structured interviews	TD siblings experienced aggressive behaviours and negative attitudes from the public. Participants reported feeling proud of and having fun with their sibling with ASD. Participants commented on formal and informal support.
Bachraz and Grace (2009) Australia	To explore the nature of sibling relationships when one child in the family has ASD	3 TD siblings Mean = 5.43 years Range = 4.4 to 6.1	Collective case study approach Semi-structured interviews and naturalistic observations	Participants received less parental attention and had additional levels of responsibility for their sibling with ASD.

Growing up with a Sibling with Autism Spectrum Disorder

Author(s)(Date) Country	Aim(s)	Number of participants Mean age SD Range	Methodological approach Method(s) of data collection	Key findings
Hwang and Charnley (2010) Korea	To explore children's experiences of living with a sibling with ASD in Korea	9 TD siblings Mean = 11.22 years Range = 7.0 to 15.0	Visual ethnography	Participants experienced feelings of shame and embarrassment.
Sage and Jegatheesan (2010) US	To understand two TD children's relationships with ASD in two culturally different families	2 TD siblings aged 7.0 years	Qualitative methodology Case studies	Participants accessed knowledge of ASD from parents.
Mouzourou, Santos and Gaffney (2011) Cyprus	To explore one family's experiences of living with a child with ASD	3 TD siblings Mean = 9.33 years Range = 6.0 to 12.0	Case study approach Semi-structured interviews and participant observations	Participants reported receiving less parental attention from parents and accessed knowledge of ASD from parents. Concerns for the future were reported.
Moyson and Roeyers (2011) Belgium	To investigate how siblings of children with ASD describe and define their quality of life	17 TD siblings Mean = 10.41 years SD = 2.26 Range = 6.0 to 14.0	Phenomenology Phenomenological interviews and focus groups	A source of support for participants was having another TD sibling. Participants enjoyed spending time with their sibling with ASD.
Petalas, Hastings, Nash, Reilly and Dowey (2012) UK	To explore the experiences of adolescents who have a sibling with ASD	12 TD siblings Mean = 15.71 years SD = 1.55 Range = 14.0 to 17.0	Interpretative Phenomenological Analysis Semi structured interviews	Participants experienced aggressive behaviours. Positive experiences were related to the personality traits of sibling with ASD.

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Author(s)(Date) Country	Aim(s)	Number of participants Mean age SD Range	Methodological approach Method(s) of data collection	Key findings
Latta et al. (2014) US	To use photo elicitation to capture perspectives of siblings living with a child with ASD	14 TD siblings Mean = 10.79 years SD = 2.29 Range = 8.0 to 16.0	Qualitative descriptive design Photo elicitation	Participants often spoke about the positive characteristics of sibling with ASD.
Cridland, Jones, Stoyles, Caputi and Magee (2016) Australia	To investigate the roles of adolescent females who have a brother with ASD	3 TD siblings Mean = 16.3 years Range = 16.0 to 17.0	Family Systems approach Semi-structured interviews	Participants had additional levels of responsibility, particularly at school, for their sibling with ASD. A growing understanding of ASD with age was reported.
Ward, Tanner, Mandleco, Dyches and Freeborn (2016) US	To explore the experiences of individuals who have a sibling with ASD	22 TD siblings Mean = 11.86 years SD = 2.90 Range = 7.0 to 18.0	Qualitative descriptive design Semi-structured interviews	Younger TD siblings reflected on how they could not play with their sibling with ASD and adolescent siblings reported learning life lessons from the experience of having a sibling with ASD.

Note: ASD, Autism Spectrum Disorder; SD, Standard Deviation; TD, Typically Developing

1.2.5 Analytical approach for synthesis

Qualitative metasynthesis is the interpretive analysis of existing qualitative research findings that contributes to an understanding of the phenomena of interest (Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004). There are various approaches to synthesising qualitative literature (e.g. meta-ethnography, meta-study) with important nuanced differences between them (Thorne et al., 2004; Barnett – Page & Thomas, 2009). The approach that I chose most closely resembles that described by Mills, Jadad, Ross and Wilson (2005), namely content analysis. The difference between a content analysis and a meta-ethnography for example, is that a content analysis does not aim to develop new conceptual understandings. The analysis took the form of four stages. The first stage of the analysis was preliminary coding. I read hard copies of each article and made notes in the left-hand margin about things that I thought were relevant to the experience of growing up with a sibling with ASD. The preliminary codes remained close to the text. The second stage involved using the preliminary codes to start defining potential themes that explained what is already known about what it is like to grow up with a sibling with ASD. I read through the articles again and the preliminary codes that I made in the left-hand margin and considered what light was shed on what it is like to grow up with a sibling with ASD. Where I felt there was something relevant, I made a note in the right-hand margin of the article. These codes were interpretive. The third stage of the analysis was to organise the themes that I had identified into meaningful clusters. To do this I thought about how each of the themes related to each other and looked for similarities and differences between the themes. The final stage of the analysis was to structure the clusters of themes into hierarchal levels of coding. This process generated four top level themes and 14 sub themes. Table 2. shows the studies contributing to each theme.

Table 2. Studies contributing to each theme.

Article	Knowledge of sibling's condition	Experiences of behaviour	Roles and responsibilities	The sibling relationship
Mascha and Boucher (2006)	X	X	X	X
Benderix and Sivberg (2007)		X	X	
Petalas et al. (2009)	X	X		X
Bachraz and Grace (2009)	X		X	
Hwang and Charnley (2010)		X		X
Sage and Jegatheesan (2010)	X			X
Mouzourou, Santos and Gaffney (2011)	X	X	X	
Moyson and Roeyers (2011)		X	X	X
Petalas et al. (2012)		X	X	X
Latta et al. (2014)				X
Cridland et al. (2016)	X		X	
Ward et al. (2016)	X	X	X	X

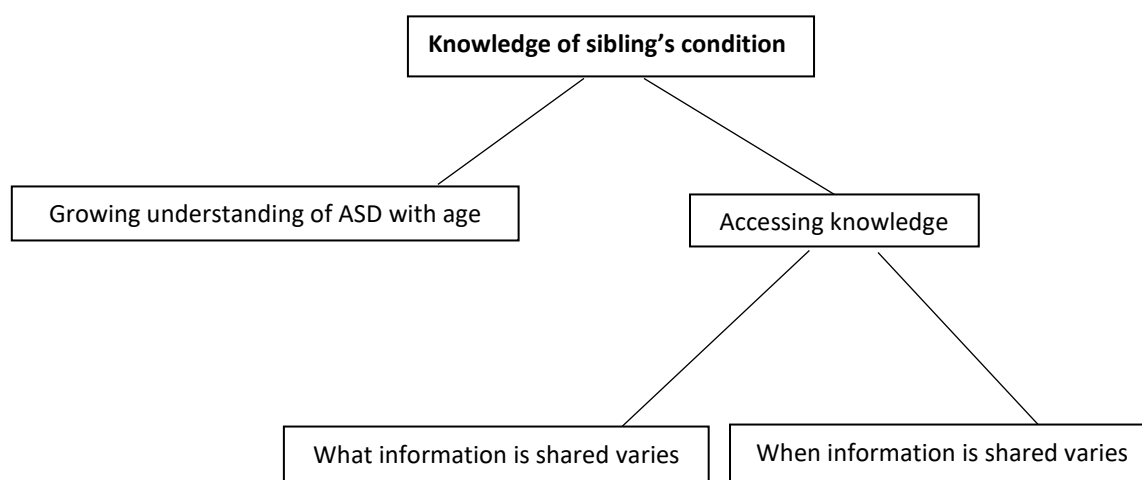
1.2.6 Results

A total of four themes was identified. These are: (a) knowledge of sibling's condition, (b) experiences of behaviour, (c) roles and responsibilities and, (d) the sibling relationship. Each theme will be discussed below.

1.2.6.1 Knowledge of sibling's condition

A total of seven studies reported findings about TD siblings' knowledge of their sibling's condition and figure 2. shows that a total of four sub themes contributed to the theme.

Figure 2. Theme one: Knowledge of sibling's condition.



TD siblings reflected on their understanding of ASD when they were young and reported a growing understanding of ASD with age (Mouzourou, Santos & Gaffney, 2011; Cridland et al., 2016; Ward et al., 2016). It was found that TD siblings knew that their sibling with ASD was different from a young age, but they did not understand why:

“When I was younger I used to see him, and I cry. I knew something is wrong with him and he is unlike me” (Mouzourou, Santos & Gaffney, 2011 p.704)

“In primary school I just knew that Matthew was different.... I had no knowledge of Asperger's whatsoever.... It's different now.... I just am more understanding of what he is like” (Cridland et al., 2016 p.201).

“I didn't really understand when I was little what was wrong with him” (Ward et al., 2016 p.72).

However, as TD siblings have got older, they have acquired knowledge about ASD, which they feel has facilitated a better understanding of their sibling. This includes, knowing that their sibling with ASD is not to blame for their behaviour (Mouzourou, Santos & Gaffney, 2011) and learning how to better communicate with their sibling (Cridland et al., 2016).

In terms of accessing knowledge, the identified literature suggests that TD siblings access knowledge about ASD from their parents. This includes, what ASD is (Petalas et al., 2009; Sage & Jegatheesan, 2010; Mouzourou, Santos & Gaffney, 2011), the challenges that their sibling with ASD may experience and the reasons for their sibling's behaviour (Mascha & Boucher, 2006). No other sources of knowledge were reported. If the only source of knowledge for TD siblings is parents, and their parents' knowledge of ASD is limited, this is an issue because TD siblings may be accessing limited knowledge, and this was suggested in the identified literature.

Mouzourou, Santos and Gaffney (2011) carried out a case study of one family's experience of having a child with ASD. The mother and the father of the family reported believing that a vaccine (Diphtheria, Pertussis & Tetanus) that their son received at two months old triggered his ASD. One of the TD siblings in the family reported that his peers at school asked what ASD is and he informed his peers that ASD is a disorder that he believes is caused by a vaccine. This suggests that the parents, in this study, may have provided their TD son with limited information about ASD because no link between vaccines and ASD has been found. Taylor, Swerdfeger and Eslick (2014) conducted a meta-analysis that aimed to quantitatively assess data from studies regarding the relationship between ASD and childhood vaccination. A total of five cohort studies involving 1,256,407 children and five case-control studies involving 9,920 children were included. The cohort data suggested no link between ASD and childhood vaccination and the case-control data suggested no evidence for increased risk of developing ASD following childhood vaccination. The belief that there is a link between ASD and vaccinations is an issue because it could lead to the risk of vaccine preventable diseases increasing. In contrast, Sage and Jegatheesan (2010) conducted two case studies on two different families who have a child with ASD. They found that the parents from one family informed their TD son that his brother with ASD processes things differently, may behave differently to other children and that some things such as light and sound may upset him. Thus, it seems that what information is shared by parents may vary across families depending on parents' own understanding of ASD.

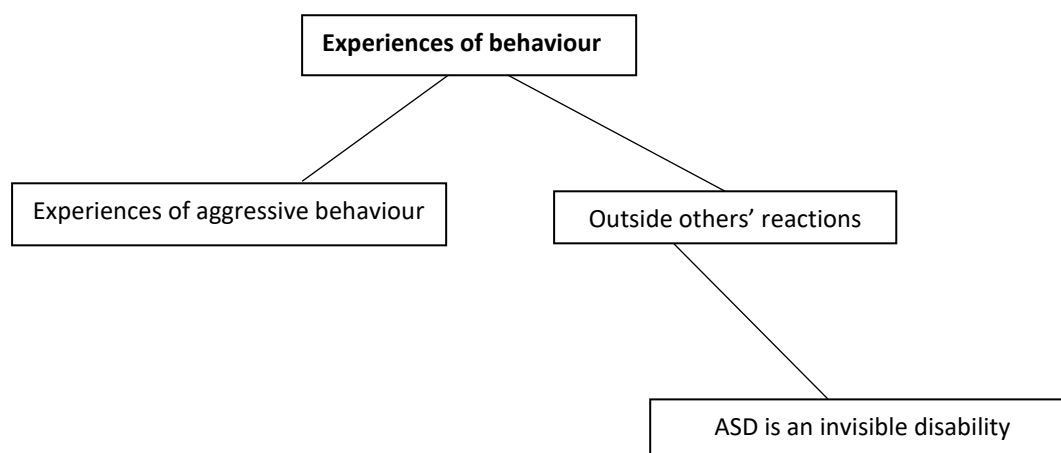
When information about ASD is shared to TD siblings may also vary across families. As mentioned, Sage and Jegatheesan (2010) carried out two different case studies on two different families who have a child with ASD. They found that one family began educating their TD son about his sibling's condition immediately after diagnosis and one family did not begin educating their TD son for almost two years post diagnosis, and from then on, provided him with limited information because they did not want him to reveal his brother's condition to the rest of the community. Similarly, Bachraz and Grace (2009) conducted three case studies on three different families who have a child with ASD. They found that the parents, across all three families, believed that their TD children were not old enough to receive information about ASD. Despite this, TD siblings did demonstrate an understanding of ASD. Thus, TD

siblings may learn about ASD through their own experiences of having a sibling with ASD or other sources. Overall, it seems that TD siblings may receive varying information based on their parents' own understanding of ASD which also may be varied and possibly limited.

1.2.6.2 Experiences of behaviour

A total of eight studies reported findings about TD siblings' experiences of behaviour and figure 3. shows that a total of three sub themes contributed to the theme.

Figure 3. Theme two: Experiences of behaviour



The identified literature suggests that some TD siblings may experience physically (e.g. hitting, kicking and destroying objects) and/or verbally (e.g. shouting and screaming) aggressive behaviour from their sibling with ASD (Mascha & Boucher, 2006; Benderix & Sivberg, 2007; Petalas et al., 2009; Mouzourou, Santos & Gaffney, 2011; Moyson & Roeyers, 2011; Petalas et al., 2012; Ward et al., 2016). However, not all TD siblings in the included studies experienced these behaviours. Mascha and Boucher (2006) reported that six of 14 TD siblings spoke of their sibling's aggressive behaviour, Petalas et al. (2009) reported that four of eight TD siblings experienced physically and verbally aggressive behaviour from their sibling, and finally, Petalas et al. (2012) reported that four of 12 TD siblings spoke of their brother's aggressive behaviour. Thus, less than half of the TD siblings, in three of the included studies, experienced aggressive behaviour from their sibling with ASD.

The aggressive behaviour exhibited by their sibling with ASD, made TD siblings feel unsafe, frightened and anxious as reported by Benderix & Sivberg (2007); angry and moody as reported by Petalas et al. (2009) and that their efforts to interact with their sibling go unrewarded as reported by Petalas et al. (2012). In terms of sampling, Benderix and Sivberg (2007) interviewed TD siblings of children with ASD who were moving into residential care (which suggests that they had high care needs and more severe ASD), thus, it was a unique sample. Those children with ASD had very little, or no, verbal language.

This may explain why they exhibited aggressive behaviour that made their TD sibling feel frightened, unsafe and anxious.

Some of the TD siblings in the studies spoke of the challenge of ASD being an 'invisible disability'. One participant reported that the most difficult part of having a sibling with ASD is:

“Trying to explain to other people what his problem is because he looks quite normal” (Mascha & Boucher, 2006 p.23).

There is no visible indicator to say that their sibling has ASD, thus, TD siblings reported experiencing negative attitudes from those who do not understand ASD. For example, one participant reported people staring at his family in public:

“People look at us in funny ways... so if he starts swearing or starts kicking, you know, it's quite embarrassing because people might think, oh you know, their mother or father taught him to do that, so it's quite embarrassing” (Petalas et al., 2009 p.388).

Another participant reported experiencing misunderstanding from the public:

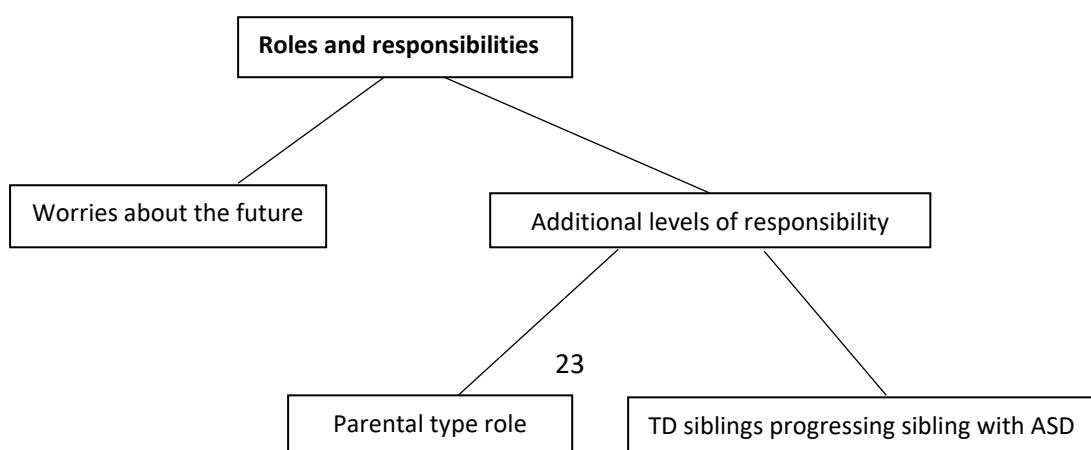
“It doesn't look like there's anything wrong with him.... When people see him walking down the street they just all look funny, it's like, why is he like that? If he's angry or agitated, some people will pass and say, oh mum can't look after him” (Petalas et al., 2012 p.308).

Whilst Mascha and Boucher (2006) found that three of 14 TD siblings reported that the most difficult part of having a sibling with ASD was other peoples' attitudes, Hwang and Charnley (2010) found that all nine TD siblings in their visual ethnographic study were frequently confronted by other peoples' reactions (e.g. pointing, staring and dehumanising terminology). Overall, some TD siblings may experience aggressive behaviours from their sibling with ASD and negative attitudes from the public. However, it was found that not all TD siblings across the 12 included studies experience those things.

1.2.6.3 Roles and responsibilities

A total of eight studies reported findings about TD siblings' roles and responsibilities as a sibling to someone with ASD and figure 4. shows that a total of four sub themes contributed to the theme.

Figure 4. Theme three: Roles and responsibilities.



The identified literature suggests that TD siblings, who have a sibling with ASD, may have additional levels of responsibility for their sibling. This includes having a parental type role, which is characterised by TD siblings being responsible for their sibling with ASD when their parents are not there (Benderix & Sivberg, 2007; Cridland et al., 2016; Ward et al., 2016). In terms of birth order, adolescent sisters, who have a younger brother with ASD, reported roles at school, which included advocating for their brother with teachers (Cridland et al., 2016) and Ward et al. (2016) found that TD siblings who have a younger sibling with ASD reported having extra responsibility. These findings suggest that TD siblings who have a younger sibling with ASD may have additional levels of responsibility for their sibling with ASD. A 'role cross over' was also found. Despite being younger than their brother with ASD, the TD siblings in Bachraz and Grace's (2009) collective case study, surpassed their sibling with ASD and assumed a 'big sister' role, which included helping their older brother with self-help tasks and academic skills. Similarly, Mouzourou, Santos and Gaffney (2011) carried out a case study of one family's experience of having a child with ASD and found that the family predicted that their youngest son will take care of and guide his older brother with ASD in the future. These findings suggest that younger TD siblings may experience a roll 'cross over' and assume a caregiving role.

TD siblings expressed worries about the future for their sibling with ASD:

"So, the first thing I've got to worry about is when he gets to high school he might get bullied" (Petalas et al., 2012 p.310).

"When I think about my brother and his future I feel sorry for him.... I also think about what will happen when our parents die, because neither my siblings nor I will ever take care of him as they have done" (Benderix & Sivberg, 2007 p.414).

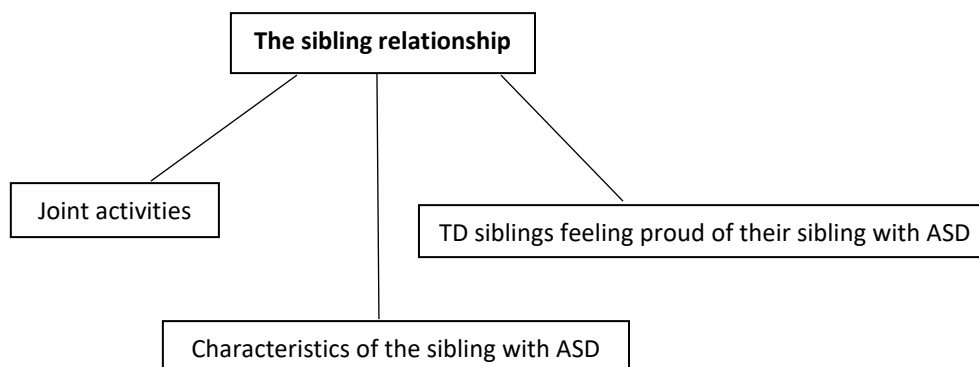
The most frequently reported worry was that their sibling with ASD will experience bullying at high school (Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Mouzourou, Santos & Gaffney, 2011; Petalas et al., 2012). Worries also extended beyond the school years to whether their sibling will get a job and whether they will be able to live independently (Benderix & Sivberg, 2007; Moyson & Roeyers, 2012; Petalas et al., 2012). Mascha and Boucher (2006) also found that six of 14 TD siblings were concerned about their own future responsibilities for their sibling with ASD.

It seems that some TD siblings may experience additional levels of responsibility for their sibling with ASD, experience worries about their sibling's future and their own future responsibilities, and some younger TD siblings may experience a 'role cross over' and assume a caregiving role for their sibling with ASD. However, the level of the caring role and concerns for the future will be dependent on the level of functioning of the child with ASD.

1.2.6.4 The sibling relationship

A total of seven studies reported findings about TD siblings' relationship with their sibling with ASD and figure 5. shows that a total of three sub themes contributed to the theme.

Figure 5. Theme four: The sibling relationship.



In the included studies, TD siblings recounted times that they enjoyed interacting with their sibling with ASD; spoke positively of their sibling's qualities and traits and reported feeling proud of their sibling. In doing so, TD siblings were able to describe a positive sibling relationship with their sibling with ASD:

"He's really nice sometimes.... At night's we'd always go into one of our rooms and play paper games... noughts and crosses, and hangman.... And watch TV in his room" (Petalas et al., 2009 p.390)

"He's a very sweet boy.... He has brought a lot of joy into our family" (Ward et al., 2016 p.72).

Various shared activities were reported by TD siblings including watching television with their sibling with ASD, imaginative play (e.g. playing train together), playing games (e.g. noughts and crosses and hangman), tickling one another, playing video games together, bike riding and playing baseball (Mascha & Boucher, 2006; Petalas et al., 2009; Sage & Jegatheesan, 2010; Moyson & Roeyers, 2011; Petalas et al., 2012). However, the extent to which TD siblings can engage in joint activities with their sibling may depend on how their sibling is affected by ASD (e.g. their sibling's ability to engage in reciprocal exchanges). Some TD siblings' experiences of joint activities with their sibling may only be watching television together because it requires no reciprocal exchange from the individual with ASD. Older children, or adolescents, with ASD may have developed skills in reciprocal exchanges over time at school for example, thus, other TD siblings' experiences of joint activities with their sibling with ASD may be more complex activities (e.g. turn taking games).

Although some TD siblings did speak about their sibling's aggressive behaviour (please see section 1.2.6.2), TD siblings also spoke about their sibling's good nature and described their sibling with ASD

as someone who is funny, loving, smart and fun to be around (Mascha & Mascha, 2006; Petalas et al., 2009; Sage & Jegatheesan et al., 2010; Petalas et al., 2012; Ward et al., 2016). Finally, some TD siblings spoke of their sibling's achievements (Petalas et al., 2009; Hwang & Charnley, 2010; Petalas et al., 2012), no matter how big (e.g. communication skills getting better) or small (e.g. taking part in a competition) TD siblings acknowledged the importance of these achievements, suggesting that they understand the challenges that their sibling with ASD may experience:

"I think slowly his listening is getting better. He can talk better now. Before he couldn't say what he really meant all the time but now he can finish what he is saying by using full sentences.... He can understand me. For example, he answers my questions and he now tells me what I want to eat, and he completes his sentences" (Hwang & Charnley, 2010 p.588)

"Last year, I'm not quite sure, he won a computer by doing horse riding. He didn't win, but he got it for doing so well, which I was really pleased by him for doing that" (Petalas et al., 2009 p.391).

Overall, the findings suggest that TD siblings reported that they were able to share a positive relationship with their sibling with ASD, however, the extent to which TD siblings can engage in joint activities with their sibling may depend on how their sibling is affected by ASD.

1.2.7 Conclusion

The aim of this literature review was to understand what is already known about what it is like to grow up with a sibling with ASD from the TD sibling's own perspective. The identified literature suggests that TD siblings access knowledge about ASD from their parents and what information is shared with TD siblings may vary across families based on parents own (possibly limited) understanding of ASD. Some TD siblings may experience aggressive behaviour from their sibling with ASD, and negative attitudes from the public. However, the identified literature also suggests that not all TD siblings experience these things. Both older and younger TD siblings of children with ASD may have caregiving responsibilities and some TD siblings may have worries about the future for their sibling with ASD and their own future role and responsibility for their sibling. Finally, the identified literature suggests that TD siblings can share a positive relationship with their sibling with ASD. Therefore, in conclusion, TD siblings' experiences of growing up with a sibling with ASD is varied and this may be because each child is affected by ASD differently.

1.2.8 Limitations

There are several limitations of the present literature review. A limitation of the search strategy was a failure to use methodological terms (e.g. qualitative, phenomenology, interviews) in addition to the subject terms. Dixon-Woods, Booth and Sutton (2007) suggest that methodological terms increase the specificity in retrieving qualitative studies, thus, relevant literature may have been unidentified. Due

to time constraints, the search terms were not replicated across other databases (e.g. Medline, PubMed, Embase, Cochrane), again, this may have resulted in unidentified relevant literature. A quality appraisal (e.g. Critical, Appraisal Skills Programme) of the identified literature was not carried out, thus, studies without methodological rigour may have been included. Finally, data were extracted and reviewed by one person. Consequently, themes may have been missed or interpreted differently.

A limitation of the identified literature is that eight of the 12 studies grouped together child, adolescent and adult participants. Children, adolescents and adults are at different points in the life cycle, they have different needs and may experience things differently. There is a small amount of research that has explored the experiences of adolescent TD siblings. Of the 12 studies, two (Petalas et al., 2012; Cridland et al., 2016) interviewed adolescent siblings about their experiences of having a sibling with ASD and to my knowledge there has been one study conducted in the UK (Petalas et al., 2012). Thus, the aim of this study is to understand what it is like to grow up with a sibling with ASD from the TD sibling's own perspective and the inclusion criteria will be TD siblings aged 16 to 18 years old. There is limited research about TD siblings' knowledge of ASD. Thus, this study aims to understand how TD siblings access and utilise knowledge of ASD.

Chapter two: Methods

This chapter begins by presenting the aim(s) of the study, I will then go on to explain the methodological approach of the study. I chose to use Template Analysis (TA) from an interpretive phenomenologically informed stance. Thus, I will explain some of the key concepts and my understanding of transcendental (descriptive) and existential, or hermeneutic, (interpretive) phenomenology. I will then consider phenomenology as a research methodology and justify my choosing of an interpretive phenomenologically informed stance for this study and explain what TA is. I will outline the procedure, discuss ethics and outline the method of analysis.

2.1 Aim(s)

The aim of this study is to understand what it is like to grow up with a sibling with ASD from the TD sibling's own perspective and how they access and utilise knowledge of ASD.

2.2 Phenomenology as a philosophy

There is not a single agreed method of carrying out phenomenologically grounded research (King & Brooks, 2017). This, as well as the complex terminology and philosophy (Ihde, 1986), can be a difficulty for the novice researcher. Despite this, an understanding of the terminology and philosophy is inherent to phenomenology as a research methodology. Thus, I will first consider phenomenology as a philosophy and this will aid the application of phenomenology as a methodology for this study.

Phenomenology has derived from the philosophy of Edmund Husserl (1859-1938). Husserl challenged the methods used by the natural sciences to examine human experience. He believed that scientists posed their own theories, on the topic under investigation, in order to formulate explanations (King & Horrocks, 2010), and suggested that science needed to set aside these preconceptions and focus on the '*things in their appearing*' (Husserl, 1931; 1960).

Phenomenology is concerned with human experience (King & Brooks, 2017). It is the meaning that humans attach to phenomena that create the existence and the reality of phenomena for humans. Thus, the notion of an objective reality is questionable (Spinelli, 2005). Although an objective reality does exist, that is independent of human interpretation, Husserl (1931; 1960) argued that the objective reality is unknowable because humans only have access to the phenomena through their awareness of it. Thus, it is subjective experience that becomes reality (Spinelli, 2005), and the reality is open to more than one interpretation, and broadly speaking, phenomenological research is concerned with making sense of peoples' reality of their experience (King & Brooks, 2017).

Central to Husserl's transcendental phenomenology (and subsequent strands of phenomenology, e.g. Merleau-Ponty's (1908-1961) existential phenomenology) is the concept of *intentionality*.

Intentionality refers to Husserl's idea that when humans are conscious, they are always conscious of something (Husserl, 1931; 1960). Thus, the self and the world cannot be separated. *Intentionality* is the correlation between what it is we experience (the *noema*) and how it is experienced (the *noesis*) (Moustakas, 1994), and Husserl wanted to explore the relationship between the *noema* and the *noesis*.

As mentioned, Husserl wanted to discover the '*things themselves*'; the way in which phenomena appear to human consciousness (Hammond, Haworth & Keat, 1991). He believed that by employing phenomenological methods (e.g. *epoche*, *phenomenological reduction*, *imaginative variation*) it is possible to transcend bias and presupposition to discover concrete and meaningful experience as it is experienced and perceived (the *lifeworld*) (King & Horrocks, 2010). Once this is achieved, it becomes possible for the *essence* of experience to be identified. For Husserl, the *essence* of a phenomenon is the reality of something and not what something may appear to be (Grieder, 1999). However, the extent to which said phenomenological methods are achievable is debated; transcendental phenomenologists (e.g. Giorgi, 1992) argue that it is, whereas existential phenomenologists (e.g. Merleau-Ponty, 1945;1962) reject the idea that it is possible for humans to step outside of experience because we are inherently 'in-the-world' (through *intentionality*) and are therefore inseparable from it (King & Horrocks, 2010).

2.2.1 The existential turn

The existential turn is characterised by a shift from Husserl's epistemological (how we know what we know) focus to Heidegger's (1927-1976) ontological (what we can know) focus.

According to Brooks (2015), Heidegger was interested in how each individual experiences living in and among the world in their own way. Heidegger posits that humans are always situated in context. Thus, to understand someone's reality, both detailed experience and the bigger picture (e.g. language, temporality, history and culture) needs to be understood. This is known, within phenomenology, as the *hermeneutic circle* because neither the whole nor the individual parts can be understood without reference to the other (Brooks, 2015). In summary, my understanding is that descriptive phenomenology is concerned with the *essence* of experience and interpretive phenomenology is concerned with understanding meaning.

2.3 Phenomenology as a research methodology

I will now consider phenomenology as a research methodology and justify my choosing of an interpretive phenomenologically informed stance for this study.

As previously mentioned (in section 2.2), there is not a single agreed method of carrying out phenomenological research. It is a broad church of approaches (King & Brooks, 2017) that includes descriptive and interpretive phenomenology and each approach has their own philosophical underpinnings and methods. According to Langridge (2007), descriptive phenomenology is the most traditional approach to phenomenological psychology. It aims to describe the *essence* of phenomenon through *epoche* and *phenomenological reduction* and data is collected through detailed and rich descriptions of experience. Interpretive phenomenology moves away from the search for *essence* and is concerned with hermeneutics and interpretation. Interpretive phenomenology aims to understand the meaning of experience and how people perceive an experience (Langridge, 2007), and is therefore an appropriate methodological approach for this study because I want to go beyond description and understand how TD siblings perceive their experience of growing up with a sibling with ASD from their own perspective.

Interpretive phenomenology considers the role of the researcher in the research process because the researcher cannot entirely step out of their own position in producing the analysis (King & Horrocks, 2010), and this was an additional practical reason for my choosing of an interpretive phenomenologically informed stance for this study. My interest in the phenomenon under investigation derived from working with children who have ASD and their families. I have worked as an Applied Behaviour Analysis (ABA) tutor for over two years with eight different children and their families in their homes. This involved working one to one with children and their families to teach children with ASD communication, self-help, social and academic skills. Whilst working as an ABA tutor, I got to know the siblings of the children that I worked with and because I worked in the family home, I sometimes formed personal relationships with the whole family. I do not believe that it was possible for me to fully *bracket* off my preconceptions and experiences for this research project because I have already formed my own opinions and ideas about the experiences of those who have a sibling with ASD. Thus, my interpretation of the data will be different to someone who has not worked with children who have ASD. I also recognise that the experience and knowledge that I have of ASD is professional experience and is not personal experience. Thus, my interpretation of the data will also be different to someone who has personal experience and knowledge of ASD. Interpretive phenomenology allows me to think about my own assumptions about the research topic and consider how these assumptions might have influenced the data that emerged and the analysis.

2.4 Template Analysis

Qualitative researchers have developed various ways in which textual data can be analysed (King & Brooks, 2017). Many of these ways can be described as ‘thematic’ approaches that aim to identify themes in a data set. Some methods are encompassed in a wider methodology and are grounded in

particular philosophical assumptions, such as Grounded Theory (Glaser & Strauss, 1967) and Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). Other methods, such as Braun and Clarke's (2006) approach to thematic analysis and Template Analysis (TA) (King & Brooks, 2017) are not encompassed in a wider methodology and are thus, not grounded in particular philosophical assumptions (King & Brooks, 2017). TA is a form of qualitative data analysis and King and Brooks (2017) characterise it as a style of thematic analysis, which aims to balance both flexibility and structure in how it manages textual data. A coding structure is constructed, which organises levels of hierarchical coding (King & Horrocks, 2010). I chose to take an interpretive phenomenologically informed stance for this research project because I wanted to understand how TD siblings perceive their experience of growing up with a sibling with ASD from their own perspective. TA allowed me to do this because as King and Brooks (2017) explain, the onus is on the researcher to choose and clearly explain their philosophical position.

I chose TA rather than another approach to analysis (e.g. IPA) due to practical reasons. IPA stipulates that all data, typically interviews, must be collected before data analysis can begin and analysis usually proceeds on a case by case basis (Forrester, 2010; King & Horrocks, 2010), and this was not practical for this MSc study. Other studies have successfully used TA from a phenomenologically informed stance. To give some examples, Turley, Monro and King (2017) used TA phenomenologically to explore the lived experience of participating in consensual bondage, discipline, dominance and submission, and sadism and masochism and King, Carroll, Newton and Dornan (2002) used TA to examine the experience of adaption to diabetic renal disease from a phenomenological perspective.

2.5 Procedure

The following sections will explain the procedure of carrying out this study. I will explain how I recruited participants, the method of data collection, ethical procedures and finally the method of data analysis.

2.5.1 Recruitment and participants

As mentioned (in section 1.2.8), there is limited literature on the experiences of TD adolescents who have a sibling with ASD. Thus, the inclusion criteria were TD 16 to 18 years old with a sibling with ASD. Adolescents are likely to be in a phase of the life cycle where they may be planning their own future (e.g. thinking of where to apply to University or thinking about a job they may like) but still living at home with their sibling with ASD. This means that participants may be able to reflect on their experiences and also think about the future. Siblings older than 18 may not be living at home with their sibling with ASD and recruiting siblings younger than 16 presents ethical challenges that I did not have time to respond to due to the time constraints of a MSc research project.

Growing up with a Sibling with Autism Spectrum Disorder

The inclusion criteria for disorders of siblings with ASD is: Autism, Asperger Syndrome, Pervasive Developmental Disorder (PDD), Global Developmental Delay with Autistic Tendencies, Pathological Demand Avoidance (PDA) and siblings going through the diagnosis process.

I wanted to collect individual and detailed accounts about the experience of growing up with a sibling with ASD, thus, a small sample of participants was suitable. I aimed to recruit no less than six participants and no more than ten participants.

Following ethical approval from the School Research Ethics Panel (SREP) (please see appendix 1 for the SREP application) at the University of Huddersfield, opportunistic sampling was used to recruit participants through social media. An advert for the recruitment of participants (please see appendix 2 for the recruitment advert) was posted on Facebook pages which were local and national support groups for families affected by ASD. Permission from the person in charge of the Facebook pages was obtained before the advert was posted. The advert informed prospective participants to email the researcher if they wished to take part in the research project. Prospective participants were emailed an information sheet (please see appendix 3 for the participant information sheet) and a link to Qualtrics to fill in an online consent form (please see appendix 4 for the consent form).

I was able to recruit seven participants. There were two participants who responded to the recruitment advert who were not eligible for the study due to their age and three individuals showed an initial interest but then declined. Participants were aged between 16 and 18 years old, and their siblings with ASD were aged between five and 16 years old. In terms of gender, five participants were female, and two participants were male. In regard to birth order, all participants were older than their sibling with ASD. Finally, all participants identified as White. A summary of participant information is presented in Table 3. and a biographical summary of each participant is presented below (pseudonyms have been used).

Olivia

Olivia is a 16-year-old female and she has a 14-year-old brother (Ben) with ASD. Olivia and Ben attended the same primary school and now they attend the same secondary school, where Olivia is in her final year. Olivia and Ben both live at home with their mum and dad.

Christopher

Christopher is a 17-year-old male and he has a 15-year-old brother (James) who has global developmental delay with autistic tendencies. Christopher also has an older brother (Josh) and an older sister (Leanne). Christopher and James live with their mum and dad at home, and Josh and Leanne are living away from home.

Growing up with a Sibling with Autism Spectrum Disorder

Jenny

Jenny is a 16-year-old female and she has a 13-year-old sister (Gemma) and a five-year-old brother (Edward) with PDA. Edward and Jenny do not share the same dad. Jenny also has another younger sister (Bethany). Jenny lives at home with her mum, step-dad, Gemma, Edward and Bethany and stays at her dad's house on a weekend.

Jacob

Jacob is an 18-year-old male and he has a 12-year-old brother (David) with ASD. Jacob also has another younger brother (Thomas) who is nine-years-old and an older brother (Daniel) who is 20-years-old. Jacob, David and Thomas live at home with their mum and dad, and Daniel lives away from home at University.

Rachel

Rachel is a 17-year-old female and she has a six-year-old brother (Gareth) with ASD. Rachel also has two sisters (Charlotte and Georgia). Gareth received his diagnosis one year ago and goes to a school for children with Special Educational Needs (SEN). Rachel lives at home with her mum, her mum's fiancé, Gareth, Charlotte and Georgia. Rachel occasionally sees her dad throughout the year.

Becky

Becky is an 18-year-old female and she has a 16-year-old sister (Ellie) with ASD. Ellie received her diagnosis when Becky was seven-years-old. Becky and Ellie live at home with their mum and dad.

Alesha

Alesha is an 18-year-old female who has a seven-year-old brother (Adam) with ASD and a five-year-old sister (Chloe) who is currently going through the diagnostic process. Alesha also has another sister (Jersey). When Alesha was doing her GCSE's, she became a young carer for Adam. This would mean getting Adam ready for school in the morning (e.g. making his breakfast, getting him dressed and, brushing his teeth) and when he got home from school she would get him ready for the evening (e.g. making his tea and bathing him). Alesha, Adam, Chloe and Jersey live at home with their mum and step-mum.

Table 3. Summary of participant information

Participant pseudonym	Gender	Age	Ethnicity	Pseudonym of sibling with ASD	Gender of sibling with ASD	Age of sibling with ASD	Has the participant ever received free school meals?
Olivia	Female	16-years-old	White British	Ben	Male	14-years-old	No
Christopher	Male	17-years-old	White British	James	Male	15-years-old	No
Jenny	Female	16-years-old	White British	Gemma Edward	Female Male	13-years-old Five-years-old	Yes
Jacob	Male	18-years-old	White British	David	Male	12-years-old	No
Rachel	Female	17-years-old	White European	Gareth	Male	Six-years-old	Yes
Becky	Female	18-years-old	White British	Ellie	Female	16-years-old	No
Alesha	Female	18-years-old	White British	Adam Chloe	Male Female	Seven-years-old Five-years-old	Yes

2.5.2 Method of data collection

Traditionally, phenomenological interviews are carried out face to face. However, I collected data using online, asynchronous emails. I believe that email interviews are suitable for adolescents because they allow participants to participate in their own space, at their own pace and at the time of their choosing. This may be particularly suitable for 16 to 18-year-olds who may be in their final year of high school and doing their GCSE's or be in sixth form/college and doing their A-levels. McDermott, Hughes and Rawling's (2017) study of the behaviour of vulnerable adolescents highlight online research methods as beneficial for helping to preserve the anonymity of vulnerable participants. Although the participants in the present research project were not necessarily vulnerable, they are a group of young people who may have found it difficult to talk about a sensitive topic face to face. Online research methods allowed me to engage young people in research and capture their individual accounts of their experience of growing up with a sibling with ASD from their own perspective. Online methods also facilitated the inclusion of participants who were geographically distant.

Following informed consent, participants were emailed a link to Qualtrics asking them to fill in an online survey (please see appendix 5 for the online survey), detailing their age, gender, ethnicity, the age of their sibling with ASD, their living arrangements and information regarding their socio-economic status.

I needed to choose a method of data collection that produced an account of the participants personal experience, and semi-structured interviews provide participants with the freedom to express their own thoughts and feelings. Semi-structured interviews also facilitate a rapport between researcher and research participant, which minimises the power imbalance between researcher and participant (Busso, 2007; Smith, 2008), and Kazmar and Xie (2008) suggest that a rapport can be built with online participants allowing interviews of depth to be carried out.

I developed a qualitative topic guide of six questions:

1. Can you tell me what it has been like to grow up with a sibling with ASD?
2. Can you tell me about information, or anybody that has helped you understand (insert name here) disability?
3. Please could you explain how living with a sibling with ASD when you were younger is different to living with a sibling now that you're (insert age here) years old?
4. What has helped and supported you through the difficult times, or, what has helped and supported you through the already difficult times?
5. Do you know anybody else who has a sibling with ASD?
6. What are your thoughts and feelings about the future?

Participants were emailed one interview question per week and participants were also sent probe questions so that they could expand on their initial answers and I could obtain more depth in their response. I did not prepare probe questions prior to the interviews, I devised them during the interviews following initial responses. To give an example, when asked what it has been like to grow up with a sibling with ASD, Olivia spoke about how she walks her brother with ASD to school (the same school as hers) so that he gets there safely and on time. I found this interesting, thus, I sent Olivia two probe questions: (a) you mentioned that you walk Ben to school, how do you feel about this? (b) you also mentioned that you and Ben go the same school, please could you tell me more about that - how do you feel about you and Ben going to the same high school?

A total of seven interviews were carried out. Of the seven interviews, four were complete and three were incomplete due to participant withdrawal, participant none response and time constraints. Of the completed interviews, the longest interview was 4271 words, the shortest interview was 2201 words and the average word count was 3465 words. The data was rich and detailed enough for a phenomenological analysis. The data included reflections, detailed descriptions of specific experiences and thoughts and feelings. A summary of information about the data is presented in Table 4.

Table 4. Information about the interview data

Interview transcript	Complete/Incomplete	Word count
Olivia	Complete	2207
Christopher	Incomplete	757
Jenny	Incomplete	1922
Jacob	Complete	4721
Rachel	Complete	3864
Becky	Incomplete	1301
Alesha	Complete	3525

2.5.3 Ethics

The research project was reviewed by the SREP at the University of Huddersfield and full ethical approval was obtained on the 13.01.17.

2.5.3.1 The age of participants

Individuals under the age of 18 participated in this study. Arguably, it would have been unnecessary to obtain parental consent. Both the British Psychological Society (BPS) (2011) Code of Human Research Ethics and the National Children's Bureau (NCB) (2011) Guidelines for Research with Children and Young People (CYP) state that for research involving CYP under the age of 16 the consent of a parent is required. Thus, it was unnecessary to obtain parental consent because the young people who participated in this study were not under the age of 16. The Health Research Authority (HRA) (2014) highlights that common law presumes, that in most cases, young people aged 16 to 18 are competent to give consent for treatment, and in the absence of law relating to research, the principles of *Gillick competence* can be applied.

I recognised that competence to understand was influenced by how information was presented. Thus, I maximised participant understanding of what participating would entail by asking two young people, outside of the study (a male aged 17 and a female aged 18), to give feedback on the participant information sheet and consent form. Feedback included not fully understanding terms such as *confidentiality*. Thus, I explained said terms in simple language in the participant information sheet (please see appendix 3). However, the understanding of complex information may depend on educational level. Thus, I also put the information through a Flesch-Kincaid reading age test, which indicated that the reading age of the participant information sheet and consent form (please see appendix 4) was 14 to 15 years. The HRA (2014) also state that although consent from those with parental responsibility is not legally necessary for those aged 16 to 18, it is good practice, where possible, to involve parents and carers in the decision making as to whether or not to take part in research. Thus, the participant information sheet suggested participants discuss their involvement with their parents/carers.

2.5.3.2 The unplanned disclosure of information

I recognised that there was a risk of the unplanned disclosure of information that I would be obliged to act on. The NCB (2011) guidelines highlight that when carrying out research with CYP child protection procedures should be in place. Thus, I developed a procedure for reporting risks and adverse events. Please see Table 3. for the risk inventory which details the level of risk, possible risk and the procedure for reporting the risk to the appropriate authority. In the event that a participant revealed that they were at a medium risk or they or anybody else were at high risk, it would have been

necessary to break confidentiality. However, this was outlined in the participant information sheet. Additionally, participants were required to consent to the researcher contacting the appropriate authority.

2.5.3.3 Confidentiality

Information regarding participants was only known to the research team. King and Horrocks (2010) highlight that the nature of the Internet means that absolute confidentiality cannot be promised when carrying out interviews via email (e.g. system administrators have access to University email account). To minimise the risk of the inadvertent disclosure of information interview data was transferred to a word document and the raw data was deleted from the University email account.

2.5.3.4 Anonymity

Participants remained anonymous throughout the research process. I asked participants for their full name, Date of Birth (DOB) and the first half of their post code on the Qualtrics survey. To ensure anonymity, I kept this information separate from their data and a coding system was used where numbers in an excel spreadsheet needed to be matched against names, DOB's and post codes. Each interview was electronically saved anonymously (e.g. participant one). The aims of the research did mean that there may be concerns regarding the anonymity of the individual with ASD. However, participants were not asked to disclose personal information about their sibling or directly talk about their sibling, they were asked about their own experiences. Finally, both the research participants and their siblings were given pseudonyms and where necessary, quotes have been edited so that participant and sibling identities are not disclosed.

2.5.3.5 Right to withdraw

Participants were given the right to withdraw throughout the interviews. Participants also had the right to withdraw any data up until the 01.05.17. This was detailed in the participant information sheet and participants were required to consent to this.

2.5.3.6 Psychological support

Psychological support for participants was detailed in the debrief document (please see appendix 6 for the debrief document).

2.5.3.7 Data protection and storage

In line with the University guidelines, interview transcripts will be stored on the University data drive for 10 years.

Table 5. Risk inventory detailing the level of risk, possible risk and the procedure, recommended by the CCPAS, for reporting risk to the appropriate authority.

Level of Risk	Possible risks	Procedure for reporting risk
High	<ul style="list-style-type: none"> • Participant reveals that they or anybody else are in a life-threatening situation 	<p>The Researcher would call 999 and give the participants name, DOB and, the first half of their post code. Participants will be required to give this information in their consent form and survey</p>
Medium risk number one	<ul style="list-style-type: none"> • Participant reveals that their sibling with autism is physically hurting them • Participant reveals that they are being physically/emotionally/sexually abused by any other person • Participant reveals that they are being neglected 	<p>The researcher would contact the Local Authority (LA) that the participant belongs to, and report the details of the risk (including participant details) to the local duty and advice team. The researcher will be able to identify which LA that the participant belongs to through the first half of their post code. To give an example, if a participant revealed that are at risk of medium harm and the first half of their post code was LS29, the researcher would contact the Leeds duty and advice team (0113 3760336) and report the medium risk to a social worker</p>
Medium risk number two	<ul style="list-style-type: none"> • Participant reveals that someone else is being physically/emotionally/sexually abused by any other person • Participant reveals that someone else is being neglected • Participant reveals that their parents/carers are suffering from mental health difficulties 	<p>The researcher will contact the LA that the participant belongs to and report the details of the risk to the local duty and advice team. However, the source of the information will not be disclosed to the LA without permission from the participant</p>
Low	<ul style="list-style-type: none"> • Participant reveals that they are feeling sad 	<p>The researcher would give the participant information on where they can seek help/advice/support from the following places:</p>

Level of Risk	Possible risks	Procedure for reporting risk
	<ul style="list-style-type: none"><li data-bbox="817 228 1422 343">• Participant reveals that they are suffering from mental health difficulties (e.g. feeling depressed or anxious)<li data-bbox="817 343 1422 413">• Participants reveals that they or anybody else are being bullied	(a) Their school pastoral/counselling team, (b) Sibs – The UK charity for brothers and sisters of disabled children and adults or, (c) Their GP.

2.5.4 Data analysis

There are seven (main) procedural steps to follow when utilising TA. However, King and Brooks (2017) clearly outline that researchers should adapt these to the needs of their own research project. I will now explain how I utilised TA for this study.

2.5.4.1 Stage one of data analysis

The first step of data analysis was to familiarise myself with the data which I did by reading through the email interviews several times. I began analysis with a subset of data (Jacob, Alesha & Olivia) which represented a good cross section of my whole data set. The subsample varied in terms of age, gender, number of siblings with ASD and proximity in age of siblings.

2.5.4.2 Stage two of data analysis

The second step of data analysis was preliminary coding. I made notes in the left-hand margin of paper copies of the transcripts about things that I thought were relevant to the participant's experience of growing up with a sibling with ASD and how they accessed and utilised knowledge of ASD. Although I was doing an interpretive analysis, the preliminary codes remained close to the data. Examples of some of the preliminary codes are presented in table 6.

Table 6. Stage two of data analysis: Examples of preliminary coding.

Interview transcript	Preliminary codes
Jacob	Age Sibling's achievements Listening to other peoples' experiences Social support Thoughts about the future Roles and responsibilities Parents' feelings Reflective Brother's behaviour

2.5.4.3 Stage three of data analysis

The third step involved using the preliminary codes to start defining potential themes that explained the participants' experience of growing up with a sibling with ASD and how they access and utilise knowledge of ASD. A theme is defined by King and Horrocks (2010) and King (2012) as a recurring and distinctive aspect of participants' accounts which the researcher feels is relevant to the research question(s). I read through the transcripts again and the preliminary codes that I made in the left-hand margin and considered what light was shed on participants' experiences of growing up with a sibling with ASD and how they access and utilise knowledge of ASD. Where I felt there was something relevant, I made a note in the right-hand margin of the transcript. Codes relating to participants'

experiences of growing up with a sibling with ASD were interpretive and codes relating to how they access and utilise knowledge of ASD remained close to the data. Examples of the second stage of coding are presented in Table 7.

Table 7. Stage three of data analysis: Examples of second stage of coding.

Interview transcript	Preliminary codes	Second stage of coding
Jacob	Sibling's achievements	Comparisons to TD children
	Reflective	Perception changes with age
	Age	Growing understanding of sibling's condition with age
	Listening to other peoples' experiences	Utilising knowledge of sibling's condition

2.5.4.4 Stage four of data analysis

The fourth stage of the analysis was to organise the themes that I had identified into meaningful clusters. To do this I needed to think about how each of the themes related to each other. For example, I clustered the themes of; growing understanding of sibling's condition with age, accessing knowledge of sibling's condition and utilising knowledge of sibling's condition because they are all concerned with participants' knowledge of their sibling's condition.

2.5.4.5 Stage five of data analysis

The fifth stage was to produce an initial template (please see Figure 6. for the initial template). This involved the structuring of the clusters of themes into hierarchical levels of coding. A specific number of levels of coding is not stipulated (King & Brooks, 2017). The theme of impact had five levels of coding, whereas the theme of thoughts about the future had three levels of coding. I used three subthemes to explain the theme of impact and within the subthemes deeper levels of coding were used to identify distinctions. For example, the subtheme of emotional impact explains how some participants felt angry towards statutory services and it also explains how some participants felt proud of their sibling with ASD.

Figure 6. Initial template.

1. Impact

1.1 Emotional Impact

1.1.1 Anger

1.1.1.1 Statutory services

1.1.1.2 Other peoples' reactions

1.1.1.2.1 Invisible disability

1.1.2 Sharing achievements

1.1.2.1 Feeling proud

1.1.2.2 Feelings of relief

1.1.3 Not knowing how to help

1.2 Impact on the whole family

1.2.1 Physical needs

1.2.2 Sensory needs

1.2.3 Other family members

1.2.3.1 Mindful of the impact on parents

1.3 Self-development

2. Knowledge of sibling's condition

2.1 Understanding ASD

2.1.1 Understanding the individual

2.1.1.1 Seeing the person before seeing the disability

2.1.2 Perception

2.1.2.1 Medical model of disability

2.1.2.2 Not blaming the sibling

2.1.2.3 Scientific explanation

2.1.2.3.1 Giving a reason 'why'

2.1.3 Age

2.1.3.1 Acceptance

2.1.3.2 Awareness

2.2 Wanting to learn about ASD

2.2.1 Own research

2.2.1.1 Internet

2.2.1.2 Learning to support sibling

2.2.1.2.1 Listening to other peoples' experiences

2.2.1.2.2 Researching additional services

3. Roles and Responsibilities

- 3.1 Supporting the whole family
 - 3.1.1 Supporting parents
 - 3.1.2 Housework
 - 3.1.3 Challenging
- 3.2 Supporting sibling
 - 3.2.1 Caring role
 - 3.2.1.1 Emotional support
 - 3.2.1.1.1 Special relationship
 - 3.2.1.2 Academic support
 - 3.2.1.3 Intimate care
 - 3.2.1.3.1 Behaviour
 - 3.2.2 Role at school
 - 3.2.3 Duty to protect
 - 3.2.4 Making adjustments
- 3.3 Impact on life outside of family
 - 3.3.1 Peers
 - 3.3.2 Education

4. Thoughts about the future

- 4.1 Hopeful
 - 4.1.1 Reflecting on achievements
 - 4.1.2 Wider society
- 4.2 Concerns
 - 4.2.1 Living arrangements
 - 4.2.2 Education
- 4.3 Forward planning

5. Support for siblings living with ASD

- 5.1 What is supporting siblings now
 - 5.1.1 Social support
 - 5.1.1.1 Parents
 - 5.1.2 Recognising challenges
 - 5.1.2.1 Seeking advice
 - 5.1.2.1.1 Professional advice
 - 5.1.2.1.2 Informal advice
- 5.2 Not aware of available support services

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5.3 What could support siblings living with ASD

5.3.1 Sharing experiences

5.3.1.1 Someone who understands

5.3.1.1.1 Difficulties

5.3.1.2 Context

5.3.1.3 Sharing advice

5.3.1.3.1 Supporting sibling

2.5.4.6 Stage six of data analysis

Once the initial template was developed, I applied and redeveloped the template. Template version number two (please see Figure 7.) was adapted from the initial template. I applied the initial template to a further three interviews. Some of the themes on the initial template did not readily incorporate the data from the new transcripts, thus, they were removed (e.g. codes 3.1.2 and 3.1.3). Other modifications included inserting new top-level themes (e.g. growing up with a sibling with ASD). Template version number three (please see Figure 8.) was adapted from template version number two following discussions with my supervisory team. The modifications included making codes clearer about what it was about the participants' experiences that I was referring to. For example, code 2.1.1 (age) was renamed to growing awareness of ASD with age. Further iterations of the template were developed following its application to new data and further discussion with my supervisory team. The final template (version eight) is presented in Figure 9. (please see appendix 7 for template version number four, appendix 8 for template version number five, appendix 9 for template version number six and appendix 10 for template version number seven).

Figure 7. Template version number two.

1. Impact

1.1 Emotional impact

- 1.1.1 Anger
 - 1.1.1.1 Statutory services
- 1.1.2 Other peoples' reactions
 - 1.1.2.1 Invisible disability
- 1.1.3 Sharing achievements
 - 1.1.3.1 Feeling proud
 - 1.1.3.2 Feelings of relief
- 1.1.4 Behaviour
 - 1.1.4.1 Not knowing how to help

1.2 Impact on the whole family

- 1.2.1 Missing out
- 1.2.2 Other family members
 - 1.2.2.1 Mindful of the impact on parents

1.3 Self-development

2. Knowledge of sibling's condition

2.1 Understanding ASD

- 2.1.1 Age
 - 2.1.1.1 Awareness
 - 2.1.1.1.1 Sibling's needs
- 2.1.2 Perception
 - 2.1.2.1 Seeing the person before the disability
 - 2.1.2.2 Medical model of disability
 - 2.1.2.2.1 Giving a reason 'why'
 - 2.1.2.3 Not blaming the sibling

2.2 Learning about ASD

- 2.2.1 Own research
 - 2.2.1.1 Internet
 - 2.2.1.2 Listening to other peoples' experiences
 - 2.2.1.2.1 Learning to support sibling
 - 2.2.1.2.2 Needs of sibling
 - 2.2.1.3 Additional services
- 2.2.2 Parents
- 2.2.3 Professionals

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3. Roles and responsibilities

- 3.1 Supporting the whole family
 - 3.1.1 Supporting parents
- 3.2 Supporting sibling
 - 3.2.1 Caring role
 - 3.2.1.1 Emotional support
 - 3.2.1.1.1 Special relationship
 - 3.2.1.2 Academic support
 - 3.2.1.3 Intimate care
 - 3.2.1.3.1 Behaviour
 - 3.2.2 Role at school
 - 3.2.3 Duty to protect
 - 3.2.3.1 Parents absent
- 3.3 Impact on life outside the family
 - 3.3.1 Peers
 - 3.3.2 Education

4. Thoughts about the future

- 4.1 Hopeful
 - 4.1.1 Reflecting on achievements
 - 4.1.2 Wider society
- 4.2 Concerns
 - 4.2.1 Living arrangements
 - 4.2.2 Education
- 4.3 Forward planning

5. Support for siblings living with ASD

- 5.1 What is supporting siblings now
 - 5.1.1 Social support
 - 5.1.1.1 Parents
 - 5.1.1.1.1 Spending 1:1 time with parents
 - 5.1.1.1.2 Parents sharing knowledge
 - 5.1.2 Recognising challenges
 - 5.1.2.1 Seeking advice
 - 5.1.2.1.1 Professional advice
 - 5.1.2.1.2 Informal advice
- 5.2 Not aware of support services available
- 5.3 What could support siblings living with ASD

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5.3.1 Sharing experiences

5.3.1.1 Someone who understands

5.3.1.1.1 Challenges

5.3.1.2 Context

5.3.1.3 Sharing advice

5.3.1.3.1 Supporting sibling

6. Growing up with a sibling with ASD

6.1 Acceptance

6.2 Comparisons

6.2.1 Peers

6.2.2 TD children

6.3 Making adjustments

Figure 8. Template version number three.

1. Identity as a sibling to someone with ASD

1.1 “My life is different”

- 1.1.1 Perceptions of the ‘norm’
- 1.1.2 Seeking advice
 - 1.1.2.1 Interactions with sibling
 - 1.1.2.2 Supporting sibling
- 1.1.3 Roles and responsibilities
 - 1.1.3.1 Supporting the whole family
 - 1.1.3.2 Parental role
 - 1.1.3.3 Caring for sibling with ASD
 - 1.1.3.3.1 Emotional support
 - 1.1.3.3.2 Intimate care
 - 1.1.3.3.3 Academic support

1.2 “My sibling with ASD is different”

- 1.2.1 Growing awareness of ASD with age
 - 1.2.1.1 Sibling’s needs
 - 1.2.1.2 The impact on parents
- 1.2.2 The emotional impact of behaviour on TD siblings
 - 1.2.2.1 Not knowing how to help
 - 1.2.2.2 Invisible disability
 - 1.2.2.2.1 Other peoples’ reactions
- 1.2.3 TD siblings feeling proud of their sibling’s achievements

1.3 “My life is normal”

- 1.3.1 Family dynamics – sibling spacing
- 1.3.2 Normalising adjustments
 - 1.3.2.1 Self-development
- 1.3.3 Comparisons to non-ASD families
- 1.3.4 Accepting that their sibling is different

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2. Knowledge of sibling's condition

2.1 Perception of ASD

2.1.1 Growing awareness of ASD with age

2.1.2 Medical model of disability

2.2 Accessing knowledge of ASD

2.2.1 Own research

2.2.1.1 Internet

2.2.1.2 Listening to other peoples' experiences

2.2.2 Parents

2.2.3 Professionals

2.3 Utilising knowledge of ASD

2.3.1 Learning how to support their sibling

2.3.1.1 Understanding their siblings needs

2.3.1.2 Knowledge of additional services

3. Support for siblings living with ASD

3.1 Not aware of support services available

3.2 Social support

3.3 Professional support

3.3.1 Statutory services

3.4 Sharing experiences

3.4.1 Context

4. Thoughts about the future

4.1 Hopeful

4.1.1 Reflecting on achievements

4.1.2 Wider society

4.2 Concerns

4.2.1 Living arrangements

4.2.2 Education

4.3 Forward planning

Figure 9. The final template.

- 1. Understanding sibling's condition**
 - 1.1 Absence of understanding
 - 1.1.1 Growing understanding of ASD with age
 - 1.1.1.1 Limited knowledge of how ASD affects their sibling
 - 1.1.1.2 Feeling as though sibling with ASD received preferential treatment from parents
 - 1.2 Experiential learning
 - 1.2.1 Learning from their own lived experience
 - 1.2.2 Learning from other peoples' lived experience
 - 1.2.2.1 "Understanding my sibling before their disability"
- 2. Negotiating normality**
 - 2.1 "It's different but it's normal for me"
 - 2.1.1 Comparisons to non-ASD families
 - 2.2 "My sibling is unique"
 - 2.2.1 Comparing sibling with ASD to TD children
- 3. Roles and responsibilities: Understanding my sibling**
 - 3.1 Insightfulness
 - 3.1.1 Parental type role
 - 3.2 Empathising with parents
- 4. Experiences of behaviour**
 - 4.1 "It can be hard at times"
 - 4.1.1 Emotional responses to sibling with ASD having a 'meltdown'
 - 4.2 Outside others' reactions
 - 4.2.1 Emotional responses to outside others' reactions
- 5. Support for TD siblings**
 - 5.1 "It's ever-present"
 - 5.1.1 Spending 1:1 time with parents
 - 5.2 Sharing experiences and learning from others
 - 5.2.1 The value of shared experience
 - 5.2.1.1 Feeling 'heard'
 - 5.2.2 The opportunity to give and receive advice
 - 5.3 Absence of support

2.5.4.7 Stage seven of data analysis

The final stage of the analysis was to use the template to analyse the full data set to develop the final interpretation of my data and to structure an account of the findings for presentation. The findings are presented in the following chapter.

Chapter three: Findings

This chapter will present the findings of the study. The final template encompassed five main themes: (a) understanding sibling's condition, (b) negotiating normality, (c) roles and responsibilities: Understanding my sibling, (d) experiences of behaviour and, (e) support for TD siblings. Each theme will be discussed below.

3.1 Understanding sibling's condition

Theme summary: Participants understanding of their sibling's condition has evolved over time through their experience of growing up with a sibling with ASD and accessing their own information about ASD. This theme is explained with two sub themes: (a) absence of understanding and (b) experiential learning.

Absence of understanding

Some participants reported that they have gained a better understanding of their sibling's condition over time. They described an absence of understanding when they were young. Christopher explained that he struggled to find reasons for his brother's behaviour when he was young:

"He seemed to constantly act like a baby no matter how old he was" (Christopher)

Jacob suggested that as he got older, he started to form links between his brother's behaviour and his knowledge of ASD:

"David was just David and the things he did due to his autism I didn't attribute to his autism. It was only around the age of 15 that I started to realise he was behaving in those ways because of his autism" (Jacob)

Becky and Jenny also described an absence of understanding when they were young and suggested that their experience of growing up with a sibling with ASD has changed with increased understanding of their sibling's condition. When they were younger, they did not understand what ASD is and how it affects their sibling and explained that they experienced feelings of frustration because they perceived that their sister received preferential treatment from their parents. As they have got older they have learnt about ASD, and this knowledge of their sibling's condition has changed their experience of one of feeling frustrated to one of understanding their sibling. Becky described her sister's condition as a 'label over her', suggesting that it is something that 'protected' her from having to do things that she had to do:

"Learning more about autism over the years has helped me understand Ellie's needs more. When I was younger, I sort of felt like Ellie got away with not doing as much because she had this label over her, but I can see now that she wasn't asked to do that stuff because she wasn't ready, and mum and dad knew it wouldn't work out" (Becky)

"When I was younger I struggled to understand what autism actually is.... When I was younger I found it hard because it seemed like Gemma was getting special treatment, she wouldn't get told off for the things I

would get told off for and was treated very different to me. By the time my little brother Edward was born (he also has autism) I was 11, so it was very different with him, by that age I understood more about autism” (Jenny)

Experiential learning

When asked about information that has helped them understand their sibling’s condition, some participants spoke about learning from their own lived experience, and some participants spoke about learning from other peoples’ lived experience. Becky and Jenny explained that their understanding of their sibling’s condition has evolved over time from their experience of growing up with a sibling with ASD. This suggests that some of their knowledge about their sibling’s condition may not be accessible through sources of information, such as books and the Internet, it may only be knowable through their lived experience of growing up with their sibling with ASD:

“I’ve just learnt from my own experiences” (Becky)

“I have pretty much just learnt from experience” (Jenny)

Alesha, Rachel and Jacob spoke about how they listened to other peoples’ accounts of their lived experience of having ASD. They talked about how accessing this subjective knowledge about their sibling’s condition was not about trying to understand what ASD is, it was about trying to understand their sibling with ASD and how their sibling sees the world:

“I watched videos such as Carly Fleishmann’s story of her experience which helped me to understand why my brother finds certain situations difficult” (Alesha)

“What I found particularly helpful was videos on YouTube of people with ASD describing their own experiences.... The explanation of ASD was coming directly from the person affected, and in their own words – less clinical. These accounts helped me understand the everyday effects ASD has on the persons themselves” (Rachel)

“Speaking to people with autism broadened my understanding of how the condition can affect individuals and how it does this on a person by person basis” (Jacob)

3.2 Negotiating normality

Theme summary: Participants recognised that their life and their sibling with ASD are different when compared to non-ASD families. However, their lived experience of what the world may call ‘different’ is their normality. This theme is explained with two sub themes: (a) “it’s different but it’s normal for me” and (b) “my sibling is unique”.

“It’s different but it’s normal for me”

When asked “Please can you tell me what it has been like to grow up with a sibling with ASD?”, Olivia, Becky, and Christopher spoke about normality. They talked about two types of normality: (a) their perceived normality of the general population and (b) their lived experience of normality, suggesting that they have a dual understanding of what normality is. They made social comparisons to non-ASD families and suggested that they feel that their life has been different to other people who do not

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have a sibling with ASD. However, they accept these differences because their lived experience of normality is growing up with a sibling with ASD:

“Well it’s been different but nothing it hasn’t been much stranger than the average upbringing. Some things however have been a little different.... So yes, it’s mostly a normal life for me but a few things are different” (Olivia)

“Growing up with a sibling with autism was hard compared with my friends who had “normal” siblings, but it’s all I’ve ever known. Which, if anything, makes it the norm for me. (Becky)

“When my brother was five he started ABA therapy.... he was able to learn things like toilet training, how to wash himself.... that meant my life from the age of 11 was basically ‘normal’ if I were to compare it someone without an autistic family member” (Christopher)

Christopher expressed a sense of gratitude for his unique experience of growing up with a sibling with ASD. He felt that his experience has provided him with a more open view of the world, which other people who do not have a sibling like his may not have:

“I think that my experience so far with James has actually helped me as I don’t really judge people on preconceptions like others may” (Christopher)

“My sibling is unique”

Rachel and Jenny talked about the distinct and unique ways that set their sibling apart from other people. Jenny suggested that while others may consider her siblings with ASD to be ‘abnormal’, she accepts how her siblings are different and spoke as though other people do not understand her siblings and their different way of being in the world as she does. She described a sense of curiosity about the unique way in which they see the world:

“I found reading the books that my siblings don’t fit into any of the categories.... This made me feel they were even more unique and I became interested in the way they think.... I don’t think of my sibling as abnormal as some of these books were making children with autism out to be, I consider them to be extraordinary but not in a bad way” (Jenny)

“Still to this day, his intelligence and attention to fine detail astound me” (Rachel)

Rachel and Jacob ‘normalised’ their sibling with ASD by comparing them to TD children. Jacob recognised that his brother is different to other children. However, he does not perceive this difference negatively and suggested that he accepts how his brother is different to TD children:

“He could be quite difficult at times, but I’m sure the same goes for any young child” (Rachel)

“All children face unique challenges that they’ll need help with.... David just needed help with a few more challenges than a usual child of his age” (Jacob)

Rachel suggested that her brother with ASD is different from other children and that other people outside of the home may consider him not to be 'normal'. However, the ways in which he is different to TD children is her reality of her brother:

"He is 'normal' at home, normal as in what I'm used to" (Rachel)

3.3 Roles and responsibilities: Understanding my sibling

Theme summary: Participants have a deep understanding of their sibling's needs and challenges. This theme is explained with two sub themes: (a) insightfulness and (b) empathising with parents.

Insightfulness

Olivia and Becky described having a parental type role for their sibling with ASD when their parents are not there. Olivia identified herself as someone who can make sense of and help others understand her brother's behaviour. She almost described herself like an interpreter, someone who is an intermediary between her brother and his teachers. Becky feels that she can use her understanding of her sister's behaviour to support her sister when her parents are not there:

"The decision to bring Ben to the same school as me was quite easy for us all to make. It meant that I could help Ben if he had any problems and teachers could ask me what I thought if Ben was behaving 'oddly'." (Olivia)

"When we stay at my grandmas, I can tell when my sister is about to have a meltdown, and know how to calm her down when mum and dad aren't around" (Becky)

Rachel described having a sense of protectiveness for her brother. She empathised with her brother and suggested that she feels this responsibility comes from having a deep understanding of his behaviour that other people may not have:

"I think that since his diagnosis I feel more protective of him.... Because I know that he can't always help what he says or does, and other people might not understand that" (Rachel)

Alesha identified herself as a young carer for her brother with ASD. Alesha talked about this role and responsibility as though it was not a matter of choice, it was something that had to be done, and it was not only about supporting her brother, it was about helping her whole family:

"It wasn't until a couple of years ago and being older that having a sibling with autism affected me as we went through some family problems which meant that I had to take on a massive role in the family and become a young carer. This meant that I had become a massive support for my brother and had to be available as much as I can to help my mum out" (Alesha)

Alesha spoke about her young carer role as though it has created a special bond between her and her brother with ASD. She suggested that she understands the challenges that he experiences and his needs, and she can use this insight to reassure her brother and make him feel at ease when he is distressed:

"I have had to be hands on a lot of the time at home and my siblings will often come to me for support and comfort.... I support my brother by helping him get dressed, bathing him, brushing his teeth. I also help him with learning to read... I also provide him with support when he is distressed over situations that have occurred during the day.... we have a very close relationship, so he comes to me for comfort a lot of the time" (Alesha)

Empathising with parents

Some participants spoke empathetically about what it is like for their parents to raise a child with ASD. This suggests that they understand the needs of their sibling and are aware of the impact that these needs have on their parents. Jacob has become more aware of the impact on his parents as he has got older. This may be linked to the first theme (understanding sibling's condition). Jacob reported that he has gained a better understanding of his brother's condition as he has got older. As he has learnt about ASD and the needs of his sibling, he may have become more aware and learnt about the impact of having a child with ASD on his parents:

"It wasn't taxing on me when things were bad because I was blissfully unaware that the way things were, weren't ideal for my parents" (Jacob)

"I thought that when we got the diagnosis that we would be very upset and that there would be a lot of crying, especially for Mum. (She did and still does cry a lot, but usually just because of exhaustion.)" (Rachel)

"My dad gets very upset and frustrated, because he would like to have a close relationship with Gemma like her and my mum share, but anything he tries to do to make the two of them closer seems to drive her further away and I know how much that upsets him" (Jenny)

"My life has been very easy in all ways compared to my parents" (Christopher)

3.4 Experiences of behaviour

Theme summary: Participants often used the term 'meltdown' to describe their sibling's behaviour and this term was notably linked to 'distress' for the participants. This theme is explained with two sub themes: (a) "It can be hard at times" and (b) outside others' reactions.

"It can be hard at times"

Alesha talked about her siblings having 'meltdowns' as though it is the 'hard' part of having siblings with ASD. She described a sense of 'loss of control' when her siblings have 'meltdowns'. The term 'meltdown' implies something that is shutting down or exploding and suggests that her siblings do not have any control of their behaviour when they are having a 'meltdown'. Alesha suggested that she has no control when her brother has a 'meltdown', and this makes her feel helpless. It is distressing for her to watch her siblings distressed:

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“Growing up with a sibling with autism can be challenging.... having siblings with autism can be very emotional at times as when my siblings are having a meltdown it can become very distressing, especially if you don’t know in what way you can help” (Alesha)

“For me I find him having meltdowns is emotionally watching him so distressed as I don’t know what ways I can help without making the situation worse” (Alesha)

Rachel has a six-year-old brother with ASD and he received his diagnosis around the time of interview. Rachel’s views about her brother’s behaviour have changed. Pre-diagnosis, there was no explanation for it and she struggled to find reasons for it, and therefore she misinterpreted his ‘meltdowns’ and ‘tantrums’ as ‘bad behaviour’. Post-diagnosis, her views have changed because the diagnosis gave meaning to his behaviour. She suggested that she began to understand that her brother’s ‘meltdowns’ and ‘tantrums’ are a secondary consequence of the challenges that he experiences and are not necessarily his fault or something that he can control. She described a sense of understanding about her brother’s behaviour that she previously could not make sense of and found ‘hard’:

“Until a year ago we just assumed that my brother was a misbehaved, hyperactive boy.... Dealing with what we thought was just a naughty boy in itself was very difficult.... his frequent tantrums and meltdowns were tiring and often upsetting” (Rachel)

“When we finally got a diagnosis managing his behaviour was still a challenge but our attitudes towards him had changed.... whenever he had a meltdown we used to try and change his behaviour, but we now try and change whatever has triggered him to have a meltdown in the first place” (Rachel)

Outside others’ reactions

Rachel, Alesha, and Jenny talked about other peoples’ reactions to their sibling’s behaviour. They each drew on a specific experience of their sibling with ASD having a ‘meltdown’ in public. Rachel spoke about her brother having a ‘meltdown’ at his mainstream primary school. She described anticipating and worrying about her brother’s ‘meltdown’ and having a sense of fear about what other people would think about it. She explained that she tried to conceal her distress from other people. She experienced feelings of panic and felt out of her depth, and the worry about what other people were thinking and their reactions to her brother’s behaviour added to her distress. She described a sense of exposure when she was ‘left crying in front of everyone’:

“I remember one occasion last summer when I was sent to the school to collect him.... They sent the usual lady to collect him. She came back a minute later and told me that he had kicked off.... I was a bit worried.... Ten or fifteen minutes go by and I start to worry but I try to contain it as I’m in the main foyer bit and there are lots of people around. Suddenly I hear Gareth’s screaming coming closer.... Gareth’s teacher emerges with Gareth struggling in his arms.... I grapple with Gareth to restrain him as he is as still kicking and screaming. I try to calm him, but he probably couldn’t hear me over himself. I would have loved to slink off into a side room to avoid people’s glares.... I was clearly struggling and upset. I run into the schoolyard looking for someone whose phone I could use to call mum.... I was left crying in front of everyone” (Rachel)

Alesha talked about her brother having a 'meltdown' in public and suggested that it was not her brother's behaviour that made her feel distressed, it was other peoples' reactions to it that made the situation a distressing one:

"One situation which was the most distressing was when we were out in public and he had a meltdown and it became very hard for my mum to get him to calm down and people were staring and commenting saying things like 'isn't he a naughty boy' which made me feel angry and helpless because I wasn't able to do anything to make him feel better" (Alesha)

Jenny's brother and sister both have Pathological Demand Avoidance (PDA) which Jenny described as a mild form of ASD. She feels that her siblings have an 'invisible disability' because there is no visible indicator to show that they have ASD and people often misinterpret their behaviour as 'bad behaviour':

"Gemma and Edward both have PDA which is quite a mild form of autism, if you met them in the street you wouldn't be able to tell they have autism.... The fact that it isn't obvious they have autism is often a challenge because if they behave in a way they don't see as misbehaving, people often frown upon them and this tends to make them quite upset and anxious" (Jenny)

Jenny spoke about her sister having a 'meltdown' in a shop and talked about this as though she understands that her sister is not to blame for her behaviour and it is a response to the challenges that she experiences. She explained that her feelings about other peoples' reactions to her siblings' behaviour have changed as she has got older. When she was younger, she experienced feelings of embarrassment about it because she was worried about what other people thought about it. Other peoples' lack of understanding and compassion about her siblings' behaviour now make her feel angry. She described her sister's behaviour as 'outbursts' which suggests that it may be unpredictable and something that happens suddenly:

"When I was younger sort of 14ish I used to get very embarrassed if I thought anyone was frowning upon Gemma and Edward's behaviour I think that was to do with my age though as at that age everyone wants to go unnoticed and fit in, a typical example would be when we used to go shopping and Gemma would see something she wanted, once that happened she wouldn't let it go, so if we went shopping to try and find something she had seen online or in a magazine we couldn't, then she wasn't able to understand that we couldn't physically get it her all she understood was that she wanted it, this would make her very frustrated and she would often have outbursts in public places because she didn't care about what people thought, of course I did and when people walked past shaking their heads and looking at my mum as if to say why can't you control her I was just mortified. I think as I have got older.... I don't get embarrassed, more annoyed that people can see my mum in that situation doing her best to control them and just turning up their noses at her I think it's awful and those kinds of people simply have no empathy" (Jenny)

3.5 Support for TD siblings

Theme summary: Participants spoke about two types of support: (a) spending special time with their parents without their sibling with ASD and (b) peer support. Some participants also reported being without support. This theme is explained with three subthemes: (a) it's 'ever present', (b) sharing experiences and learning from others, and (c) absence of support.

It's 'ever-present'

Jenny, Christopher, and Olivia spoke about their sibling having ASD like it is something that is 'ever-present'. Jenny and Christopher talked about receiving less parental attention than their sibling with ASD because their sibling(s) takes up a large part of their parents' time. Christopher and Olivia emphasised that they get to do the things that they want to do when they spend time with their parents without their sibling with ASD, suggesting that in day to day life their sibling's needs are usually of greater importance than their wants. They explained that spending special time with their parents without their sibling with ASD is important to them because it is a time that is different from what is usual, they feel that their needs and wants take priority during this time, opposed to their sibling's:

"The fact that Gemma and Edward have PDA means that my mum does have to focus quite a lot of attention on them, but we often go on days out just us two to make up for it.... It's really important to me that me and my mum go on days out, because we get to escape all the madness for a while" (Jenny)

"Due to James taking up a lot of my parents' time, my Dad and I would always go away in the summer for about a week or so to catch up on the time which he couldn't spend with me.... When we did go on trips it was to places like London or Legoland when I was younger, places I wanted to go" (Christopher)

"What helps me is having one to one time with my parents and spending a day focused around what I want to do with them and having time to focus on myself. This helps as it shows that not everything that happens at home or that involves family has to revolve around your sibling and can instead revolve around you.... It reminds me that while Ben is one of the most important aspects of their life I am just as important to them" (Olivia)

Sharing experiences and learning from others

Some participants spoke about how they would like the opportunity to share their experiences with others who also have a sibling with ASD because it would give them the opportunity to 'feel heard' by people who understand their unique experience of having a sibling with ASD. They felt that it would also offer the opportunity to use others in a similar situation as a source of information:

"When we need to have a break from home for a bit we will go for a coffee and chat, which is nice as I now know that there are people who understand what it is like to have siblings with autism and being a young carer" (Alesha)

"I think it would help a lot as we would be able to talk about what they do to help their siblings and what we do and share advice. It would also give us a chance to talk to someone who understands the struggles and how hard it can sometimes be having a sibling with autism" (Olivia)

"Another good thing that could come out of a support group is making friends with families who are sympathetic to our situation" (Rachel)

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Becky suggested that she felt like she was the only person in the world who had a sibling with ASD when she was in primary school and feels that a support group would have helped her realise that she was not alone and that there are other children who also have a sibling with ASD:

“There isn’t any support groups for siblings of people with autism.... I think if there had been group for children with siblings with autism, it would’ve let me know from an early age that I wasn’t the only one. I think for me it’s more about having that social connection with people who can relate to you” (Becky)

Jacob felt that a support group would be a ‘safe’ environment for him to comfortably share his experiences with other people about living with a sibling with ASD and felt it would be a place where others would listen nonjudgmentally:

“I think it would offer somebody to talk to who could empathise and possibly offer useful advice.... but in order to get the most of this empathy I believe you’d have to know/meet them in the right situation. Knowing them casually through school or work wouldn’t allow you to fully appreciate and help each other in living with a sibling with autism. I do believe however, that if you met them in an environment where you could easily and freely share life experiences without judgement, then this would allow you to explore your own experiences in living with autism better and possibly give/receive some very useful advice” (Jacob)

Absence of support

Rachel and Alesha talked about feeling unsupported. Rachel feels that her family were not supported as well as they should have been by statutory services after her brother with ASD received his diagnosis. She felt ‘let down’ and spoke as though they were left feeling ‘in the dark’ about what to do next:

“Once we received the diagnosis, we were not given any information about Disability Living Allowance or external support that we can seek or were entitled to.... I believe that this should not have been the case.... Almost all of what has been helpful has either been sought out ourselves or found by accident.... I looked up all the different laws about disability rights in education and any other laws that Gareth might have been affected by.... I think they also should have told us all about the different support groups and entitlements that mum had to find for herself, such as DLA” (Rachel)

Alesha felt that she was unsupported by her family when she was a young carer for her 5-year-old brother with ASD. She felt as though she was expected to ‘get on with things’ and spoke with a sense of having ‘no idea where to turn’. She talked as though she desperately wanted somebody to stop and ask her about how she was feeling:

“When going through the challenging times with my siblings I have never received any help or support from anyone.... nobody in the family would notice when it was too much for me or anyone else. I guess it made it more difficult having so much to handle and having to carry on with everything without anybody stopping to see how I was doing while supporting my siblings.... all I wanted to do was speak to someone about the challenging times to get it off my chest, but I didn’t have the support” (Alesha)

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The findings will be discussed in the context of existing literature, policy and practices in the following chapter.

Chapter four: Discussion

The study aimed to understand what it is like to grow up with a sibling with ASD from the TD sibling's own perspective and how they access and utilise knowledge of ASD. The data were gathered from semi-structured email interviews with seven TD 16-18-year-olds who have a sibling with ASD. TA was used from an interpretive phenomenologically informed stance to analyse the data thematically, and five themes emerged. Understanding sibling's condition explains how participants accessed their own information to help them understand how ASD affects their sibling not just information about what ASD is. Negotiating normality explains how although participants recognised that their life is different from other people who do not have a sibling with ASD, growing up with a sibling with ASD is their lived experience of normality. Roles and responsibilities: Understanding my sibling's needs and challenges explains how participants felt that they have an insight into their sibling's thoughts, feelings, and behaviour that other people do not have. Experiences of behaviour explains how participants experienced feelings of distress when their sibling with ASD had a 'meltdown' in public and other peoples' reactions to their sibling's behaviour added to their feelings of distress. Finally, support for TD siblings explains how participants spoke about their sibling having ASD like it is something that is 'ever-present' and what supports them is spending one to one time with their parents. In this chapter, I will first discuss the findings in the context of existing literature, and I will then discuss the real-world implications of the findings and suggest future directions for research. I will also discuss the strengths and limitations of the study and reflect on the research process.

4.1 Discussion

To my knowledge, there has been one previous study (Petalas et al., 2012) conducted in the UK that interviewed TD adolescents about their experiences of having a sibling with ASD. Thus, this study adds to the existing, relatively small, literature on the experiences of TD adolescents with a sibling with ASD in the UK. Although I did not systematically sample for birth order, what makes my study different to the previous study conducted in the UK (Petalas et al., 2012) is that all the TD siblings in this study were older than their sibling with ASD.

Some participants in this study reported receiving less parental attention than their sibling with ASD, yet they reported that spending one to one time with their parents is important to them. These findings are consistent with those of Cridland et al. (2016) who interviewed TD adolescents and found that the most frequently discussed negative impact of having a brother with ASD was a perceived reduction in attention from parents, and of importance to them was time spent alone with parents. These findings are echoed by the previously identified qualitative literature. Mouzourou, Santos and Gaffney (2011) explored one family's experiences of living with a child with ASD and found that TD siblings felt that their sibling with ASD 'stole time' from them because they received less parental

attention than their sibling. Ward et al. (2016) interviewed TD siblings about their experiences of having a sibling with ASD and found that participants felt that they receive less attention from their parents than their sibling. Finally, Moyson and Roeyers (2011) investigated how TD siblings of children with ASD describe and define their quality of life and found that spending one to one time with parents was of importance to them. Respite services have been found to be of value to TD siblings in the UK because they give TD siblings the opportunity to go on family days out to places that their sibling with ASD would not like to or is not able to go (Petalas et al., 2009). Overall, the findings from this study and existing literature suggest that although TD siblings may make accommodations (e.g. receive less parental attention) to meet the needs of their sibling with ASD, the impact may be mitigated by spending special time with their parents without their sibling.

Some TD siblings in this study reported experiencing distressing behaviour from their sibling with ASD and the participants that reported this also reported experiencing negative attitudes from the public about their sibling's behaviour. These findings are consistent with the previously identified qualitative research. Mascha and Boucher (2006) interviewed TD siblings, and they reported that one of the most difficult parts of having a sibling with ASD was other peoples' attitudes. Similarly, Petalas et al. (2009) interviewed TD siblings who have a sibling with ASD, and they reported experiencing a lack of understanding and negative attitudes from strangers about their sibling's behaviour. Adolescents with a brother with ASD in the UK have reported that members of the public misinterpreted their brother's challenging behaviour as 'bad behaviour' (Petalas et al., 2012). Finally, Hwang and Charnley (2010) found in their visual ethnographic study in Korea that all nine TD siblings who had a sibling with ASD were frequently confronted by other peoples' reactions (e.g. pointing, staring, dehumanising terminology). Taken together, the findings from this study and existing literature suggest that TD siblings who have a brother or a sister with ASD may experience negative attitudes and misunderstanding from members of the public about their sibling's behaviour. A possible explanation for this is that ASD is an 'invisible' disability (Mullins & Preyde, 2013). There is no visible indicator (e.g. wheelchair) to show that someone with ASD has a disability. Thus, the behaviour of someone with ASD (e.g. shouting, throwing self to floor, hand flapping, screaming, touching, kicking) can be misinterpreted by observers as 'bad' or 'naughty behaviour' (especially someone who does not understand ASD and how it can affect a person) rather than an understanding that the person has a disability.

Some TD siblings in this study reported that they did not have any knowledge of their sibling's condition when they were young, suggesting that parents may not have shared information about ASD with them. This finding further supports the idea that when parents share information about ASD to TD siblings may vary across families. Bachraz and Grace (2009) conducted three case studies on

three different families who have a child with ASD and found that the parents, across all three families, believed that their TD children (with a *mean* age of 5.43 years and a *range* of 4.4 to 6.1 years) were not old enough to receive information about their sibling's condition. Similarly, Sage and Jegatheesan (2010) carried out two different case studies on two different families who have a child with ASD and found that one family began educating their TD son (aged 7.0 years) about his sibling's condition immediately after diagnosis and one family did not begin educating their TD son (aged 7.0 years) for almost two years post-diagnosis, and from then on, provided him with limited information.

In terms of how TD siblings access knowledge of their sibling's condition, in reviewing the literature, it was found that TD siblings access knowledge about ASD from their parents, and no other sources of information were reported (Mascha & Boucher, 2006; Petalas et al., 2009; Sage & Jegatheesan, 2010; Mouzourou, Santos & Gaffney, 2011). However, in the current study, participants reported using the Internet and listening to other peoples' experiences to access knowledge about their sibling's condition. A possible explanation for this may be when the previous studies were conducted. Mascha and Boucher (2006) and Petalas et al. (2009) interviewed TD siblings about their experiences of having a sibling with ASD one decade ago and so the results regarding how they access knowledge about ASD may reflect a time of less digital engagement. This may explain why parents were their only reported source of knowledge and other sources such as the Internet were not reported. Another possible explanation may be the age of the participants. For example, Petalas et al. (2011) interviewed TD siblings with a *mean* age of 11.19 years ($SD = 1.32$), and the TD siblings in Sage and Jegatheesan's case study were aged 7.0 years. Thus, it is likely that they did not have access to other sources such as the Internet and explains why parents were their only reported source of knowledge. Some participants in this study also reported accessing information about their sibling's condition from professionals. However, those who did reported that these were professionals with whom they, their sibling or family member had close (and sometimes personal) relationships. For example, Rachel reported that a good friend's mother is a psychologist and was able to answer some questions about her brother's condition for her. This suggests that professional knowledge about ASD may not be available as standard practice to all TD siblings and may explain why accessing knowledge from professionals was not reported by participants in the previously identified literature.

It was found that participants in this study wanted to access information to understand how ASD affects their sibling. In other words, they were interested in practical knowledge, not just general knowledge about what ASD is. Similarly, Mascha and Boucher (2006) interviewed TD siblings and found that they asked their parents questions about the challenges their sibling with ASD experiences and the reasons for their behaviour. Overall, the findings from this study and the previous literature

suggest that TD siblings who have a sibling with ASD may have a need for information about their sibling's condition to understand their sibling throughout childhood and adolescence.

Previously, peer support has been found to be a valuable source of support for TD siblings who have a sibling with ASD because it gives them the opportunity to exchange experiences with people who understand (Petalas et al., 2009; Moyson & Roeyers, 2012). Likewise, some participants in this study spoke about how they would like the opportunity to meet others with a sibling with ASD because it would allow them to share their experiences with someone who understands. Despite this, only one participant reported accessing peer support (Alesha). A possible explanation for this may be regional variations in peer support availability. Another finding from this study is that some TD siblings feel that they have an absence of support. This finding is consistent with the findings of Petalas et al. (2009) who interviewed TD siblings who have a sibling with ASD in the UK and found that some participants felt lonely and lacking in support. These findings suggest that TD siblings may not be aware of where they can access information about support services (e.g. peer support) that are available to them.

The findings of this study suggest that TD adolescents who have a younger sibling with ASD may have caregiving roles and responsibilities for their sibling. Some participants reported having a parental type role, which is characterised by being responsible for their sibling when their parents are not there (e.g. when their parents are not in the house or at school). One participant (Alesha) identified herself as a young carer for her younger brother with ASD and reported that this role included intimate care (e.g. washing, bathing, brushing teeth, putting to bed) and practical care (e.g. making breakfast and dinner, getting bag ready for school, getting to school on time). These findings are consistent with those of Cridland et al. (2016) who found that TD adolescent siblings undertook caregiving roles for their younger brother with ASD at school, and Ward et al. (2016) who found that TD siblings who have a younger sibling with ASD felt that they have additional responsibilities (e.g. ensuring that their sibling is safe) for their sibling. Taken together, these findings suggest that TD siblings who have a younger sibling with ASD may have higher than usual levels of involvement with the care of their younger sibling(s). However, older siblings may naturally have more responsibilities than younger siblings and assume a caregiving role (Cridland et al., 2016).

4.2 Real-world implications

As discussed (in section 4.1), one thing of value to participants in this study and participants in the previously identified literature is spending one to one time with parents. Short Breaks (Department of Education, 2010) are a way to facilitate this. Funded by social care and comprised of outreach services, day care and sessional services and overnight stays, Short Breaks are a service which support children with disabilities and their families (Department of Education, 2010). In 2010, the government

committed to spending £100m on short breaks over the following four years so that Local Authorities (LAs) could meet their legal duties under The Breaks for Carers of Disabled Children Regulations (2011). The regulations provide LAs details as to how they must provide short breaks to carers of children with disabilities under the Children Act (1989). However, despite this, Every Disabled Child Matters (EDCM) (2015) found that 58% of 126 LAs that responded to their Freedom of Information (FoI) request cut spending on Short Breaks between 2011/12 and 2015/16. Mencap (2013) also found that 63% of 152 LAs that responded to their FoI request cut spending on Short Breaks for children in 2011/12 and 43% projected cuts for 2012/13. Regarding parent carers' experiences of accessing Short Breaks, 53% of 1978 parent carers reported that they had never accessed Short Breaks services and 56% reported that it is becoming more difficult to access Short Breaks (EDCM, 2015). Mencap (2013) found that 50% of 264 respondents to their survey did not know how to access Short Breaks and seven out of ten respondents who cared for a child with a disability were unaware of their LAs Short Breaks statement. The findings from EDCM (2015) and Mencap (2013) suggest that families of children with disabilities are finding it difficult to access Short Breaks. Not being able to access Short Breaks may affect TD siblings' opportunity to spend time with their parents without their sibling with ASD, which some TD siblings in this study and previous studies valued. LAs could publicise their local offer on various platforms and in different formats so that more families know about how to access Short Breaks.

The Department of Education's (2011) Short Breaks for children with disabilities departmental advice for LAs states that access to Short Breaks must not be judged on impairment alone. The impact of a child's disability on their TD sibling must be an integral part of a family's assessment to access funding for Short Breaks because one of the most frequently mentioned benefits of Short Breaks is time for parent carers to focus on their relationship with their TD children (Department of Education, 2011). Tozer, Atkin and Wenham (2013) interviewed TD adults who had a sibling with ASD, and when reflecting on their childhood experiences, they reported feeling ignored and excluded by social workers who visited their family home and felt that social workers engaged only with parents. However, the findings from this study and the previous literature suggest that TD siblings are capable of explaining what they need. Participants were able to explain that they receive less parental attention than their sibling with ASD and what supports them is spending one to one time with their parents without their sibling. Thus, in terms of assessing the impact of a child's disability on their TD sibling, practitioners (typically social workers) who carry out the assessment of funding to access Short Breaks could involve TD siblings in the assessment by asking them about existing one to one time spent with parents and their perceived needs for one to one time spent with parents. A direction for future

research would be to evaluate the impact of Short Breaks on the wellbeing of TD siblings who have a sibling with ASD.

Short Breaks (Department of Education, 2010) may not be accessible for some families because there needs to be an assessment of need undertaken by social services. Therefore, it is recommended that practitioners (e.g. social workers) inform parents of the need to create some 'special time' for their TD children. In this study, one participant (Christopher) reported that he goes on holiday with his father to make up for the time that he does not usually get to spend with him. Other participants (Jenny and Oliva) reported that they often go on days out with one parent to make up for the time that they do not usually get to spend together.

As discussed (in section 4.1), some participants in this study and participants in the previous literature experienced negative attitudes and misunderstanding about their sibling's behaviour from the public. Thus, it may be helpful to raise awareness of ASD in the community. There are Government policies such as The Think Autism Strategy (2014) and awareness campaigns such as World Autism Awareness Week (National Autistic Society, 2017) which aim to educate those who may be unaware of ASD. The National Autistic Society's (NAS) Too Much Information campaign report (NAS, 2016) outlines that a YouGov poll carried out in 2015 found that over 99.5% of 2,159 adults in the UK have heard of ASD. However, despite this, the NAS (2016) found that 87% of families of people with ASD, when asked about how members of the public respond to the behaviour of people with ASD, reported that members of the public stare at them and 74% reported that members of the public tut or make disapproving noises. The NAS (2016) also report that 75% of parent carers feel that the most common labels given to their children by members of the public are 'naughty' and 'strange'. Finally, 70% of family members of people with ASD reported that they feel socially isolated (NAS, 2016) (statistics are based on 4,409 parent carers of people with ASD and 545 family members of people with ASD). These findings suggest that although members of the public may know what ASD is, they may not understand ASD in a meaningful way and this may explain why some participants in the present study and previous literature experienced misunderstanding and negative attitudes about their sibling's behaviour from the public. Therefore, it may be helpful for future Government policies such as The Think Autism Strategy (2014) and awareness campaigns such as World Autism Awareness Week (NAS, 2017) to raise awareness about the situations that someone with ASD may find distressing and the behaviours and coping strategies that someone with ASD may respond to those distressing situations with. Such awareness may reduce the misunderstanding and negative attitudes that families of people with ASD experience from the public. A future direction for research would be an evaluation of public awareness campaigns such as The Think Autism Strategy (2014) to assess whether public awareness of the needs of individuals with ASD has improved since the inception of The Think Autism Strategy (2014).

As discussed (in section 4.1), TD siblings who have a sibling with ASD may have a need for information about their sibling's condition throughout childhood and adolescence that facilitates an understanding of their sibling. Thus, information giving should be an ongoing process, reflecting the age of the TD sibling and changes in their sibling with ASD. Professionals (e.g. social workers) working with families with a child with ASD could offer age-appropriate resources to parents to share with TD siblings. For example, social stories, short animations or age-related fact sheets about ASD could be offered to young TD siblings. Some of the adolescents in this study reported that they wanted to access information to understand how ASD affects their sibling not just information about what ASD is. Sibs (2010-1028) is a UK charity for those who have a sibling with a disability. Their website has various information pages for TD siblings, and their ASD page explains how ASD can affect individuals. This is information that the adolescents in this study reported to be of value to them and some participants reported searching for information on the Internet. Therefore, practitioners could signpost families to the Sibs (2010-208) website. However, not all adolescents will be able to access the Internet or may not want to. Thus, information should be produced on multiple platforms and in various formats, such as an age-appropriate information leaflet.

As discussed (in section 4.1), TD siblings who have a brother or a sister with ASD may not be aware of where they can access information about support services (e.g. peer support) that are available to them. Therefore, practitioners working with families with a member with ASD could signpost families to support services for TD siblings. For example, there are small local charities such as The Whole Autism Family (2015) in Kirklees that offer peer support to parents, carers, siblings and other family members of those with ASD. Regular informal meetings are held where family members can share their experiences, thoughts, and feelings. There is also a Facebook page for family members to write about their experiences and give and receive advice if they do not want to (or cannot) attend the informal meetings. There are also bigger charities such as Sibs (2010-2018) that support those who have a sibling with a disability. They offer an online forum for TD siblings to share their thoughts, feelings, and experiences with other TD siblings.

4.3 Strengths and limitations

In this section of the chapter I will discuss the strengths and limitations of the study.

4.3.1 Recruitment and social media

To my knowledge there has been one previous UK study that has explored the experiences of adolescents who have a sibling with ASD in the UK (Petalas et al., 2012), and a limitation of that study is that all participants came from the same geographical region. A strength of this study is that participants were recruited from across England (the North of England, the Midlands and the South of

England). This might be a strength because there may be regional variations in sibling support services, ASD diagnosis waiting times and disability services which may affect TD siblings' experiences of growing up with a sibling with ASD. Participants were recruited through social media and this suggests that social media may be an efficient way of recruiting participants across the country. However, I also had access to a parent carer of a child with ASD who advertised the recruitment advert on their social media channels (e.g. Facebook, Twitter) and this may have influenced the geographical location of participants.

4.3.2 The sample

A limitation of the existing literature on TD siblings of children with developmental disabilities is that much of the research has been carried out with Caucasian samples and European samples (Kao et al., 2011). No non-white participants were recruited in this study. It seems that the experiences of ethnic and racial minority populations are not represented, and ethnicity and race may be an important aspect of the experience of growing up with a sibling with ASD. A direction for future research would be to conduct peer research where a member of the research team is from the target population (e.g. Black and Minority Ethnic).

4.3.3 Email interviews

A limitation distinctive to email interviews is that participants can fail to respond to emails and 'vanish' (King & Horrocks, 2010) and this is a limitation of this study. Although seven participants were recruited, and seven email interviews were carried out, only four of the interviews were fully completed. A total of two participants withdrew from the study and one interview could not be completed due to time constraints. This is a limitation because not all participants responded to all the questions on the interview topic guide. If all seven participants had responded to all the questions on the interview topic guide, different themes may have emerged or more data may have provided better insight.

A participant non-response can present ethical challenges. One participant did not respond to an email within the agreed time frame and also failed to respond to two reminder emails. Thus, I had to make the decision as to whether I should retain the data that they had already provided. Previous research has taken different positions on this ethical dilemma. Hunt and McHale (2007) view a non-response as a full withdrawal from a research project, while Kivits (2005) included data from participants who had ceased involvement in the research project. King and Horrocks (2010) explain that an ethical case can be made for both positions. The second email reminder that I sent to the participant included an explicit question as to whether they wanted to cease involvement in the research project, and if so, whether they wanted to withdraw the data that they had already provided. As the participant did not

explicitly say that they wanted to withdraw their data, I deemed it ethical to retain the already provided data. On reflection, I think it would have been better for me to address this in the information sheet and have got explicit consent in the consent form to retain already given data.

The data that emerges from qualitative interviews depends on the situation and the location of the participant and the researcher, and I recognise that the data that emerged from this study would be different if I had carried out face to face interviews. I was not able to read the facial expressions, body language, make eye contact or hear the voice tones of participants. This means that some important visual and non-verbal information may have been missed that may have been observed in face to face interviews.

In terms of phenomenology, email interviews enhanced the phenomenological nature of this study because a distinctive feature of email interviews is that they allow participants to ruminate. Although I did ask participants reflective questions, such as, 'please can you explain to me what it has been like to grow up with a sibling with ASD?', having the time to think about their experiences may have given participants the opportunity to share anecdotes and specific memories that they may not have shared in face to face interviews. For example, one participant reflected on the specific moment that her mother told her about her sister's ASD diagnosis when she was seven-years-old.

4.3.4 Sensitivity to ethical issues

A priority throughout the research process was to ensure that no harm came to those participating. Thus, I always followed the ethical protocol (outlined in section 2.5.3). As mentioned (in section 2.5.3.2) I recognised that there was a risk of the unplanned disclosure of information that I would be obliged to act on. Therefore, I had a child protection procedure in place. I identified a low-level risk when interviewing one participant (Alesha). Alesha reported that she was a young carer for her five-year-old brother with ASD and that it was sometimes challenging. Alesha also reported that she has never received any support during the times that she found challenging and that it has become normal for her to keep her thoughts and feelings to herself because she is not aware of anyone who can support her:

"When going through the challenging times with my siblings I have never received any help or support from anyone as the challenging times became a norm and that nobody in the family would notice when it was too much for me or anyone else. I guess it made it more difficult having so much to handle and having to carry on with everything without anybody stopping to see how I am doing while supporting my siblings" (Alesha)

"It has now started to become a norm for me to just keep thoughts and feelings of challenging times to myself as I don't have the support around me and not aware of anyone who can support me through the challenging times" (Alesha)

According to my ethics protocol, I sign posted Alesha to Sibs (a UK charity for those who have a sibling with a disability):

Hi Alesha, thank you for your reply to the probe question. Just to let you know, there's a charity called Sibs which is a charity that offers support to individuals who have a sibling with a disability. You can follow Sibs on Facebook and Twitter and another way to access them is through their website (www.sibs.org.uk)
(Researcher)

No other ethical issues arose.

4.3.5 Quality checks

King and Brooks (2017) outline some of the ways in which to assess quality in TA. I will focus on two of the quality check procedures outlined: (a) keeping an audit trail and (b) thick descriptions and use of participant quotes.

I kept an audit trail to record the way my analysis developed and the analytical decisions that I made. For example, template version number two (please see figure 7) was adapted from the initial template after it was applied to Christopher, Becky, and Rachel's interview transcripts and was completed on 04.07.17. Template version number three (please see figure 8) was adapted from template version number two after supervision with my supervisors and was completed on 26.07.17. Please see section 2.5.4.6 (stage six of data analysis) for explanations of why particular modifications were made. Keeping an audit trail of the way my analysis has developed has helped enhance the quality of my research because as Koch (2006) suggests, a study's trustworthiness (rigour) may be established if a reader is able to audit the analytical decisions made and assess whether the analytical decisions were logical. Keeping an audit trail enabled me to reflect on the analytical decisions that I made and will enable other readers (e.g. examiners) to better understand how I reached those analytical decisions and whether the findings are grounded in the data.

I provided detail about the focus of the study and the context. For example, I used an online survey to collect contextual data about participants (e.g. their living arrangements, the age of their sibling with ASD), I wrote a biographical summary about each participant and have used participant quotes throughout my analysis. This has helped enhance the quality of my research because it will help readers (e.g. examiners) to judge how the conclusions I have drawn may be applied more widely and judge whether the interpretation that has emerged from my analysis is consistent with the descriptions that I have presented.

4.4 Author reflexivity

In this section of the chapter I will discuss my personal reflections of the research process.

4.4.1 Power

Power, during the interactions between interviewers and interviewees is regarded as unequal (Guillemin & Gillam, 2004; Busso, 2007) and the power is generally held by the interviewer. Similarly, there is an inequity in the relationship between adult researchers and CYP because within society, adults are considered to have greater authority (Curtin & Murtagh, 2007). It was important for me, as a researcher, to develop a relationship with the adolescents that participated in my research project, which equalised, or at least minimised, the differences in power. The aim of this study was to understand what it is like to grow up with a sibling with ASD from the TD sibling's own perspective and how they access and utilise knowledge of ASD. Therefore, in seeking their experiences, thoughts and feelings I was referring to them as the experts who could assist me in my research project. I stressed that I was the one who was learning from them about their experiences that I had asked them to share with me.

Utilising email interviews may have reduced the power imbalance between myself and the participants because they may have felt less obliged to answer questions that they did not want to answer via email. To encourage openness from the participants and to create an informal and friendly context, I began my interviews by telling the participants about myself – for example, my age, which University I study at and what course I do, my job working with children with ASD and what the aim of my study was. On reflection, I think I could have invited participants to share something about themselves with me. Regarding the quality of participant responses, there was one participant (Olivia) who was under communicative. Olivia often provided very short and undetailed responses. Although I did use probe questions, I was careful not to use too many so that it did not feel as though I was harassing her. I frequently thanked Olivia for her responses and explained that the information that she was giving me was of great value. Another participant (Becky) was often over apologetic for not responding to emails 'straight away'. I reassured her that it was not a problem and that I was very grateful for her involvement in the project. Jacob, Jenny, and Rachel provided in-depth responses to the interview questions. They often drew on specific experiences to explain their thoughts and feelings. They seemed very open and often thanked me for giving them the opportunity to share their experiences, thoughts, and feelings. Rachel and Jacob hoped that their interviews would 'help others with a sibling with ASD' and said that they looked forward to reading the results of the study (I informed participants that I would send them a summary of the results).

4.4.2 Data

In terms of the data that emerged from the present study, I think that I could have asked additional probe questions to collect more detailed data. For example, the data that emerged about participants' knowledge of their sibling's condition describes what sources of information were useful at a basic

level. One participant explained that she accessed knowledge about ASD by watching videos on YouTube of people with ASD describing their own experiences. On reflection, I could have probed further information such as specific stories of YouTube videos and what the story was like as this may have produced more insightful data that explained why watching YouTube videos was useful.

As previously mentioned (in section 2.3), I have worked with eight children who have ASD and their families for over two years and I acknowledge that my experience of working with these children and their families will have shaped the research findings. For example, the data that emerged about some participants feeling distressed and upset when their sibling has a 'meltdown' may not have made sense to another researcher who has not experienced children with ASD having 'meltdowns' or may appear striking. I did not have to ask the participants to explain what a 'meltdown' is because I frequently experience children with ASD having 'meltdowns' at work and was able to understand why participants feel distressed and upset when they experience their sibling having a 'meltdown'. However, I could never have been in a position of 'knowing' what the participants were feeling or experiencing because I could only interpret the data from my own (professional) perspective. I was also aware that I work with young children who are severely affected by ASD and when their ASD is likely to be the most profound. I was careful not to assume the participants' experiences based on the children and the families that I work with.

4.4.3 Representation

It is inconceivable that I can establish a relationship with participants during the frequent exchanging of emails and then be absent from the text which represents the experiences, thoughts and feelings of the participants (Meloy, 1993; Sparkes, 1995). Alcoff (1991) suggests that a way forward is to recognise that the final text produced is a collaborative one and that researchers should not speak for participants; they should speak with them. This collaboration results in a text that reflects both the participant(s) and the researcher. Richardson (1990) argues that no matter how text is written, researchers control how it is written and therefore the text cannot be neutral and separate from the researcher. For example, I have decided which quotes stay in the final write up of the findings and which quotes are not included. Thus, I have decided what is important to the participants and what is not important. Inevitably, the email exchanges between myself and the participants have become interview transcripts, the transcripts have been coded into themes and combined with other interview transcripts, which have ultimately become a thesis. Thus, the final form is a passing resemblance of the original email exchanges between myself and the participants. I recognise that I am ultimately accountable and responsible for the voice, and the voice that is written, of the adolescents that participated in this study.

4.5 Conclusion

The aim of this study was to understand what it is like to grow up with a sibling with ASD from the TD sibling's own perspective and how they access and utilise knowledge of ASD. This study contributes to the, relatively small, literature on the experiences of TD adolescents with a sibling with ASD in the UK. The participants' experiences of growing up with a sibling with ASD were varied and this may be because each child is affected by ASD differently.

Some participants spoke about their sibling's condition like it is something that is 'ever – present'. Thus, spending one to one time with their parents without their sibling with ASD is important to them because it is a time that from what is usual. Their needs and wants take priority during this time, opposed to their sibling's. Some participants reported experiencing feelings of distress when their sibling with ASD had a 'meltdown' in public. However, it was not their sibling's behaviour that made them feel distressed, it was other peoples' reactions. In terms of how participants access and utilise knowledge of ASD, some participants talked about 'experiential learning'. This included learning about their sibling's condition through their lived experience of having a sibling with ASD and learning about ASD through others' subjective experience of having ASD so that they could understand how ASD affects their sibling. In terms of the real -world implications of this study, the findings highlight the importance of social care funding for services such as Short Breaks and a need for meaningful public awareness of ASD.

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Appendices

Appendix 1 – SREP application

THE UNIVERSITY OF HUDDERSFIELD

School of Human and Health Sciences – School Research Ethics Panel

APPLICATION FORM

Please complete and return via email to:

Kirsty Thomson SREP Administrator: hhs_srep@hud.ac.uk

Name of applicant: Jasmine Mason

Title of study: Living with a sibling with autism

Department: CAPHR

Date sent: 14.12.16

Please provide sufficient detail below for SREP to assess the ethical conduct of your research. You should consult the guidance on filling out this form and applying to SREP at <http://www.hud.ac.uk/hhs/research/srep/>.

Researcher(s) details	Jasmine Mason Postgraduate research student MSc Psychology (By research)
Supervisor(s) details	Dr Joanna Brooks Professor Elizabeth Hughes
All documentation has been read by supervisor (where applicable)	YES
Aim / objectives	This project aims to contribute to a comprehensive understanding of the perceived needs and experiences of siblings who have a brother or a sister with autism. Therefore, the research will be guided by two central research questions: (a) What are the lived experiences of individuals, who have a brother or a sister with autism? (b) What are the perceived support needs of individuals, who have a brother or a sister with autism?

<p>Brief overview of research methods</p>	<p>An advert for the recruitment of ten participants, who are between the ages of 16 and 18 years old and have a sibling with autism, will be posted on several Facebook pages. The advert will inform prospective participants to email the researcher if they wish to take part in the project. The researcher aims to recruit a total of ten participants and the recruitment advert will make it clear that participating in the project will be on a first come first serve basis. After ten participants, have been recruited the researcher will email (please see Appendix A for the email) individuals, who still want to take part in the project, explaining why it is no longer possible to be involved.</p> <p>Prospective participants will be emailed (please see appendix B for the email) an information sheet and a link to Qualtrics to fill in a consent form. Following informed consent, participants will be emailed (please see appendix C for the email) a link to Qualtrics asking them to fill in a survey.</p> <p>Semi structured interviews will be the method of data collection and data will be gathered online, via email. The duration of data collection will be six weeks, in which participants will be emailed one interview question per week. Participants will also be sent personal probe questions. These questions will be personal to each participant and will explore further meaning and interests that emerge to the researcher throughout the week. Participants will be asked to reply to interview questions within five working days and the expected timescale will be outlined in the participant information sheet. King and Horrocks (2010) give guidelines on how to react if a participant fails to respond to an email within the expected timescale. They suggest to send an initial reminder quite soon after the expected timescale. Therefore, if a participant fails to respond to an email, within five working days, an initial email (please see appendix D for the email) reminder will be sent to participants two working days beyond the expected timescale. Should there still be no response, King and Horrocks (2010) suggest sending participants a further reminder, including an explicit question as to whether they wish to cease involvement in the project and, if so, whether they wish to withdraw the data already provided. So, one week beyond the agreed timescale, participants will be sent a further email (please see appendix E for the email) reminder. Finally, King and Horrocks (2010) suggest that a participant non-response to all email reminders should be viewed as a full withdrawal from the project. Therefore, participants who fail to respond to all emails will no longer be involved in the project and their data will be 'destroyed' and not included in the project. All emails, throughout the project, will be sent to participants from a University email account (Jasmine.Mason@hud.ac.uk).</p> <p>In terms of ethics, several ethical issues have been identified and discussed at length with the supervisory team – please find the ethical discussion document attached.</p>
<p>Project start date</p>	<p>January 2017</p>

Project completion date	September 2017
Permissions for study	Please see document attached
Access to participants	Participants will be accessed through social media. An advert for the recruitment of participants will be posted on the following Facebook pages: ABAA4All, ABA Liverpool, ABA Manchester, Autism Parent Empower, and The Whole Autism Family (please see appendix F for information about each of the Facebook pages).
Confidentiality	All information about the research participants will be kept confidential and will only be known to the researcher and supervisory team. King and Horrocks (2010) highlight that, the nature of the internet means that absolute confidentiality cannot be promised when carrying out interviews via email (e.g. system administrators have access to University email accounts). To minimise the risk of the inadvertent disclosure, interview transcripts will be transferred onto a word document and the raw data will be deleted from the University email account.
Anonymity	Participants will remain anonymous; they will participate in the study online. This will be explained to them in the information sheet. Participants will be asked for their name and date of birth on Qualtrics, which will be kept separate from their data. This will preserve their anonymity as a coding system will be used where numbers in an excel spreadsheet would have to be matched against the names and dates of births of participants. Each interview transcript will be named and saved anonymously (e.g. Participant one, email one). The aims of the research mean that the participants are going to be talking about living with a brother or a sister with autism, so it is appreciated that there may be concerns regarding the anonymity of the individual with autism. However, participants are not going to be asked to disclose personal information about their sibling or talking directly about their sibling, they are going to be talking about their own experience of living with their sibling. Both the research participants and the siblings will be given pseudonyms in the write up of the research project. Finally, where necessary, quotes will be edited in the write up of the project, so that participant and sibling identities are not disclosed.
Right to withdraw	Before the interviews start and during the interviews, participants will have the right to withdraw from the project at any time and withdraw the data that they have already given. After the interviews have finished, participants have the right to withdraw their data up until 01.05.17. This is detailed in the participant information sheet and consent form.
Data Storage	Interview transcripts will be transferred onto a word document and the raw data will be deleted from the University email account. All data and participant information will be saved electronically on a University computer and University drive. During data analysis, paper documents will be kept in a locked drawer. In line with the University guidelines, raw data will be stored on the University data drive for ten years.

Growing up with a Sibling with Autism Spectrum Disorder

Psychological support for participants	Psychological support for participants will be detailed in the debrief. Please see document attached.
Researcher safety / support (attach completed University Risk Analysis and Management form)	Please see document attached
Information sheet	Please see document attached
Consent form	Please see document attached
Letters / posters / flyers	Please see recruitment advert attached
Questionnaire / Interview guide	<p>Please see participant survey attached.</p> <p>Participants will be sent the following six questions:</p> <ol style="list-style-type: none"> 1. What information or who has helped you understand your brother/sister's disability? 2. Can you tell me about what it has been like to grow up with a sibling with autism? Or, how did your life change when your sibling with autism was born? Depending on the birth order of siblings. 3. How has your sibling's disability affected your relationship with your other family members? (E.g. parents/carers, other siblings, grandparents). 4. What help and support do you think would be helpful for you? 5. How is your life different to your friend's life whose brother or sister does not have autism? 6. What advice would you give to other people who have a bother or a sister with autism?
Debrief (if appropriate)	Please see document attached.
Dissemination of results	The results will be written up for the project thesis and may also be written up in a report for a journal article and presented at a conference. A short report of the results will also be sent to the participants and people who would have liked to have taken part in the project but it was no longer possible to take part.
Identify any potential conflicts of interest	None

Growing up with a Sibling with Autism Spectrum Disorder

<p>Does the research involve accessing data or visiting websites that could constitute a legal and/or reputational risk to yourself or the University if misconstrued?</p> <p>Please state Yes/No</p> <p>If Yes, please explain how you will minimise this risk</p>	<p>No</p>
<p>The next four questions in the grey boxes relate to Security Sensitive Information – please read the following guidance before completing these questions:</p> <p>http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/oversight-of-security-sensitive-research-material.pdf</p>	
<p>Is the research commissioned by, or on behalf of the military or the intelligence services?</p> <p>Please state Yes/No</p> <p>If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data</p>	<p>No</p>
<p>Is the research commissioned under an EU security call</p> <p>Please state Yes/No</p> <p>If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data</p>	<p>No</p>

Growing up with a Sibling with Autism Spectrum Disorder

<p>Does the research involve the acquisition of security clearances?</p> <p>Please state Yes/No</p> <p>If Yes, please outline how your data collection and storages complies with the requirements of these clearances</p>	<p>No</p>
<p>Does the research concern terrorist or extreme groups?</p> <p>Please state Yes/No</p> <p>If Yes, please complete a Security Sensitive Information Declaration Form</p>	<p>No</p>
<p>Does the research involve covert information gathering or active deception?</p> <p>Please state Yes/No</p>	<p>No</p>
<p>Does the research involve children under 18 or participants who may be unable to give fully informed consent?</p> <p>Please state Yes/No</p>	<p>Yes</p>
<p>Does the research involve prisoners or others in custodial care (e.g. young offenders)?</p> <p>Please state Yes/No</p>	<p>No</p>

Does the research involve significantly increased danger of physical or psychological harm or risk of significant discomfort for the researcher(s) and/or the participant(s), either from the research process or from the publication of findings? Please state Yes/No	No
Does the research involve risk of unplanned disclosure of information you would be obliged to act on? Please state Yes/No	Yes
Other issues	None
Where application is to be made to NHS Research Ethics Committee / External Agencies	NA
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	

All documentation must be submitted to the SREP administrator. All proposals will be reviewed by two members of SREP.

If you have any queries relating to the completion of this form or any other queries relating to SREP's consideration of this proposal, please contact the SREP administrator (Kirsty Thomson) in the first instance – hhs_srep@hud.ac.uk

Appendix A – Recruitment email

RE: Research project

Hi (insert name)

Thank you so much for expressing an interest in my project – I really appreciate it as without people like you, my project wouldn't be possible! Unfortunately, it's no longer possible to take part in the project due to a large number of responses and time constraints - I only have one year to plan the project, collect the data and write it all up so I must stick to strict deadlines.

Growing up with a Sibling with Autism Spectrum Disorder

Once I have completed this project, I am hoping to do a bigger piece of research about the experiences of siblings who have a brother or a sister with autism. So, if you would like me to, I can keep a record of your email address and email you when I will be needing research participants again.

Thank you again for expressing an interest in my project and I'm very sorry it's no longer possible to take part,

Jasmine

Appendix B – Prospective participants email

RE: Research project

Hi (insert name)

Thank you so much for expressing an interest in my project – I really appreciate it as without people like you, my project wouldn't be possible!

My name is Jasmine and I work as an Applied Behaviour Analysis (ABA) tutor with children with autism, I tutor them academic, communication, and self-help skills in their home and I also tutor one boy at school. I'm also a research student at the University of Huddersfield and I'm doing an online research project about the experiences of siblings who have a brother or a sister with autism.

I've attached a participant information sheet which has all the details about the project but I'll quickly tell you here what you would need to do if you want to take part, all the research is online so you could take part from home or school/college -

1. Fill in an online consent form
2. Fill in an online survey
3. Then I would email you one interview question per week for six weeks and you would email me your answer back

Please take time to read the information sheet before you decide if you would like to take part and if you have any questions or would like to know any more information then please email me 😊

If you don't want to take part in the project – that's absolutely fine and thank you again for expressing an interest! If you decide you would like to take part in the project, please follow the link below. This is an online consent form, which you must fill in if you would like to take part.

(insert link to Qualtrics consent form)

Thank you again – your help is very much appreciated,

Jasmine

Appendix C – Survey email

RE: Research project

Hi (insert name)

Growing up with a Sibling with Autism Spectrum Disorder

Thanks so much for deciding to take part in my project! Remember, you can stop taking part in the project at any time and if you have any questions or want to know more information about anything you can email me 😊

The first part of the project requires you to fill in a short survey. I want you to fill in this survey so that I can get to know some information about you and your family, it's quite short so shouldn't take you very long to fill in! I have copied the link to the survey below.

(Insert Qualtrics survey link)

After you have filled in this survey, I Will be in touch with the first interview question.

Thanks a lot,

Jasmine

Appendix D – Email reminder number one

RE: Research project

Hi (insert name)

It's Jasmine, just emailing you about the research project. Did you receive the last interview question that I sent you? If you did and you need longer to reply that's absolutely fine – please can you just let me know. If you didn't receive it, also let me know and I'll send it to you again 😊

Hope to hear from you soon and thank you again for your participation,

Jasmine

Appendix E – Email reminder number two

RE: Research project

Hi (insert name)

It's Jasmine, just emailing you about the research project. I hope you would still like to take part in my project but if you've decided you don't want to that's absolutely fine! If you don't want to take part anymore, are you happy for me to use your earlier answers or do you want me to remove them from the project?

If you still want to take part and need me to email you the question again – just let me know and I can send it to you again 😊

I hope to hear from you soon and thank you again for your participation in my project,

Jasmine

Appendix F – Facebook group information

The Whole Autism Family

The Whole Autism Family was formed in October 2014 and is a local support group in Kirklees, supporting families affected by autism. Their aim is to offer a provision of support network to the whole family, from individuals affected by autism, parents and carers, siblings to extended family members. They also offer access to literature, training courses and professional guests. Informal meetings are held weekly at Carlinghow and Wilton Children's Centre and can be attended by anyone who has a family member who has an Autism Spectrum condition. This is an opportunity for family members to share their experiences and develop a support network. The Whole Autism Family also raise awareness of autism within the wider community and publish a quarterly newsletter detailing the latest news within autism and events that are taking place. The family also campaign for change to waiting times for an autism diagnosis. The majority of people access the charity and support network through The Whole Autism Family Facebook group, which currently has 354 members.

ABAA4ALL

ABAA4ALL is a parent campaign that aims to promote awareness, understanding and a wider access to professionally managed ABA (Applied Behaviour Analysis) for children and adults with autism. The campaign raises awareness of ABA through media channels and on social networks. The campaign began with 200 parents seeking a legal opinion on whether the UK's failure to provide autistic children with ABA might be judicially reviewable. Judicial review proceedings are now ongoing. The campaign has also wrote enclosing a signed submission to the chairman of NICE, asking them to review their guidance on autism. The forefront of the campaign remains a busy and well informed Facebook page, with over 4,000 followers.

ABA Manchester and Liverpool

ABA Yorkshire, ABA Liverpool and ABA Manchester are three separate Facebook groups that were set up by Focus Yorkshire, Focus Liverpool and Focus Manchester to gauge interest in ABA Saturday schools. The Facebook groups are also platforms for local families and ABA tutors to post asking for additional advice and support and advertise ABA programmes and hours.

Autism Parent Empower

Autism Parent Empower aims to empower parents and other family members to succeed on their 'autism journey'. They recognise that early intervention for children with autism is vital. However, they also recognise that evidence based interventions are costly and long waiting lists and several consultations take up time. So, Autism Parent Empower has collaborated with Child Autism UK (ABA provider), Brainstorm health (Clinical nutritionists and biomedical specialists) and the Sue Stone Foundation (life coaches) to deliver a 12 week, evidence based intervention, programme to parents and families of children with autism.

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Growing up with a Sibling with Autism Spectrum Disorder

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Appendix 2 – recruitment advert

Living with a sibling with autism
What's your story?
I want to hear from you about your experiences!

Do you have a sibling with autism?
Are you aged 16 – 18?
Would you like to take part in an online research project?

To take part or for more information email jasmine.mason@hud.ac.uk
Once a total of 10 participants are recruited it will no longer be possible to take part in the research project.



University of
HUDDERSFIELD



Appendix 3 – participant information sheet



Living with a sibling with autism

Information sheet

My name is Jasmine and I work as an Applied Behaviour Analysis (ABA) tutor with children with autism. I'm also a postgraduate researcher at the University of Huddersfield. Thank you for taking an interest in this project. Before you decide to take part, it is important for you to understand why the project is being done and what you will have to do if you take part. Please take time to read the following information carefully and talk with your parents/carers or anybody else you feel will help. If you need any more information about anything, please contact me – my contact details are on the last page of this information pack.

What is the research project about?

You are being invited to take part in this project to help learn more about the experiences and support needs of individuals who have a brother or a sister with autism, which I hope will inform support services for families living with autism.

Why have I been approached?

I would like 10 teenagers, who have a brother or a sister with autism, to take part in this project and I would like to interview teenagers who are between the ages of 16 and 18 years old. To understand the experiences and support needs of individuals who have a brother or a sister with autism, I should ask the people who know most about it – individuals who have a sibling with autism themselves, like you! You have lots of valuable experience that I would like you to share with me, to help me understand what your support needs are.

Do I have to take part?

No, it is your decision whether you take part in this project. If you would like to take part, you will first be asked to fill in an online consent form. You can stop taking part in the project at any time (without giving me a reason) and you can withdraw the information that you have given to me until the 01.05.17.

What will I need to do?

If you agree to take part in the project, I would ask that you are involved for six weeks. After you have filled in an online consent form, I would like you to fill in an online survey. This survey will help me to get to know some information about you and your life, such as your age, gender and, who you live with. I would then like to email you one interview question, per week, for six weeks. These questions will explore your experience of living with a brother or a sister with autism and here are some examples of the types of questions you will be asked:

- Can you reflect on growing up with a brother or a sister with autism?
- How is your life different to your friend's life whose brother or sister does not have autism?
- What advice would you give to other brothers/sisters of siblings with autism?

When you have answered my interview question, I will read your answer and I might email you a personal probe question. A personal probe question will ask you to explain something in more detail, or ask you to give an example of when something happened or of when you felt a certain way. I would like you to answer each interview question within five working days, via email. If you can't answer an interview question within five working days or would like some more time to think about what you would like to say, that's absolutely fine, you can just email me to let me know. It's important for you to know that you do not have to answer any questions that you don't want to and you don't have to give me a reason either.

What will happen to the information?

All the information that you give me will be kept confidential, which means that no one other than me and my two supervisors, (information about who they are and their contact details can be found at the bottom of this information pack) will ever know that your information came from you. The information will not be shared with your parents/carers, other family members, or your friends.

After I have collected all the information that I need, I will be writing a report, but I will change your name, your siblings' name, and, anyone else's name that you might mention. I will use made up names instead – this means that you will be kept anonymous. However, if you tell me that you or anyone else is at risk I must inform the appropriate authority. Quotes, from the information that you give, will be used in the write up of the research project, however, they will be edited so that they are not identifiable to you. I will send you a copy of the research findings when I have written the report.

What will happen next?

If you think that you would like to take part in this research project, please contact me! 😊 My contact details can be found at the bottom of this information pack.

How do I make a complaint?

I hope that you will not need to, but if you do find that you wish to complain about anything to do with this project then you can contact Dr Joanna Brooks at the University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, Tel: 01484 472546 or Professor Elizabeth Hughes at the University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, Tel: 01484 473 417.

Who can I contact for further information?

Please contact me if you have any questions or want any more information. My name is Jasmine Mason and my email address is Jasmine.mason@hud.ac.uk.

Supervisor information

This project is supervised by Dr Joanna Brooks (senior research fellow at the University of Huddersfield) and her email address is j.m.brooks@hud.ac.uk and Professor Elizabeth Hughes (Chair of applied Mental Health research at the University of Huddersfield) and her email address is e.c.hughes@hud.ac.uk. You can also contact them if you would like to.

Thank you so much for taking the time to read this information pack and considering participating in this project, I really appreciate your help! 😊

Jasmine

Appendix 4 – consent form

The University of Huddersfield

Consent form: Living with a Sibling with autism

Please enter the following information

1. Name:
2. Date of birth:/...../.....
3. Email address:

Please tick the boxes below

1. I have read and understood the information sheet for the above project (version number x, dated xx/xx/xx)
2. I have had the opportunity to ask questions about the project
3. I understand the purpose of the project and how I will be involved
4. I understand that I can stop taking part in the project at any time without giving a reason
5. I understand that I can withdraw the information I have given up until 01/05/17
6. I understand that I do not have to answer any interview questions that I do not want to
7. I understand that direct quotes may be used in research reports/publications, but that my identity will be protected, and my personal information removed, and no information that could lead to me being identified will be included
8. I give permission for the researcher to get in touch with the appropriate authority if I tell her about harm to myself or others
9. I agree to take part in the above project

Appendix 5 – online survey

- 1. Please enter your name**
- 2. Please enter your date of birth**

dd/mm/yyyy

- 3. Please select one of the following options:**

I am Male

I am Female

- 4. Please specify your ethnic group from one of the following options:**

White English/Welsh/Scottish/Northern Irish

White Irish

White Gypsy or Irish Traveller

White and Black Caribbean

White and Black African

White and Asian

Asian/Asian British Indian

Asian/Asian British Pakistani

Asian/Asian British Bangladeshi

Asian/Asian British Chinese

Black/Black British African

Black/Black British Caribbean

Arab

Other

- 5. How old is your sibling with autism?**
- 6. Please describe your living arrangements (e.g. I live with my Dad and my Step Mum and my Sister with autism all of the time/ I live with my Mum and my brother with autism for half of the week and live with my Dad, Step Mum and Step Sister for the other half of the week).**
- 7. Have you ever received free school meals? Please choose one of the following options:**

Yes

No

- 8. What are the first two letters and the first number of your postcode? (e.g. WF3/LS29)**

Appendix 6 – debrief document



Living with a sibling with autism

Debrief sheet

Thanks so much for taking part in my project – without the participants it wouldn't have been possible!

What happens next?

I will now analyse the interviews using something called template analysis, which means I will look for the same themes in all of the interviews. Once I have finished the analysis, I will write up the results and I will also write a summary of the results to send to you 😊

After I have finished this project, I hope to do some more research about the experiences of siblings who have a brother or a sister with autism. So if it's okay with you I will keep a record of your email address and contact you about taking part in some more research in the future – you can email me and let me know – my contact details are on the last page of this debrief pack.

Help and support

I understand that talking about personal experiences is sometimes difficult and can make you feel quite down or you might be interested in talking to people who also share some of the same experiences as you do – so below are the details of two charities that I know offer information and support to siblings of disabled people.

Sibs – Sibs is a UK charity that exists to support people who grow up with a disabled brother or sister. You can follow them on Facebook and Twitter to access lots of information. Another way to get information and support from Sibs is to go to their website (www.sibs.org.uk) and fill in a form with your details and they can either email or ring you within three days. Their email and phone service is confidential – they will only break confidentiality if they think you or anyone else is at risk of harm. Sibs also have a sibling forum, where you can chat to other siblings who have a disabled brother/sister.

The Whole Autism Family – The Whole Autism Family is a support group in Kirklees that supports families affected by autism. If you don't live nearby you can access their Facebook page – where there is lots of information and support you can access. They also have a website where you can access lots of information (thewholeautismfamily.co.uk).

If you attend school/college/sixth form they can also offer you information, guidance and support for however you're feeling.

Who can I contact for further information?

Please contact me if you have any questions or want any more information about the project. My name is Jasmine Mason and my email address is Jasmine.mason@hud.ac.uk.

Supervisor information

This project is supervised by Dr Joanna Brooks (senior research fellow at the University of Huddersfield) and her email address is j.m.brooks@hud.ac.uk and Professor Elizabeth Hughes (Chair of applied Mental Health research at the University of Huddersfield) and her email address is e.c.hughes@hud.ac.uk. You can also contact them if you would like to.

How do I make a complaint?

I hope that you do not need to, but if you do find that you wish to complain about anything to do with this project then you can contact Dr Joanna Brooks at the University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, Tel: 01484 472546 or Professor Elizabeth Hughes at the University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, Tel: 01484 473 417.

Thank you so much again for taking part in my project, I really appreciate your help 😊

Jasmine

Appendix 7 – template version number 4

- 1. “My life is different”**
 - 1.1 Perceptions of the ‘norm’
 - 1.2 TD siblings’ accounts of the impact of living with ASD on themselves
 - 1.2.1 The emotional impact
 - 1.2.1.1 The emotional impact of behaviour
 - 1.2.1.1.1 Not knowing how to help
 - 1.2.1.2 The emotional impact of other peoples’ reactions
 - 1.2.1.2.1 ASD is an invisible disability
 - 1.2.2 Roles and responsibilities as a sibling to someone with ASD
 - 1.2.2.1 Supporting the whole family
 - 1.2.2.2 Parental responsibility
 - 1.2.2.3 Caring role for sibling with ASD
 - 1.2.3 Impact on their own characteristics
 - 1.2.4 Worrying about the future
- 2. “My life is normal”**
 - 2.1 Family dynamics
 - 2.2 Normalising adjustments
 - 2.3 Social comparisons to non-ASD families
 - 2.4 TD siblings accepting that their sibling with ASD is different
- 3. Understanding sibling’s condition**
 - 3.1 Growing understanding of ASD with age
 - 3.1.1 Limited knowledge of ASD
 - 3.1.2 Limited knowledge of how ASD affects sibling
 - 3.1.3 Feeling as though their sibling with ASD received preferential treatment from their parents
 - 3.2 Accessing knowledge of sibling’s condition
 - 3.2.1 Own research
 - 3.2.1.1 Internet
 - 3.2.1.2 Listening to other peoples’ experiences
 - 3.2.2 Knowledge about sibling’s condition from professionals
 - 3.3 Utilising knowledge of sibling’s condition
 - 3.3.1 Understanding how ASD affects their sibling
 - 3.3.2 Learning how to support sibling with ASD
- 4. Support for TD siblings living with ASD**
 - 4.1 Support from parents
 - 4.1.1 Tangible support
 - 4.1.1.1 Spending 1:1 time with parents
 - 4.2 The value of shared experience
 - 4.2.1 The opportunity to give and receive advice
 - 4.3 Formal support
 - 4.4 Not aware of available support services

Appendix 8 – template version number 5

- 1. Understanding sibling's condition**
 - 1.1 Growing understanding of ASD with age*
 - 1.1.1 Limited knowledge of ASD
 - 1.1.2 Limited knowledge of how ASD affects sibling
 - 1.1.3 Feeling as though their sibling with ASD received preferential treatment from parents
 - 1.2 Accessing knowledge of sibling's condition*
 - 1.2.1 Own research
 - 1.2.1.1 Internet
 - 1.2.1.2 Listening to other peoples' experiences
 - 1.2.2 Knowledge from professionals
 - 1.3 Utilising knowledge of sibling's condition*
 - 1.3.1 Understanding how ASD affects their sibling
 - 1.3.2 Learning how to support sibling with ASD
- 2. "My life is my normal"**
 - 2.1 Family dynamics – sibling age gap*
 - 2.2 Accepting adjustments*
 - 2.3 "How different is my ASD sibling really?"*
 - 2.3.1 Social comparisons to typical developing children
 - 2.3.2 Reflecting on sibling's achievements
- 3. "My life is different"**
 - 3.1 Comparisons with the 'norm'*
 - 3.2 Siblings' accounts of the impact of living with ASD on themselves*
 - 3.2.1 The emotional impact
 - 3.2.1.1 The emotional impact of behaviour
 - 3.2.1.1.1 Not knowing how to help
 - 3.2.1.2 The emotional impact of other peoples' reactions
 - 3.2.1.2.1 ASD is an invisible disability
 - 3.2.2 Roles and responsibilities as a sibling to someone with ASD
 - 3.2.2.1 Supporting the whole family
 - 3.2.2.2 Parental type responsibility
 - 3.2.2.3 Practical role in caring for sibling with ASD
 - 3.2.3 Impact on their own characteristics
 - 3.2.4 Worrying about the future
 - 3.3 Siblings' accounts of the impact of living with ASD on parents*
- 4. Support for siblings living with ASD**
 - 4.1 Support from parents*
 - 4.1.1 Spending 1:1 time with parents
 - 4.2 The value of shared experience*
 - 4.2.1 The opportunity to give and receive advice
 - 4.3 Formal support*
 - 4.4 Not aware of available support services*

Appendix 9 – Template version number 6

- 1. Understanding sibling's condition**
 - 1.1 Growing understanding of sibling's condition with age
 - 1.1.1 Limited knowledge of sibling's condition
 - 1.1.1.1 Limited knowledge of how condition affects sibling
 - 1.1.1.2 Feeling as though sibling with ASD received preferential treatment
 - 1.2 Accessing knowledge of sibling's condition
 - 1.2.1 Own research
 - 1.2.1.1 Internet
 - 1.2.1.2 Listening to other peoples' experiences
 - 1.2.2 Knowledge from professionals
 - 1.3 Utilising knowledge of sibling's condition
 - 1.3.1 Understanding how condition affects sibling
 - 1.3.2 Learning how to support sibling with ASD
- 2. Social comparisons**
 - 2.1 Comparing sibling with ASD to TD children
 - 2.2 Comparisons to non-ASD families
- 3. Roles and responsibilities**
 - 3.1 Additional levels of responsibility
 - 3.2 Parental type role
 - 3.3 Worries about the future
 - 3.4 Siblings' accounts of the impact ASD has on parents
- 4. Responses to behaviour**
 - 4.1 Emotional responses to sibling's behaviour
 - 4.2 Outside others' reactions to sibling's behaviour
 - 4.2.1 ASD is an invisible disability
 - 4.2.2 Siblings' emotional responses to outside others' reactions
- 5. Support for TD siblings**
 - 5.1 Support from parents
 - 5.1.1 Spending 1:1 time with parents
 - 5.2 The value of shared experienced
 - 5.2.1 The opportunity to give and receive advice
 - 5.3 Formal support
 - 5.4 Not aware of available support services

Appendix 10 – Template version number 7

- 1. Understanding sibling's condition**
 - 1.1 Absence of understanding
 - 1.1.1 Growing understanding of ASD with age
 - 1.1.1.1 Limited knowledge of how ASD affects sibling
 - 1.1.1.2 Feeling as though sibling with ASD received preferential treatment from parents
 - 1.2 Experiential learning
 - 1.3 Understanding my sibling before their disability
 - 1.3.1 Listening to other peoples' experiences
- 2. Negotiating normality**
 - 2.1 "It's different but it's normal for us"
 - 2.1.1 Comparisons to non-ASD families
 - 2.2 "My sibling is different"
 - 2.2.1 Comparing sibling with ASD to TD children
- 3. Roles and responsibilities: Understanding my sibling's needs and challenges**
 - 3.1 Insightfulness
 - 3.1.1 Parental type role
 - 3.2 Empathising with parents
 - 3.3 Worries about the future
- 4. Experiences of behaviour**
 - 4.1 "It can be hard at times"
 - 4.1.1 Emotional responses to sibling with ASD having a 'meltdown'
 - 4.2 Outside others' reactions to sibling with ASD having a 'meltdown'
 - 4.2.1 Emotional responses to outside others' reactions
- 5. Support for TD siblings**
 - 5.1 "It's ever-present"
 - 5.1.1 Spending 1:1 time with parents
 - 5.2 Sharing experiences and learning from others
 - 5.2.1 The value of shared experience
 - 5.2.1.1 Feeling 'heard'
 - 5.2.2 The opportunity to give and receive advice
 - 5.3 Feeling unsupported