

**Having a Brother or Sister with Autism:
Children's Experiences of the Sibling Relationship.**

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Declaration

I confirm that the literature review and research report contained within this thesis have not been submitted for any other degree, or to any other institution.

Summary

The literature review synthesises the literature examining the impact of having a sibling with autism on siblings unaffected by autism. Four electronic databases and two journals were scrutinised in a systematic literature search for studies focusing on the effects of having a sibling with autism. Studies published between 1979 and 2007 were elicited for inclusion. The literature suggests that having a sibling with autism is not necessarily a harmful experience. The review indicates that the impact a child with autism has on their typically developing sibling can have positive and negative aspects, which are likely to change over time and are mediated by various factors. The experience of the sibling relationship when one child has autism has yet to be fully explored from the perspective of the siblings without autism themselves.

Early quantitative research examining the impact of having a sibling with autism indicated various negative effects. Qualitative studies have begun to explore the factors determining the positive and negative effects of having such a sibling, from child sibling perspectives. In this study child sibling's perceptions and experiences of the quality of the sibling relationship with their brother or sister with autism were explored using semi-structured interviews and a grounded theory methodology. Fifteen siblings without autism aged between six and thirteen with a sibling with autism aged between four and fourteen were interviewed. A theoretical account and process model of children's perceptions and experiences of their relationship with their sibling with autism were generated. The analysis indicated that for children who have a brother or sister with autism, a deep need for a relationship with their sibling is apparent. The analysis is discussed in terms of supplementing previous research findings and going some way to explaining the processes behind positive adaptation and negative adaptation to having a sibling with autism. Clinical implications are discussed and suggestions for further research are made.

The critical appraisal offers an examination of the research process and the research journey as an enlightening learning experience.

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Part 1

Literature Review

The effects of autism on siblings during childhood.

The effects of autism on siblings during childhood

Purpose: To synthesise the literature examining the impact of having a sibling with autism on siblings unaffected by autism.

Method: Four electronic databases and two journals were scrutinised in a systematic literature search for studies focusing on the effects of having a sibling with autism. Studies published between 1979 and 2007 were elicited for inclusion.

Results: The literature suggests that having a sibling with autism is not necessarily a harmful experience. Psychosocial functioning of siblings without autism and the sibling relationship are mediated by various factors within the family and wider social context.

Conclusions: The review indicates that the impact a child with autism has on their typically developing sibling can have positive and negative aspects, which are likely to change over time. Many of the characteristics of typical sibling relationships are also seen in sibling dyads where one child has autism. The experience of the sibling relationship when one child has autism has yet to be fully explored from the perspective of the siblings without autism themselves.

Key words: autism, impact, relationship, review, sibling

Target Journal: Journal of Autism and Developmental Disorders

1.0 Introduction

Disability within the family can have a dramatic effect on family interactions and functioning across the course of the family life cycle (DeMarle & Le Roux, 2001). The family system perspective (Broderick & Smith, 1979) suggests that when an individual in a family has a disability, there is potential for all members to be affected as they adjust to the impact of the condition. It is understandable that parents could become overwhelmed by the needs of a child with a significant disability (Rodrigue, Morgan & Geffken, 1990). It has been presumed that typically developing siblings would also be similarly overwhelmed, particularly when they may have less developed tools with which to try to understand the nature of disability (Lamorey, 1999).

Research has found that the parents of children who have an Autistic Spectrum Disorder (ASD) experience higher levels of stress than parents of children with other disabilities (Dumas et al., 1991; Bouma & Schweitzer, 1990). On top of greater financial concerns, increased demands of care giving and regular disruptions to plans and activities, (Rodrigue et al., 1990), when the child's disability is an ASD, parents face the challenges of the long and frustrating process of obtaining a diagnosis for their child, the lack of public knowledge about autism, the lack of acceptance of autistic behaviour by society, low levels of social support and disruptive 'antisocial' behaviours (Sharpley et al., 1997). It follows that ASDs may have a more striking or a qualitatively different impact on sibling functioning and the sibling relationship than other types of disability.

This review aims to synthesise the literature on the effects of autism on siblings during childhood, focussing particularly on research that has examined aspects of the relationship. In setting the context for the review, the specific nature of autism and the impact of autism on the family are discussed. Sibling relationships between typically developing children are briefly mentioned and the reasons why autism may profoundly affect the sibling relationship are discussed. Research on siblings of children with a disability is briefly reviewed followed by a thorough consideration of the effect of autism on typically developing siblings. Clinical implications for working with families affected by autism are discussed. The review concludes with a discussion of possible directions for future research.

1.1 Autistic spectrum disorders and the impact on family relationships

Autism is generally defined as a pervasive disorder of development and has been included in the Diagnostic and Statistical Manual of Mental disorders (DSM) and the International Classification of Diseases and Related Health problems (ICD) since the end of the 1970s¹. Diagnosis remains rooted in Kanner's original description of children presenting with abnormal communication, abnormal social development, ritualistic and stereotyped behaviour and resistance to change (Howlin, 1998). The autistic spectrum covers a range of ability levels and degrees of severity but there are key features, which are perhaps best conceptualised by Wing's 'Triad of Impairments' (Wing & Gould, 1979; Wing, 1996):

¹ DSM-IV (American Psychological Association, 1994), ICD-10 (World Health Organisation, 1992) are the latest versions of the classification systems used in the USA and Europe respectively.

Impairments in social relationships - These include difficulties in social interaction with others and in understanding social rules.

Impairments in social communication - These can present as a lack of interest in communicating with others, or a lack of awareness of social expectations of reciprocal communication. The individual may not demonstrate communication of emotion, or show interest in the other person's contribution to social interactions.

Lack of social imagination - Children are generally noted for unusual play behaviour, either due to a lack of play or an absence of imaginative play.

Children with autism share this triad of impairments, combined with narrow, rigid, repetitive patterns of activities and interests. However severity of features varies from individual to individual (Wing, 1996). In particular, great variance is seen in levels of linguistic and cognitive ability. Autism is more likely to present in males than females at a ratio of about 4:1 (Folstein & Rosen-Sheidley, 2001). Around 70% of children with autism also present with a level of learning disability, indicating that the cause of the disorder is more likely to be organic (Aarons & Gittens, 1999). Surveys from a range of different countries have consistently reported that between two and four children in every 10,000 develop autism (Baron-Cohen & Bolton, 2004).

Clinicians currently conceptualise autism and Asperger's Syndrome, those individuals who tend to show milder manifestations of the impairments seen in autism usually combined with higher levels of intellectual ability (Howlin, 1998), as being on the same continuum and thus refer to Autistic Spectrum Disorders. Throughout the review the

terms autism and Autistic Spectrum Disorder (ASD) will be used interchangeably, in acknowledgement of the fact that a diagnosis of autism involves much variation in degree of severity of symptoms.

Despite observed variations in presentation, social impairment relating to problems with emotional reciprocity, empathy and interaction present as the core features for all children with autism (Howlin, 1998), with social impairment remaining the most highly emphasised aspect of diagnostic criteria for autism (Wing, 1996; Volkmar et al., 1997).

The social difficulties experienced by children with autism have the potential to profoundly affect the development of relationships. Impairments of social communication, social relationships and social imagination interact with each other, having a cumulative effect on social behaviour and interaction and significant implications for sibships where one child has autism.

The findings from research examining the impact of autism on parents have implications for siblings. Siegal (1997) described autism as a disorder of social relatedness, highlighting that parent-child communication and attachment are more disequibrated than in other learning disability syndromes. Some studies have found evidence of attachment behaviours in children with autism (see Rutgers et al., 2004, for a review).

The lack of responsiveness, lack of eye contact, indifference to affection and lack of emotional reciprocity (American Psychiatric Association, 1994), shown by the majority of children with autism, are likely to be significantly distressing for parents. The type of social interaction shown by children with autism is significantly different to children

with normal development (Dissanayake & Crossley, 1996). Snow et al (1987) found that although children with autism can show positive affect in their interaction with others, it is at a lower rate than in children with comparable levels of developmental delay. Notably, in autism positive responses, such as enjoyment and engagement, tend to relate to self-absorbed activities rather than to interaction with another person. Research indicates that although actual levels of interaction between parents and autistic children may be similar to those between parents and non-autistic children, the nature of that interaction is qualitatively different (Kasari & Sigman, 1997). The social difficulties inherent in autism would be expected to disrupt the formation, development and maintenance of sibling relationships. The qualitative differences observed in interactions between parents and their child with autism are also likely to be seen in sibling interactions. The child without autism may need to offer more encouragement to prompt and sustain interaction due to their sibling's impaired reciprocity in social interaction. The fact that the capacity to relate to others is generally severely impaired in autism has complex implications for the sibling relationship dyad.

2.0 Literature review

As advances are made in research, theory and practice relating to autism, the input children with an ASD receive is likely to change and the impact on the family system may therefore alter. Several reviews of research looking at the effect of having a brother or sister with a disability were carried out in the 1980s (Hannah & Midlarsky, 1985; Lobato, 1983) and have since been updated (Sharpe & Rossiter, 2002; Williams, 1997).

Reviews looking at the effects of autism on siblings have tended to combine findings from studies with different impairments (Howlin, 1988), as recent studies have concentrated solely on autism it is more appropriate to review these separately. It is timely to carry out a literature review in the area of sibling relationships where one child has autism, taking into account current views of disability and the provision which may now be provided both for the child with autism and their brothers and sisters.

The review contains studies published between 1979 and 2007, identified through computer based searches using: ASSIA (Applied Social Sciences index and abstracts), psycINFO, psycARTICLES, and ISI Web of Science. Early studies have been included to allow a consideration of qualitative findings. The Journal of Autism and Developmental disorders and the Journal of Pediatric Psychology were searched for relevant articles. The National Autistic Society provided four articles. Appendix A contains a summary of the search terms and strategies used.

2.1 Sibling relationships

The sibling relationship is unique in its permanency and therefore has a major influence on several aspects of personal development (Seligman & Darling, 1997; Bank & Kahn, 1982). When one child has a disability, sibling relationships can be among the most important relationships for that child (Heller et al., 1999) in terms of longevity and providing support on several levels. When examining sibships it must be borne in mind that growing up together as siblings even in the absence of disability is not an easy

process. There may be feelings of resentment and jealousy when younger siblings are born, and in larger families older siblings may feel ambivalent about sharing the care of their younger siblings. Aggressiveness, arguments, strong feelings of affection and intense emotional ties are some of the many dynamics in sibling relationships, regardless of whether one of the siblings has a disability (Bank & Kahn, 1982). Individual differences must be considered, as the quality of sibling relationships differs markedly across families and within families (Dunn et al., 1999). Towards the end of the life-span, relations between siblings take on particular importance for many people as sources of support (Dunn, 2000). This may be especially true where one sibling has a learning disability.

2.2 Disability and sibling relationships

There is an abundance of research looking at the impact of disability on family relationships and functioning. This research encompasses children with developmental disabilities, learning disabilities, emotional or behavioural difficulties, physical impairments, sensory impairments and autistic spectrum disorders and has tended to group together children with various disabilities, or to use children with different disabilities as comparison groups. It seems that research has been based on the assumption that there are likenesses between disease and disability; as medical crises wax and wane, diagnosis of disability or disease creates recurring waves of grief and acceptance (Lamorey, 1999). Much has been written about the parental response to a child with disability or disease in terms of effects such as stress, depression, social

isolation, marital dissatisfaction and 'the grieving process' (Innocenti et al., 1992; Mahoney et al., 1992), with a more recent focus on sibling's responses and adjustment. Studies have tended to start from the perspective that both parents and siblings of children with disability will suffer; however reviews of these studies have revealed mixed findings.

It has been suggested that siblings of children with chronic illnesses and developmental disabilities are two to three times more likely than their peers to experience psychological adjustment problems (Sahler et al., 1994; Cadman *et al.*, 1988), whereas other findings indicate the positive influence of having a brother or a sister with a disability or chronic illness (Bagenholm & Gillberg, 1991). Difficulties experienced by children with a sibling with a disability have been cited as follows: higher levels of anxiety and depression, lower levels of self-worth, social acceptance and conduct problems (McHale & Gamble, 1987), feeling the need to compensate for their sibling's difficulties or to overachieve (Lamorey, 1999), and a negative relationship between age and internalisation for girls and externalisation for boys (Hannah & Midlarsky, 1999). Effects on the relationship include difficulties undertaking activities and communicating with their brother or sister with a disability, and worrying about the future and the health of their brother or sister (Pit-ten Cate & Loots, 2000).

However, reviews of the literature have also indicated potential positive effects, including increased sociability and tolerance of difference (Matthesis, 1998), higher levels of empathy and altruism (Bagenholm & Gillberg, 1991) and having a better self-

concept than matched peers (Hannah & Midlarsky, 1985; Lobato, 1983). It is important to note that in some cases there seems to be a narrow distinction between positive and negative effects: in the development of qualities such as altruism and increased maturity lies a potential for unhealthy development too. Also positive effects are often identified from more qualitative data, with empirical research tending to inadequately address the positive impact of children with disabilities on their families. Furthermore, some studies have found no differences in overall adjustment between siblings of children with disabilities and children without disabilities (Hannah & Midlarsky, 1999; Dyson et al., 1989; Gath & Gumley, 1987). The discrepant research findings may be partially explained by methodological flaws such as the lack of appropriate comparison groups, the fact that the studies have tended to rely on indirect measurements (based on parental reports) or the retrospective nature of most of the studies. It remains unclear whether the differences in findings are indeed inconclusive, resulting from methodological differences and deficiencies, or whether they in fact provide an accurate picture of the multidimensional impact of disability on the family. Further qualitative research may clarify this picture.

Lobato et al (1988) suggest that the impact of a child's impairment on siblings may be best conceptualised as a risk factor, the significance of which is mediated by socio-demographic features, individual and family adaptive and functional patterns, sibling constellation variables, and impairment characteristics. Although family constellation variables, such as age and gender of the siblings, birth order and characteristics of the disability or illness have yielded mixed results in terms of predicting sibling

psychological functioning (Howe, 1993). In a review of siblings of individuals with an intellectual disability, Rossiter and Sharpe (2001) found a small negative effect that could not be attributed to a publication bias or some other artefact; this was most pronounced for measures of psychological functioning. Lavigne and Faier-Routman (1992), in a meta-analysis of 87 studies of children with a chronic illness, found that in children with chronic illnesses, the risk for psychological problems varied by disease. Thus the impact may vary with the type of disability. Howe (1993) suggested that increased risk of experiencing difficulties is typically low and probably varies with the condition of the child in terms of aetiology, course, and prognosis. Lamorey (1999) postulated that much still needs to be learned about the experiences of siblings of children with disabilities or chronic disease, in terms of their attempts to accommodate 'differentness' and their search for support for their own psychosocial needs within their families.

It remains unclear whether findings from samples of families of children with learning or developmental disabilities can be generalised to other types of disabilities. Sloper and Turner (1993) suggested that physical and intellectual disabilities may produce different demands for families and may therefore have different effects on family life. For example, it has been suggested that the greater complexity and unpredictable symptoms of autism place siblings of children with autism at even higher risk for poor psychological adjustment than siblings of children with other disabilities (Morgan, 1988). Furthermore, the qualitative differences between impairments in autism and other learning disabilities, coupled with the fact that autism is often poorly understood and

misconceptualised (Aarons & Gittens, 1999), could indicate that parental and sibling adjustment to having a child with autism in the family is a unique process. In addition, the experience of stigma is somewhat different for parents of children with autism, given that the disorder presents a dramatic discrepancy between the seemingly normal appearance of the child and the reality of their disability. This disjuncture coupled with the social deficits of autism (Gray, 1998) is likely to produce a unique relationship between parent, child with ASD and siblings.

2.3 Autism and sibling relationships

This section of the review aims to examine findings regarding the areas of psychosocial adjustment of, and relationship between, siblings in a dyad where one child has autism, taking into account the research methodologies used and the mediating variables involved.

2.3.1 Psychosocial adjustment

Researchers investigating the social and emotional adjustment and wellbeing of siblings of children with autism have focused on self-concept, social competence and functioning at home and school. DeMyer (1979) compared 59 siblings of children with autism with 67 siblings of typically developing controls and found remarkably few differences between the two groups with regards to levels of emotional disturbance. However, 15% of parents reported difficulties in eating and toileting, which they attributed to the effects

of having a child with autism. It was noted that the difficulties reported for the sibling with autism also occurred in the siblings of typically developing children and it remained unclear whether or not they were connected to the presence of the child with autism. In general the children of siblings with autism were reported to be responsible, mature, and socially well adjusted, despite feeling burdened.

In a study by Hastings (2003), siblings of children with autism were rated by their mothers as having more behaviour problems and less pro-social behaviour than a normative sample. The objectivity of the mother's ratings in this and other studies is questionable, as they may have been influenced by personal feelings such as guilt. It could be argued that having behaviour problems and fewer pro-social behaviours than peers, on top of having a sibling with autism could negatively affect how the child feels about themselves; however research has tended to indicate that having a sibling with autism does not affect levels of self-esteem (Bagenholm & Gillberg, 1991; Mates 1990).

Rodrigue, Geffken and Morgan (1993), when comparing siblings of children with autism to siblings of children with Down syndrome and siblings of developmentally normal controls, found no differences in academic competence, measures of perceived self-competence or parents' reports of social competence. Although somewhat higher rates of internalising and externalising behavioural and emotional problems were found in siblings of children with autism, these were within the normal range. This study indicates that siblings of autistic children are not especially vulnerable to adjustment difficulties. Other researchers have also found evidence of a greater risk of internalising

and externalizing behaviours in siblings of children with autism compared to siblings of children with a learning disability and siblings of typically developing children (Fisman et al., 1996). Another study found siblings of autistic children to be reasonably well adjusted (Pilowsky et al., 2004). Interestingly, the severity of the disability seemed to be related to poorer adjustment, which has important implications for the studies that have not explicitly measured the level of impairment in the sibling with autism.

Mates (1990) reported that children with a sibling with autism scored more highly on measures of self-concept and there were no apparent effects on friendships or the quality of their lives. Self-concept measures were higher than average, interpersonal and caretaking skills were good and academic attainments were not affected. Howlin and Yates (1990) also found evidence that having a sibling with autism was associated with a positive self-concept and a high level of interpersonal and care-taking skills.

A more recent study provided mixed results regarding psychosocial adjustment (Kaminsky & Dewey, 2002). Siblings of children with autism reported being well-adjusted and there was evidence to suggest that larger family size and concurrent high levels of social support received helped to facilitate healthy adjustment. Howlin and Yates (1990) found better adjustment correlated with a greater number of children in the family; however this is in contrast to evidence that in some cases siblings prefer to just have the dyad with the child with autism (Bagenholm & Gillberg, 1991). Other family variables or personality variables may have influenced this finding, as it is likely that siblings offer social support and share any burden of care and responsibility. Bagenholm

and Gillberg (1991) found siblings of children with autism to have higher levels of loneliness; however, the siblings also reported problems with their peers and their loneliness could be accounted for by the perceived lack of social support received.

Gold (1993) failed to distinguish siblings of children with autism and siblings of typically developing children with regard to their social adjustment, but found siblings with autistic brothers scored significantly higher on depression than the comparison group. If the most conservative cut-off score is observed on the depression measure, 50% of the siblings fell into the depressed range. The fact that there were proportionately more adolescents in the sample than children (below the age of 12) is likely to have affected the results (Gold, 1993).

It has been suggested that in families where a child has autism, roles undergo adaptive redefinition (Lamorey, 1999). How well children develop their role when they have a brother or sister with autism is likely to be reflected in their level of psychosocial adjustment. Siblings of young children may have positive opportunities to handle added responsibility, develop greater nurturing skills, and experience healthy identity-formation with a heightened sense of self-esteem (Lamorey, 1999). If the family dynamics demand intense caregiving from siblings (Bagenholm & Gillberg, 1991), their psychosocial development could be compromised. The level of 'parentification' of the child's role, which may come to involve extreme helpfulness, hyper-responsibility, and pseudo-maturity, is likely to impact upon the child's functioning. The sibling could experience a flip side clinical picture of depression, shame, excessive guilt, unrelenting

worry, social isolation, psychosomatic problems and conduct disturbances (Lamorey, 1999).

A unique aspect of the typically developing sibling's role is the responsibility they may be given to help the child with autism to play and develop. They may involve teaching their sibling with autism and help to modify their behaviour. This side of the sibling's role is not necessarily harmful, as siblings have reported being proud of their ability to teach younger siblings with autism (Bristol & Schopler, 1984; Sullivan, 1979). It could be argued that the varied findings regarding the psychosocial functioning of siblings of children with autism reflects a continuum of possible adaptations. Also satisfaction in interpersonal relationships could be said to be a function, in part, of the ability to negotiate mutually acceptable roles and to enact those roles satisfactorily.

A further factor, which will affect the sibling's psychosocial functioning, is the way they feel about their situation and their sibling with autism. How comfortable the individual feels about expressing their feelings, and how well equipped they are to do so, is likely to contribute to their self-concept and social and emotional adjustment (Anon, 1998). It may help for them to know that feelings of anger, embarrassment and guilt are natural, as is feeling very protective towards their sibling (Anon, 1998). DeMyer (1979) found that more children with a sibling with autism, compared to typically developing siblings, reported feelings of being neglected or of having worries and anxieties about their sibling. Mates (1990) revealed that typically developing siblings had feelings of guilt, isolation and anxiety about the condition in general, and some worried that they might

catch autism. It is likely that the child without autism may experience extremes of emotions relating to their sibling, including anger and guilt (Mates, 1990).

Research looking at sibling support groups has provided a qualitative insight into the emotional experiences of children with a brother or sister with autism. Howlin (1997) studied a group of ten siblings participating in a workshop run by the National Autistic Society. All the children had complaints, which mainly related to the child with autism having temper tantrums, being noisy, demonstrating ritualistic behaviours or interfering with their belongings (most of which naturally occur in any sibling relationship). However, nine out of the ten children were able to identify some positive characteristics in their sibling including making them laugh and being friendly. Three members of the group were very anxious about the future and most had experienced some problems with peers teasing them or being overly sympathetic; one child expressed real anger and bitterness, being unable to say anything positive about her younger brother. The above findings have implications relating to the three functions of typical sibling relationships: the developmental importance; influences on relationships and experiences with others; and the dissemination of information (Lobato, 1995).

2.3.2. The relationship

Very little of the research concerning sibling influences on developmental outcomes gives any attention to the quality of sibling relationships, even though it could be a significant moderator of the links between events in the sibling relationship and changes

in one or both siblings as a result (Dunn, 2000). Over the last two decades, research has begun to focus on the specific question of how children experience their relationship with their sibling with autism.

McHale et al. (1984) examined the relationship between children with siblings with autism, a learning disability and typical development. The children were aged between six and 15 years at the time of the study, which is one of the few studies looking at siblings younger than eight years old. The children whose siblings had autism were grouped together with the children who had a brother or sister with a learning disability. The relationship between siblings and the children with autism or other disabilities was rated as more positive by parents than the relationship between typically developing siblings. The results showed that as a group, siblings of children with autism and cognitively impaired children were significantly less hostile, less embarrassed, more accepting and more supportive than siblings of typically developing children. However, upon close analysis, the findings revealed large individual differences between children in terms of difficulties experienced. Although average rates of problems were low the range was very wide, with some children having quite serious problems compared to the normal group. On the whole, difficulties in siblings seemed to be related to poorer relationships between parents, with older siblings showing greater disturbance than younger siblings. The majority of the children were extremely positive about their sibling, but some children displayed very negative attitudes. It is unclear how much these differences were also affected by the personal characteristics of the individual.

Roeyers and Mycke (1995) found a correlation between the quality of the relationship and the sibling's knowledge about autism. The study also suggested that there was an association between both stressor frequency and appraisal of the stressor with the evaluation of the relationship with the brother or sister. Children with siblings with autism or cognitive impairment reported comparatively more acceptance but children with a sibling with autism reported more embarrassment in the presence of other children and peers. This could again be linked to psychosocial functioning. Howlin and Yates (1990) also found reports of problems with peer reactions. Interestingly, findings revealed that children with a sibling with autism or learning disabilities who was older (by not more than three years) had a more negative relationship than all other children in contrast to McHale et al's. (1984) earlier study. Girls who had no other siblings had a more positive relationship than girls with more than one sibling. Grouping the siblings of children with autism and learning disability together could have influenced the findings, as impact may vary by type of sibling difficulty. Difference in the types of stressful events emerged; siblings of children with autism reported more strange and upset behaviour and used other directed cognitions to cope more frequently. However, in general the children had a positive appreciation of their relationship. The results of this study are consistent with Gamble and McHale's (1989) suggestion that the quality of the sibling relationship may be partly a function of processes involving not only the occurrence of daily stressful events, but also the children's affective reactions to those events. Furthermore, the finding that the siblings had a fair understanding of autism is in contrast to previous studies which found only a little information is given to the other children in the family regarding their sibling's diagnosis.

McHale et al. (1986) interviewed both siblings and mothers of children with autism, finding reports of positive relationships and no differences between siblings of children with cognitive impairment or normal development. In fact, mothers of the disabled children rated the sibships as more positive than normally developing pairs. Well-developed coping abilities, understanding of the sibling's disability and positive responses from parents and peers towards the child with autism encouraged positive sibling relationships. Several demographic variables were found to influence sibling perceptions; children who were younger than the child with the disability tended to feel more rejecting towards their sibling and reported more concerns about the future and a less positive role of their sibling in the family when the child was male. Larger family size buffered against feelings of embarrassment about the child with the disability and feelings of being burdened.

Studies have been criticised for only examining selected aspects involved in sibling relationships. McHale et al. (1986) and Bagenholm and Gillberg (1991) failed to consider aspects such as dominance, affection, companionship, intimacy, admiration, and competitiveness which are considered to play a significant role in the relationship of typically developing siblings, and may therefore play a part in sibling relationships involving 'difference'.

In Kaminsky and Dewey's (2001) comprehensive study such factors were investigated and findings indicated that sibling relationships in families of children with autism were characterised by less intimacy, less prosocial behaviour and less nurturance than typical

sibling relationships. The results are likely to be due to the specific social deficits of autism. Siblings reported greater admiration of their sibling with autism, and less quarrelling and competition in their relationships relative to normally developing children. Again the sibling relationships were generally viewed as positive, confirming the results of McHale et al (1986) and Bagenholm and Gillberg (1991). Notably, siblings of children with autism did not report greater parental partiality towards their sibling than normally developing controls, contrary to anecdotal reports stating that there tends to be resentment of the attention given to the child with the disability (Howlin, 1988; Lobato, 1983). Interaction is a key aspect of sibling relationships, time spent interacting and the specifics of that interaction could reflect the quality of the relationship. Knott et al (1995) found that in a dyad where one child has autism, less time tends to be spent interacting and that siblings of children with autism produce a more limited range of social bids and respond less frequently than in dyads with a sibling with Down syndrome. Interaction was also found to be less reciprocal. It could be suggested that the meaning attributed to the interactions is key here, for example, there may be fewer interactions but they may be perceived as being more meaningful.

Kaminsky and Dewey (2001) state that very little research has investigated the perspectives of non-disabled siblings on the relationship with a sibling with autism, tending to use reports from mothers instead. Even when the child sibling's view is sought, the mother's opinion is usually also obtained. This is an important consideration as research has suggested that parental and sibling views of psychosocial adjustment and sibling relationship may differ (Lobato & Kao, 2002). Reliance upon parental

perceptions means that findings are likely to be subject to biases related to how the parent views their children and sibling and their relationships with them. Rodger and Tooth (2004) suggest that, while siblings have unique concerns they are no longer necessarily considered the vulnerable, at-risk population once described in the research literature, taking into account the positive aspects pointed out in more recent research.

Although there has been some shift towards employing sibling's self-report of their own experiences, research has mainly continued to use standardized quantitative measures of the sibling relationship. Whilst investigating children's perceptions of their relationship through qualitative means is likely to capture the essence of the relationship, very few studies have used qualitative methodologies. It could be argued that a qualitative inquiry into the perceptions of the siblings themselves would provide more accurate and rich accounts of the relationship and the factors which shape it.

Such an investigation was carried out by Robertson (2002), who looked at relationships between boys with autism and their siblings to determine the extent of the resemblance to typical sibling relationships. The results indicated that children with a brother with autism reported on both positive and negative aspects of their sibling relationship, which is similar to typical sibling pairs. However, they report fewer qualities of warmth, closeness and conflict, as well as many additional qualities not evident in typical sibling pairs.

A further notable exception is a study carried out by Sullivan (1979), who invited siblings to write down some of their experiences of their relationship with their sibling with autism. Themes which emerged from the accounts included aspects of the relationship touched upon by previous quantitative studies. These were: maturing faster, gives you a better understanding of how to handle people; learning the meaning and value of individual differences, proud to be able to teach the child something; position as oldest was fortunate because the siblings were old enough to play “mommy” without the emotional stress that comes with being her; younger sisters were most affected and 'maternal feeling and guilt'. The study also picked up on striking themes which have not been explored in detail. Participants talked about positive 'life altering events' but many had a feeling of dread that something bad was going to happen. 'Child size perceptions' differing from those of parents was a key theme. Participants described a confusing picture of their sibling's characteristics and looked into reasons behind behaviours. Participants tended to talk about having 'coped through special talent of responding to the small but wonderful things'. They described acceptance over time and talked about their sibling being 'just my little brother' (rather than unusual). Finally, having learnt from their siblings with autism was a key theme, with one participant stating 'I am and will be better person because of him'. Each of the participants talked of the impact of stigma and a process of adapting to the child's autism.

Another exception is a recent preliminary study which involved using semi-structured interviews with 14 siblings of children with autism (with a mean age of 14 years), and aimed to examine the sibling relationship and establish both positive and negative

experiences (Mascha & Boucher, 2006). Categories identified from the interviews included: aggressive behaviour, embarrassment, other people's attitudes, responsibility, having fun and playing together and concern about their siblings future. The study concluded that having a sibling with autism has positive aspects for the majority of typically developing siblings, but that negative reactions are quite evident and tend to relate to the siblings behaviour; particularly aggressive or uncontrolled behaviour.

Qualitative methodologies are reputed to be well suited to describing complex phenomena and addressing theoretical questions about meanings, understanding, perceptions, and other subjectivities in and about families (Rosenblatt & Fischer, 1993). Thus it could be argued that a qualitative approach can access unique aspects of the sibling relationship where one child has autism, aspects that may be missed when using standardized measures or parent reports. Mascha and Boucher (2006) suggest that the sibling relationship may be affected by the unaffected siblings subjective perceptions and feelings about the relationship, the complexity of which may be lost if not addressed through qualitative means. Overall, the research to date indicates that although there may be negative aspects to the relationship, siblings tend to have a positive view of their relationship with their sibling with autism (Kaminsky & Dewey, 2001; Roeyers & Mycke, 1995; Bagenholm & Gillberg, 1991; McHale et al., 1986).

2.3.3 Mediating factors

It has been suggested that there are factors likely to increase the risk of negative effects on siblings of children with autism, which include poor family relationships, marital discord, depression or other psychological difficulties in the parents (Rivers & Stoneman, 2003; Dunn et al., 1999; McHale et al., 1984) and also possible minimising factors including warm, harmonious family relationships and social support (Pilowsky et al., 2004; Kaminsky & Dewey, 2002). Research has investigated whether gender differences influence the impact of having a sibling with autism. It has been suggested that girls may experience ‘parentification’ but sisters who may take a greater care-taking role have been found to experience better adjustment (Mates, 1990). It is important to consider that because the presentation of autism is much higher in males than in females, studies are likely to recruit more siblings with a brother with autism. It is also important to consider why some studies have shown brothers to have more adjustment problems. It is a possibility that this could reflect the extended phenotype of autism within first degree relatives, especially males, giving a neurological vulnerability to adjustment problems (Fombonne et al., 1997).

A literature review of experiences of children with a sibling with autism found evidence for factors such as birth order, gender of siblings, severity of disability and parental behaviour affecting the sibling relationship (Miller, 2001). Rodrigue et al. (1993) also found age of sibling and parental marriage satisfaction to be associated with sibling's psychological functioning. Quality of family relationships within the family system is

likely to serve an important role in mediating the association between family size and sibling adaptation. Although studies have tended to match comparison groups by age, birth order and gender, it is difficult to control for the abundance of family variables likely to impact on the sibling relationship. It may be helpful to match the siblings with autism in terms of their level of functioning rather than their chronological age as developmental level may impact on the quality of the relationship.

2.3.4 Methodological issues

Kaminsky and Dewey (2002) suggested that the results of sibling studies may be affected by the method of recruiting the participants, for example those recruited through parent support groups are likely to have greater access to information about autism and be more likely to interact with other families of children with autism. Bagenholm and Gillberg (1991) stressed the importance of siblings having simple words of explanation to give to others about their brother or sister with autism. Social help in support groups may facilitate healthy psychological adjustment but also have the benefit of giving the siblings the opportunity to develop their own narrative about their sibling's difficulties. Furthermore, parents have the powerful influence of being able to convey positive attitudes about the impaired child to siblings. The extent and openness of parental communication about the child's impairment appears to be a major factor in promoting sibling understanding of, and hence adjustment to, the condition (Simeonsson & McHale, 1981). Families who attend support groups may be more likely to have a positive view of having a child with autism in the family, having had the opportunity to

receive support. Alternatively, family members may only seek out support if they are having a difficult time. Findings regarding the experience of sibships have been interpreted in terms of warmth and closeness being the opposite to conflict; however, these aspects have been found to be relatively independent of each other (Furman & Buhrmester, 1985). Stoneman (2001) suggests that the issue of sibling conflict is not straightforward and probably varies among children with different disabilities and different temperaments. Sibling conflict is also likely to be influenced by parenting behaviours and attitudes.

The majority of the studies contained in this review have utilised standardised assessment measures to examine levels of psychosocial adjustment and the sibling relationship. Results may be affected by the psychometric properties of the instruments used. Reports of clinicians working with siblings of children with autism suggest that siblings may harbour concerns that go undetected by the standardised instruments used in most research (Glasberg & Belchic, 1996). Bagenholm and Gillberg (1991) also cite this methodological concern; they used a semi-structured interview of open-ended questions in their study and they found more negative views of sibling relationship and reported more problems when compared to siblings of children with or without a learning disability. Furthermore, children of different ages may interpret questions on standardised assessments in different ways. Fewer studies have given a rich qualitative account of what it is like to live with autism, using first hand accounts from children and families as data (Glass, 2005).

The reliance of studies investigating sibling relationships on reports from parents or significant others creates a number of difficulties. Parents and children are likely to differ in their perceptions of psychosocial adjustment and the relationship between siblings. Parents may respond to expected behaviour rather than actual observed behaviour. Corroboration between parents, the child, and their sibling combined with direct observation would help to substantiate any findings. It is difficult to say how far the results from the above studies are generalisable as the majority of the samples are small and are of white middle class American individuals. In addition, the studies lack statistical power (Hastings, 2003). The diversity of comparison groups used may also have influenced the findings. Few of the studies took a longitudinal approach, which may be necessary to accurately measure the process of psychosocial adjustment.

Research into sibships is methodologically difficult because of the numerous challenges involved in defining and recruiting appropriate comparison groups for family research (Stoneman, 1989). Bauminger and Yirmiya (2001) suggest that employing various comparison groups may be helpful in specifying the genetic and environmental-familial contributions to the effects of having a sibling with autism.

The research reviewed here strongly suggests that learning about children's experience, despite ethical logistics, should lead to a closer focus on the complexities of sibling relationships particularly when autism is present. Research shows how siblings can best be supported and how their relationship with their brother or sister with autism can be positively influenced (e.g. Gray, 1998; 2006; Howlin, 1998). When a sibship between a

typically developing child and a child with autism is found to be different in some way, this does not necessarily mean that these relationships are inferior or will require intervention. It may be that the relationship is mutually satisfying and positive for both children.

2.3.5 Conclusions

In conclusion, sibling relationships seem to be no less enduring or less influential when one sibling has a disability or autism. This review indicates that the impact a child with autism has on their typically developing sibling can have positive and negative aspects and is likely to change over time. Many of the characteristics of sibling relationships between typically developing children are also seen in dyads where one child has autism. The unique experience of the relationship a child has with their sibling with autism has begun to be explored through the use of qualitative means. Further exploration could give insight into the complex processes involved in adapting to having a brother or sister with autism. Psychosocial functioning and the sibling relationship are mediated by various factors within the family and wider social context in terms of stigma. Increasingly it is recognised that families with a child with a disability offer siblings unusual opportunities for growth and maturation and encourage the development of qualities such as sensitivity, non-judgemental attitudes and awareness of individual differences (Meyer & Vadasy, 1994). In reviewing the literature, there is evidence to suggest that the sibling relationship is likely to be qualitatively different when one child has autism yet maintains the characteristics of typical sibships. Recent

research indicates that, contrary to received opinion based on early research, living with autism is not necessarily a harmful experience (Howlin, 1988) in fact there are positive and negative aspects to the sibling relationship which require further examination.

3.0 Clinical implications and areas for future research

Reviewing the literature pertaining to sibling relationships when one child has autism has highlighted clinical implications and clinically useful areas for future research.

Eighty percent of disabled children have non-disabled siblings (Atkinson & Crawford, 1995) and large numbers of families include a child or children with autism. Clinicians working with the families of children with autism need to be aware that, although some siblings may be at risk for negative psychological effects, not all children will necessarily experience greater difficulties. It is necessary for a comprehensive assessment of individual sibling's needs. A systemic assessment of support in terms of family and the wider environment may be helpful, ensuring that each sibling is regarded as an individual with unique strengths and unique needs (Bischoff & Tingstrom, 1991). Although the potential mediating factors require further investigation, clinicians need to be aware that some factors contributing to psychological difficulties in siblings of children with autism may differ with respect to gender. The majority of research has looked at volunteer samples recruited through support groups, which may have biased the results; these samples are unlikely to be representative of variations in race, ethnicity and socioeconomic status. Studies with samples from different cultures may provide varying results: for example, in Japan there is generally much less social support for

families with a child with disability and much stigma is still attached to the diagnosis of disability (Ishizaki et al., 2005).

Current clinical practice advocates the importance of open and honest communication with children across a range of sensitive topics, yet there is little research to substantiate the benefits of this. As fewer children with learning disabilities are institutionalised and more live at home (Foundation for people with Learning Disabilities, 2001); Parents, grandparents and siblings will be more likely to have more direct contact with the child with autism and may therefore be more likely to have to discuss issues relating to disability, yet there is a dearth of material to guide them (Hames, 2002).

Research has shown that knowledge of the aetiology of autism is related to a positive relationship between siblings where one child has autism (Roeyers & Mycke, 1995). As the research indicates that successful adjustment is linked to children's understanding of the disorder autism, further research as to how parents or support groups can facilitate this would be beneficial. Research has indicated the positive impact of support groups on siblings of children with autism; future studies could pinpoint the most effective aspects of these groups. Further research into the support siblings can receive from Internet websites may indicate additional useful means of helping siblings (Tichon & Shapiro, 2003). In summary, further research is needed to empirically validate specific strategies that support siblings and help them develop positive, mutually satisfying relationships with each other.

As noted earlier, Lamorey (1999) suggested that much still needs to be learned about the experiences of siblings of children with disabilities or chronic disease, in terms of their attempts to accommodate 'differentness' and their search for support of their own psychosocial needs within the context of their families. Studies looking at the experience of the sibling relationship where one child has autism could provide useful information about the impact of 'differentness' on the family system. If autism does indeed have a dramatic effect on interactions and functioning across the course of the family life cycle, considering children's perspectives of sibling relationships could provide insight into the coping and adaptive processes children use to overcome difficulties. Findings may indicate factors involved in positive adaptation, which could inform clinical practice in terms of therapeutic input from clinical psychology for children and families affected by autism. It is important for clinicians to be attuned to the subjective experience children have of their sibling relationships and there are potential implications for educational and social systems in recognising and minimising any possible negative impact.

The findings of the research could help to provide information for the families of children with autism and professional caregivers in terms of understanding the impact of autism on the family. This research may help to ascertain the problems encountered by siblings of children with developmental disabilities and encourage service providers to take steps to avoid overlooking the needs of siblings. Research in this area could inform the planning of service provision by taking into account the potential impact of sibling relationships during childhood.

There is a dearth of explorative research pertaining to sibling relationships. Hughes and Dunn (2002) highlighted that there has been little direct investigation of children's accounts of real-life situations that evoke emotions, especially in close others. This gap is striking given the importance of emotion and feelings in understanding the nature of close relationships (Dunn, 2002). Bretherton et al, (1986) found evidence that children begin to talk about the causes of emotion from as early as 2 years of age. These findings have important implications for potential qualitative research into sibling relationships where one child has autism. Children frequently offer more accurate information when asked open questions (Gordon & Follmer, 1994; Poole & Lamb, 1998) and semi-structured interviews would encourage richer information about their perspective on the relationship with their brother or sister with autism. Qualitative studies may encourage disclosure of both the positive and negative effects of having an autistic sibling (Taunt & Hastings, 2002). Qualitative methodologies may help to address Pit-ten Cate and Loots' (2000) question of why studies have tended to lack reports of negative feeling.

Furthermore, as relationships involve the perspective and feelings of at least two people, it would be important to find out more about how the child with autism views the family and their sibling relationships.

Studies taking a longitudinal approach allow for the dynamic developmental course of the sibling relationship to be explored. Care giving may be lifelong for siblings; research is needed to address the impact of lifelong caring for a person with autism (Seltzer, 2001). The child's experience of their relationship with their sibling with autism may vary at different points in time. For example, younger children may be more strongly influenced by their parent's reactions to the child with autism; in cases where the

preschool child is the sibling of a younger disabled child, the parents themselves are likely to be in the initial stages of adjustment to the reality of the child's difficulties (Waisbren, 1980). Consequently these children may be particularly vulnerable to feelings of confusion and isolation. However, children's adjustment may also be affected by how old the child is before a diagnosis of autism is given. Responses and feelings of siblings towards their sibling with a disability are not static, rather they tend to change over time as the sibling adapts to living with a disabled sibling, and copes with day-to-day realities (NICHCY, 1994). Verte et al. (2003) suggest that interviewing siblings of children with autism while children allows access to their present voice and insight into their day-to-day lived experience.

Further research is required to explore the coping strategies younger children use to help them to effectively cope with the day-to-day experiences of living with a brother or sister with autism, as existing scales may not allow for more creative strategies or ways of adapting to be recorded. Sibling's attributions for their autistic siblings behaviour and possible relationships between sibling attributions and adjustment or coping style also provide potentially important areas of investigation.

4.0 Concluding summary

The traditional view, as indicated by early research studies, that siblings of children with autism suffer by having such a sibling has been overturned. More recent quantitative research presents a more mixed picture in terms of having a sibling with autism having a

mainly positive impact with some negative aspects; mediated by a number of factors.

Recent qualitative research has begun to examine the complexity of the sibling relationship experience; again indicating that there are both positives and negative aspects. Investigating child sibling's perceptions and experiences of the quality of the sibling relationship may indicate a further mediating factor of the impact of having a sibling with autism. Further in-depth qualitative studies, examining the sibling relationship from the perspective of child siblings could add to previous research by potentially providing insight into the processes involved in positive and negative adaptations. Gabriels and Hill (2002) state that the gap between the research into autism and clinical application has yet to be bridged. The suggestions for further research above may help to advance knowledge about sibships where one child has autism, and help bridge the gap between research and practice in this area.

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Appendices

Appendix 1 Summary of search strategy

Appendix 2 Guidelines for authors

Summary of search strategy

The following search terms were used to search through ASSIA (Applied Social Sciences Index and Abstracts), psycINFO, psycARTICLES, Web of Science and within the Journal of Autism and Developmental Disorders, and the Journal of Pediatric Psychology:

sibling* AND autism*

sibling* AND relationship*

sibling* AND autism* AND relationship*

sibling AND relationship* AND qualitative

sibling* AND famil* AND disability*

sibling AND chronic illness

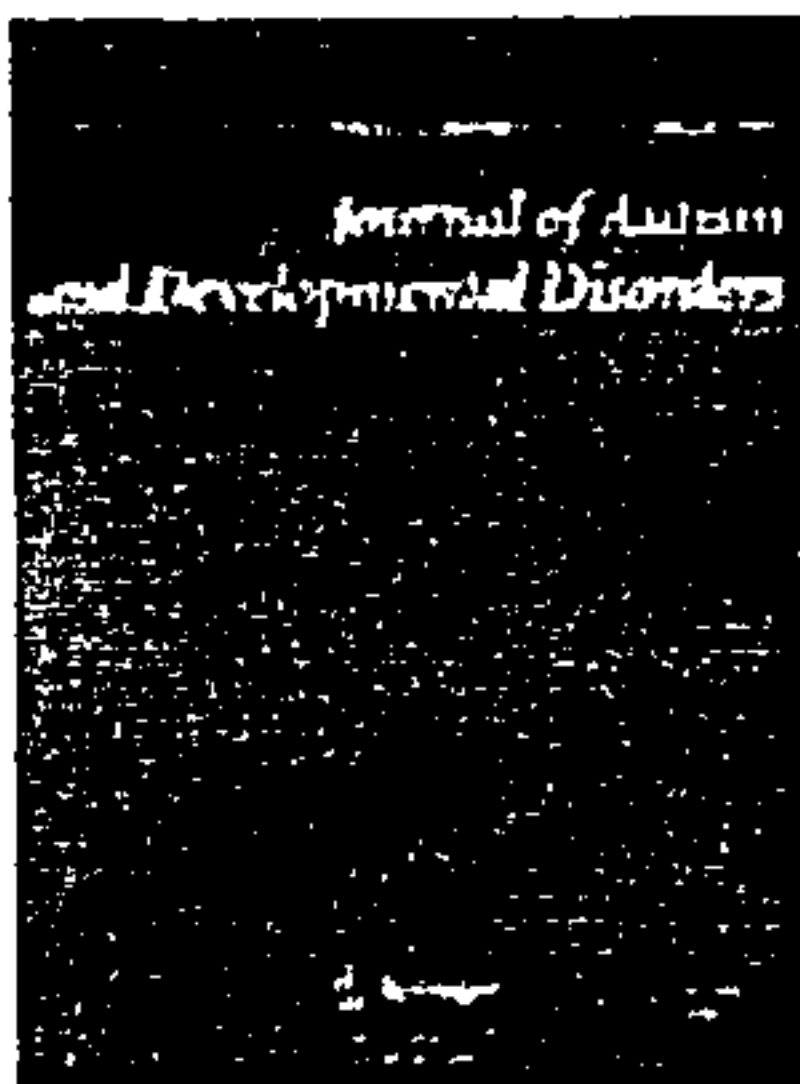
The following search terms (based on guidance from

<http://www.york.ac.uk/inst/crd/search.htm> on searching for review articles) were also

used to search through ASSIA, psycINFO, psycARTICLES, Web of Science to locate previous relevant literature reviews and ascertain whether the subject area had been recently reviewed:

review or meta-analysis (in abstract field) AND autism* AND sibling* (in all fields)

Criteria for inclusion of studies in the main review were appropriate studies, which had specifically examined siblings of children with a diagnosis of autism and as such they were separated for the purpose of the review.



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Review your manuscript for these elements

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A Commentary*** is a form of letter to the editor which is often invited by the editor to express an opposing view to the article being published.

Review your manuscript for these elements

1. Order of manuscript pages [pgs 287, 296-303]

Title Page (separate page, numbered page 1)

Abstract (separate page, numbered page 2) with 6 or fewer key words following

Text (start on separate page, numbered page 3.)

Reference List (start on separate page)

Appendix (if included)

Author Note (separate page with centered title)

Footnotes (if needed; list together and start on separate page)

Tables (start each on separate page)

Figure Caption Sheet (list together, starting the list on separate page)

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3. Title Page [pages 10-12]

The Title Page is page 1 and should contain: 1. a full title, 2. the authors' full names and institutional affiliations, and 3. a running head for publication. (see below). The preferred form for author's name is first name, middle initial (s), and last name. Omit titles and degrees. The institutional affiliation is the location where the study was conducted. Full address for the corresponding author, location of the institutions and current affiliations (if changed since the time of the study) belong in the Author Note. JADD has an open review system (not a blind review) and the title page is required for submission—the data cover sheet created by the EM does not substitute for your title page.

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5. Abstract [pages 12 -15]

"The abstract should be concise and specific, "Make each sentence maximally informative especially the lead sentence. Be as brief as possible. Abstracts should not exceed 120 words. Begin the abstract with the most important information (but do not waste space by repeating the title). This may be the purpose or thesis or perhaps the results and conclusions. Include in the abstract only the four or five most important concepts, findings, or implications." The abstract is found on page 2. Six or fewer key words should appear one line below the abstract ("Key Words:....:"). Please note: An abstract is needed for all submissions. Failure to provide an abstract, or providing one that is too long, will delay the publication of your manuscript.

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Discussion (APA pgs 26-27) (Center the heading.)

7. Reference citations [pgs 207-214]

Citations within the text guide the reader to the correct location on the reference list. Correct citation form is the surname of the authors and the year of publication, which are inserted in the text. For publications with one or two authors, cite one or two names. If there are multiple authors, cite all at first mention and only the first author at subsequent mentions. Separate multiple citations within parentheses with a semicolon.

Basic style:

"Dickens (2003) suggested that cognitive impairments...."

"In a recent study of cognitive impairments in autism (Dickens, 2003)...."

8. Reference List format [general forms page 223; 313]

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periodical:

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nonperiodical

Author, A.A. (1994). Title of work. Location: Publisher.

part of a nonperiodical (e.g. book chapter)

Author, A.A., & Author, B.B. (1994). Title of Chapter. In A. Editor, B. Editor, & C. Editor (Eds.), Title of Book (ppxxx-xxx). Location: Publisher.

9. Author Note Page 204-205

The Author note is double spaced and follows the references or appendix. The first paragraph contains a separate

phrase for each author's name and the affiliations of the authors at the time of the study (include region and country). The second paragraph identifies any changes in the author affiliation subsequent to the time of the study and includes region and country (wording: "authors name is now at affiliation".) The third paragraph is Acknowledgments. It identifies grants or other financial support and the source, if appropriate. It is also the place to acknowledge colleagues who assisted in the study and to mention any special circumstances such as the presentation of a version of the paper at a meeting, or its preparation from a doctoral dissertation, or the fact that it is based on an earlier study. The fourth paragraph states, "Correspondence concerning this article should be addressed to..." and includes the full address, telephone number and email address of the corresponding author. Fax may be included.

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14. Callouts

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15. Seriation [Pages 115-116]

A series within a sentence is identified with lowercase letters in parenthesis. A series in separate paragraphs is identified with arabic numerals and followed by a period (not enclosed in parentheses and not bulleted). These items may be considered sequential. They are conceptually parallel (thus, the numbers mean the same as a bullet. Bullets are never used.).

16. Quotations [pages 292-293, 117-118]

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17. Abbreviations (pgs 103 -110)

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Abbreviations in Figures must be explained in the caption or legend.

Abbreviations in Tables must be explained in the table title or in the table note.

Some standard abbreviations do not need to be written out at first use (pgs 106-108).

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Part 2

Research Report

Having a Brother or Sister with Autism: Children's Experiences of the Sibling Relationship.

Abstract

When an individual in a family has a disability there is potential for all members to be affected as they adjust to the impact of the condition (Broderick & Smith, 1979). Early quantitative research examining the impact of having a sibling with autism indicated various negative effects. More recent quantitative studies present mixed findings. Qualitative studies have begun to explore the factors determining the positive and negative effects of having such a sibling. With recent studies beginning to examine the complexity of the sibling relationship experience from child sibling perspectives. Findings tend to suggest that the relationships are mainly perceived as positive with some negative aspects.

In this study child sibling's perceptions and experiences of the quality of the sibling relationship with their brother or sister with autism were explored using semi-structured interviews and a grounded theory methodology. Fifteen siblings without autism aged between six and thirteen with a sibling with autism aged between four and fourteen were interviewed. A theoretical account and model of children's perceptions and experiences of their relationship with their sibling with autism were generated. The analysis indicated that for children who have a brother or sister with autism, a deep need for a relationship with their sibling is apparent. The children without autism go through processes of seeking understanding and compensating for their sibling's deficits and difficulties in order to maintain the relationship. However, when the challenges faced in the relationship become too much there is potential for becoming vulnerable, missing out, and furthermore the deep need for a relationship remains unsatisfied.

The analysis is discussed in terms of supplementing previous research findings and going some way to explaining the processes behind positive adaptation and negative adaptation to having a sibling with autism. Clinical implications are discussed and suggestions for further research are made.

1.0 Introduction

1.1 Family relationships and disability

The sibling relationship is unique in its permanency and therefore has a major influence on several aspects of personal development (Seligman & Darling, 1997; Bank & Kahn, 1982). When a child has a disability, sibling relationships can be among the most important relationships for that child (Heller et al., 1999).

Disability within the family can have a dramatic effect on family interactions and functioning across the course of the family life cycle (DeMarle & Le Roux, 2001). The family system perspective (Broderick & Smith, 1979) suggests that when an individual in a family has a disability, there is potential for all members to be affected as they adjust to the impact of the condition. It is understandable that parents could become overwhelmed by the needs of a child with a significant disability. It has been presumed that siblings in the family, unaffected by disability, would also experience a sense of being overwhelmed, particularly when they may have an under-developed understanding of disability (Lamorey, 1999). Sloper and Turner (1993) suggested that physical and intellectual disabilities may produce different demands for families and may therefore have differential effects on family life.

1.2 The impact of autism on families

Research has found that parents of children who have autism experience higher levels of stress than parents of children with other disabilities (Dumas et al., 1991; Bouma & Schweitzer, 1990). On top of greater financial concerns, increased demands of care giving and regular disruptions to plans and activities (Rodrigue et al., 1990), when the child's disability is autism, parents face additional challenges. These include: the long and frustrating process of obtaining a diagnosis, lack of lay knowledge about autism, lack of acceptance of autistic behaviour by society and low levels of social support and disruptive 'antisocial' behaviours (Sharpley et al., 1997). It follows that autism may have a more striking or a qualitatively different impact on sibling functioning and the sibling relationship than other types of disability.

It has been suggested that the greater complexity and unpredictable symptoms of autism place siblings of children with autism at even higher risk for poor psychological adjustment than siblings of children with other disabilities (Morgan, 1988). The National Autistic Society states that, "problems for younger people who have a sibling with autism can include teasing from other children, lack of privacy, disruption of home life and a feeling of resentment that the whole focus of the family is always on the autistic member". A large portion of parental energy, time and finances may go into providing treatment for the child with autism. For example, establishment and maintenance of treatment programmes such as Applied Behavioural Analysis (ABA) (Luiselli & Hurley, 2005) is resource intensive and could have a profound impact on family functioning.

Social impairment, relating to problems with emotional reciprocity, empathy, and interaction, presents as the core feature for children with autism (Howlin, 1998), and remains the most highly emphasised aspect of diagnostic criteria for autism (Volkmar et al., 1997; Wing, 1996). The social difficulties experienced by children with autism have the potential to profoundly affect the formation, development and maintenance of relationships with others. The impairments of social communication, social relationships and social imagination seen in individuals with autism, have a cumulative effect on social behaviour and interaction and as such are likely to have profound implications for sibships where one child has autism.

The qualitative differences between impairments in autism and other learning disabilities, coupled with widespread poor understanding and mis-conceptualisation of autism (Aarons & Gittens, 1999) could indicate that parental and sibling adjustment to having a child with autism in the family is a unique process. Furthermore, the experience of stigma is somewhat different for parents of children with autism, given that the disorder presents a dramatic discrepancy between the seemingly normal appearance of the child and the reality of their disability. This disjuncture coupled with the social deficits of autism (Gray, 1998), is likely to produce a unique relationship between parent and child, and the child and their siblings.

The findings from research examining the impact of having a child with autism on parents have implications for siblings. Siegal (1997) described autism as a disorder of social relatedness, which has clear implications for parent-child communication and

potentially attachment. It has been questioned whether children with autism show typical attachment behaviours. Some studies have found evidence for positive attachment behaviours in children with autism (see Rutgers et al., 2004, for a review). However most children with autism tend to display a lack of responsiveness, lack of eye contact, indifference to affection and lack of emotional reciprocity (American Psychiatric Association, 1994), all of which have the potential to be significantly distressing for both parents and siblings.

There is evidence to suggest that the type of social interaction shown by children with autism is significantly different to children with typical development (Dissanayake & Crossley, 1996). Snow et al. (1987) found that although children with autism can show positive affect in their interaction with others, it is at a lower rate than in children with comparable levels of developmental delay. Notably, children with autism tend to respond positively to activities performed in isolation rather than interaction with another person (Snow et al., 1987). Research indicates that although actual levels of interaction between parents and children with autism may be similar to those between parents and children without autism, the nature of that interaction is qualitatively different (Kasari & Sigman, 1997). The qualitative differences observed in interactions between parents and their child with autism are likely to be present in sibling interactions, in terms of the child without autism needing to offer more encouragement to prompt and sustain interaction. The fact that the capacity to relate to others is generally severely impaired in autism has complex implications for the sibling relationship where one individual has autism.

1.3 The impact of having a sibling with autism

Research investigating the impact of having a sibling with autism has tended to look at social and emotional adjustment, and the well-being of typically developing siblings; focussing on self-concept, social competence and functioning at home and school. The research has produced mixed findings (Fisman et al., 1996; Howlin & Yates, 1990; Mates, 1990). There are implications for sibships where one child has autism relating to the three functions of typical sibling relationships: the developmental importance; influences on relationships and experiences with others; and the dissemination of information (Lobato, 1995). Sibling relationships during childhood have the potential to facilitate social development and the sharing and comparing of information and knowledge about the world.

The research has shown that certain factors may mediate the impact of having a sibling with autism on siblings who do not have autism. It has been suggested that there are factors likely to increase the risk of negative effects on siblings of children with autism: poor family relationships, marital discord, depression or other psychological difficulties in the parents (McHale et al., 1984) and also possible minimising factors including warm, harmonious family relationships and social support. Research has investigated whether gender differences influence the impact of having a sibling with autism. It has been suggested that girls may experience 'parentification'. However, sisters who take a greater care-taking role have not been found to experience poorer adjustment (Mates, 1990). It is important to consider that because the presentation of autism is much higher

in males than in females, studies are likely to recruit more siblings with a brother with autism.

In terms of the sibling relationship, a literature review of experiences of children with a sibling with autism found evidence for factors such as birth order, gender of siblings, severity of disability and parental behaviour having a negative impact (Miller, 2001).

Quality of family relationships within the family system is likely to serve an important role in mediating the association between family size and sibling adaptation. Although studies have tended to match comparison groups by age, birth order and gender, it is difficult to control for the abundance of family variables likely to impact on the sibling relationship.

Kaminsky & Dewey (2001) state that very little research has investigated the impact of having a sibling with autism from the unaffected sibling's perspective, tending to use reports from mothers instead. This is an important consideration, as there is evidence to suggest that parental and sibling views of psychosocial adjustment and sibling relationships may differ (Lobato & Kao, 2002). Reliance upon parental perceptions implies that findings are likely to be subject to biases related to parental views of their children and family relationships. Older research concerning sibling influences on developmental outcomes tends not to have given attention to the quality of the sibling relationship, even though it may be a significant moderator of the links between events in sibling relationships and changes in one or both siblings as a result.

1.4 Recent research on the impact of autism on siblings

The balance does appear to be shifting, with research over the last two decades beginning to benefit from employing sibling's self-report of their own experiences, rather than relying on significant other's perceptions. Research has also started to focus specifically on how children experience their relationship with their sibling with autism (Roeyers & Mycke, 1995; Howlin & Yates, 1990). However, with a few exceptions, research has used standardised measures and quantitatively assessed aspects of the sibling relationship. Fewer studies have given a rich qualitative account of what it is like to live with someone with autism using first hand accounts as data, and what and how families are learning in the process (Glass, 2005).

Whilst investigating children's perceptions of their relationship through qualitative means is likely to capture the essence of the relationship, very few studies have used qualitative methodologies. Research looking at sibling support groups has provided a qualitative insight into the emotional experiences of children with a brother or sister with autism (Howlin, 1997). A qualitative investigation carried out by Robertson (2002) looked at relationships between boys with autism and their siblings. A further notable exception is an earlier study carried out by Sullivan (1979), who invited siblings to write down their experiences of their relationship with their sibling with autism. This study richly described the process of adaptation involved in the relationship between a sibling unaffected by autism and a sibling with autism. It could be argued that qualitative

methods utilising the perceptions of the siblings themselves would provide more accurate and rich accounts of the relationship and the factors which shape it.

1.5 Clinical implications

Studies looking at the experience of the sibling relationship where one child has autism could provide useful information about the impact of ‘differentness’ on the family system. If autism does indeed have a dramatic effect on family interactions and functioning across the course of the family life cycle, considering children’s perspectives of sibling relationships could provide insight into the coping and adaptive processes children use to overcome difficulties. Findings may indicate factors involved in positive adaptation, which could inform clinical practice in terms of therapeutic input from clinical psychology. It is important for clinicians to be attuned to the subjective experience children have of their sibling relationships and there are potential implications for educational and social systems recognising and minimising any possible negative impact relationships with siblings have on individual children.

The findings of the research could help the families of children with autism and professional caregivers working with families with a child with autism to achieve greater understanding of the impact of autism on the family. This research may help to ascertain the problems encountered by siblings of children with developmental disabilities and encourage service providers to take steps to avoid overlooking the needs of siblings. Research in this area could inform the planning of service provision by taking into

account the potential impact of sibling relationships during childhood. Knowledge of sibling's views would help clinicians to plan more sensitive treatment for families where a child has autism and involve siblings in a positive way. Furthermore, research looking at relationships where one individual has autism could provide further insight into how the relational difficulties individuals with autism have impact relationships with others.

1.6 The research questions

Lamorey (1999) postulated that much still needs to be learned about the experiences of siblings of children with disabilities, in terms of their attempts to accommodate ‘differentness’ and also in terms of their search for support for their own psychosocial needs within their families. The current study aimed to qualitatively explore how children perceive and experience the relationship they have with their sibling with autism, bridging some of the gaps in previous research.

The key questions explored by the study were:

- What are children's perspectives on their relationships with their brother or sister with autism?
- Are there positive aspects to the sibling relationship when one child has autism?
- Are there negative aspects to the sibling relationship when one child has autism?
- If so: What are the positive and negative aspects of such a sibling relationship?
- Are there any unique aspects to the sibling relationship when one child has autism?

2.0 Methodology

2.1 The research design

Qualitative studies may encourage disclosure of both the positive and negative effects of having an autistic sibling (Taunt & Hastings, 2002) and give a rich account of the impact of having a sibling with autism. Grounded theory is cited as being a suitable methodology for social research focusing on human interaction, particularly where the researcher wishes to investigate the subjective meanings that people use when interacting with others in specific settings (Denscombe, 2003).

The current exploratory study employed a qualitative research methodology combining semi-structured interviews with Grounded theory, in order for data concerned with meaning and significance to be gathered (Cohen et al., 2000). As there is a dearth of research from the perspective of child siblings on their lived experience of being siblings of children with autism, it was felt that using Grounded theory would allow for the emergence of new theory (Stern, 1995). Grounded theory was chosen in preference to other methods which emphasise the importance of subjective experience, such as Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003). It was anticipated that the model developed through using Grounded theory would be potentially more clinically useful for guiding interventions than the descriptions of themes generated in IPA.

2.2 Interviewing children

Research has been undertaken to consider the complicated process of interviewing children, taking into account the development of narrative competence and overall developmental age of children (Docherty & Sandelowski, 1999). Amato and Ochiltree (1987) found that from the age of eight, children have adequate verbal ability and understanding to cope with an interview about family life and are usually very willing to discuss upsetting family experiences. In fulfilling the interviewer's role of listening, observing with sensitivity and encouraging the person to respond, Charmaz (2006) advises using a few broad open-ended questions to encourage unanticipated statements and stories to emerge, adding questions and comments to help the participant articulate their intentions and meanings.

In interview situations, young children can lack the linguistic skill to describe experiences (Walker, 1993). Several interviewers rely heavily on non-verbal materials as props to elicit verbal information and aid describing and labeling of experiences, particularly with very young children (Boat & Everson, 1996) such as The Bene-Anthony Family Relations Test (FRT) (Bene & Anthony, 1957). This was designed to assess and examine family relationships as part of clinical interviews with children about their families. Griffin (2005) asserted that the FRT seems to be the only instrument available that explores the perceived emotional context of family relations. The above principles were used to guide the interviewing process.

2.3 Grounded Theory

The Grounded theory methodology adopted in the study was based on that of Charmaz (2006) who describes Grounded theory methods as consisting of systematic yet flexible guidelines for collecting and analysing data, to construct theories grounded in the data itself. The researcher chose Charmaz's (2006) method due to the flexibility it would allow to explore child sibling's perspectives on their relationship with their sibling with autism. Furthermore it was envisaged that Charmaz's (2006) Grounded theory, with its emphasis on the experiences and perspectives of individual's, would provide a meaningful way of constructing children's perceptions of their relationships with their siblings with autism and add an extra dimension to, and expand upon theories on the impact of a having such a sibling.

2.4 The researchers position

The current research project was chosen based upon the researchers previous clinical experience and special interests. The researcher held strong beliefs that children's voices, often missing from research should be heard. The researcher reflected on personal experiences of family relationships and was curious about how children perceive and adapt to 'difference' and disability in the family. The researcher tends to incorporate psychoanalytical ideas into her clinical practice.

A brief literature review was conducted in order to gain some understanding of the existing research in the area and develop an initial research proposal. A more comprehensive literature review was conducted following analysis of the data in order for emergent theories to be grounded in the sibling's accounts rather than influenced by previous research findings.

2.5 Participants

2.5.1 Recruitment of participants

The sample was to be generated via six voluntary organisations offering support to young people with autism and their families within Leicestershire and Rutland. Due to a low initial response rate, a request was published in 'Link up'; a tri monthly newsletter distributed to families of children with autism. To prevent the sample from consisting solely of families who would define themselves as having family or other difficulties, the recruitment strategy did not involve accessing participants through psychological services.

2.5.2 Inclusion and exclusion criteria

It was envisaged that between eight and 12 children, aged between six and 12 years who have a sibling aged between four and 16 would take part. Amato and Ochiltree (1987) found evidence to suggest that children from the age of eight generally have adequate

verbal ability and understanding to cope with interviews about family life, and tend to be willing to discuss family experiences. It was envisaged that as the interview process involved a warm up exercise, prior to interview, children younger than eight would be able to talk about their experiences of the sibling relationship. The researcher had hoped to involve children from as wide an age range as possible, with siblings of varying ages, whilst remembering the exploratory nature of the study and bearing in mind that children of different ages and developmental stages could have very different experiences of the sibling relationship and different concerns.

An initial selection questionnaire was given to the parents of potential child participants to determine if their child met the inclusion criteria, this also requested demographic information (due to the researchers awareness of the many potential mediating factors of the sibling relationship; see Appendix 1).

2.5.3 Situating the sample

A description of the participants is provided in Table 1, to give context to the participant’s families.

Interview no.	Participant	Sibling with autism	Age of participant	Age of sibling with autism	No. of children in family
1	Lucy	Edward	12	8	2
2	Sophie	Ethan	9	10	5
3	Phillip	Jake	12	10	5
4	Christina	Callum	10	13	3
5	Kay	Michael	9	11	2
6	Noelle	Olwen	6	4	2
7	Olivia	Anna	10	8	2
8	Milly	Robert	8	10	2
9	Mia	Hayden	8	14	3
10	Saskia	Corey	7	10	5
11	Naomi	Johnny, Barney	8	11 6	4
12	Riley Joe Sarah	Brian	10 13 11	14	4
13	Nathan	Jacob	10	9	3
Total = 13 interviews	11 females 4 males	2 females 11 males	Average age = 8	Average age = 8	Average no. children = 3

Table 1 The research sample

A further interview was carried out with a participant who did not want the interview to be taped, the written data noted down by the researcher was not substantial enough to be used. Interview 12 was a group interview with three siblings, who were all keen to be interviewed and the youngest sibling wished to be interviewed with his siblings.

Although the oldest sibling in the group was outside the original age range, the researcher felt that this might add a different perspective. A parent was in the room for interviews with Olivia and Nathan. In total interviews from 15 children were used.

2.6 Procedure

2.6.1 Ethical considerations

Participant's age was an important ethical consideration. The process of gaining consent from each participant was highly important. Details of the study and expectations of participant's were explained to the children in a clear and straightforward way, supported by a simplified information sheet (see Appendix 2). The researcher sought to affirm or renegotiate consent at each stage in the research process from both parent and participating child; (Mauther et al., 2002) (see Appendix 3). The sensitive and personal nature of the topic was discussed with both the participating child and their parent, in addition to what would happen if any issues of concern were raised during the interview. Once the interview process was complete, thorough and sensitive debriefing allowed the researcher to ensure that child participants were not distressed by any aspect of the interview, facilitate any questions they may have and to discuss feelings generated during the interview. All identifiable details contained in the interview transcripts were anonymised, and pseudonyms given to participating child, their sibling and any other names or places.

Although the participant group was not derived from a clinical population within the National Health Service and therefore ethical approval was not necessary, a positive ethical opinion was obtained from the Leicestershire Research Ethics Committee and the University of Leicester Ethics Committee (see Appendix 4).

2.6.2 Interview procedure

The study was divided into two phases:

Study One – pilot study: interviewing children about their sibling relationships (where neither child had a diagnosis of autism)

Study Two – study proper: interviewing children about their relationship with their sibling with autism.

A pilot study was carried out to facilitate researcher development in the skills necessary for undertaking such a task, allow possible interview content to be explored and also to provide insight into the questions to be asked and how best to deliver them. Three children aged between six and 12 who have a sibling aged between four and 16, recruited by way of opportunity through friends of the researcher, were interviewed.

The following procedure was common to Study One and Study Two. Once potential participating families had expressed an initial interest in taking part in the study, they were provided with an information pack containing two information sheets, one for the potential participating child and one for the parent(s) (see Appendix 5), a demographic questionnaire and an expression of interest form (see Appendix 6). Families were contacted directly to arrange a mutually convenient time for the researcher to visit the family to obtain verbal and written consent, provide further information, allow the

researcher to develop rapport with the child and explain confidentiality. If the child felt suitably informed and maintained interest in participating, the researcher arranged a mutually convenient date and time for the interview, or as in most cases, at the participant's request, proceeded with the interview.

2.6.3 The interview

Following an initial open question about the child's family, the modified FRT² was carried out as a warm up exercise and an aid and stimulus for the interview, to help put the child at ease, establish rapport, gently encourage the child to think about family relationships and focus on their relationship with their sibling . The children were also invited to draw a picture of themselves with their sibling. Participants were then asked the questions detailed in the semi-structured interview schedule (see Appendix 7 for copies of the original and revised schedules). The researcher aimed for interviews to be participant directed, by acknowledging themes raised and encouraging additional detail.

Pilot interview transcripts were examined to highlight questions that generated the richest narrative and helped the children to tell their story about their sibling relationship and the interview schedule revised accordingly. As the phraseology used in the pilot interview questions tended to produce short responses, several questions were added based on techniques from The Adult Attachment Interview (George et al., 1984), namely

² Administration of the FRT can be modified to focus on a particular family relationship, in this case the sibling relationship. The child was asked to pick a figure to represent their sibling and a figure to represent self. Ten statements deemed relevant to sibling relationships were read out and the child instructed to choose whether or not the statement applied to their sibling.

asking the child to use three words to describe, for example, their sibling or their sibling relationship.

Interviews were undertaken at the child’s home with minimal opportunities for distraction. Interviews lasted between 35 minutes and an hour and 45 minutes and were tape recorded and transcribed verbatim. Upon completion, the researcher recorded initial impressions of the interview in her reflective diary. An example is given below, following Interview six with Noelle.

23rd February 2007

Just finished interviewing Noelle. Noelle is the youngest child I have interviewed so far, with the youngest sibling with autism. Although Noelle talked less about how having a sibling with autism made her feel (perhaps due to her age?), Noelle conveyed strong feelings of loss and disappointment. I felt a sense of sadness during the interview. There seemed to be some tension for Noelle between ‘having’ to act older than her years, and perhaps wanting to be a six year old (extra responsibilities when have a sibling with autism/having to grow up more quickly). Her description of wanting to ‘go back into her mummy’s tummy’ was striking – does she feel like she wants to begin life again, perhaps a life that works out differently, where she can grow up at her own pace/a slower pace? Noelle also seemed to feel privileged/unique in a way, as she is the only person with a sibling with autism in her school. It will be interesting to see if interviews with other young siblings (aged six to eight) also reveal less direct expressions of negative feelings – if so – raises questions for me as to why this is.

Fig. 1 Extract from researcher’s reflective diary

2.7 Data collection and analysis

2.7.1 Line coding and focused coding

Following re-reading of the interview transcripts, line coding took place. A descriptor code was allocated to each line of written data. The researcher felt it was important to give equal attention to each line of each transcript (up to saturation point) to prevent undue emphasis being placed on parts of the data that struck a chord with preconceived ideas and assumptions. The second phase of analysis involved focused coding, referring to using the most significant and/or frequent codes to sort large amounts of data (Charmaz, 2006). Focused coding was applied to all 13 transcripts and recorded in the left hand margin. The point at which saturation was reached (interview nine) enabled the researcher to use previous interview codes to analyse the remaining four interviews. For an example of a line and focused coded extract see Figure 2.

<i>Line by line codes</i>	<i>Extract</i>	<i>Focused code</i>
<div>-Understanding and knowing</div> <div>-Realisation</div> <div>-Need for understanding</div> <div>-Need to manage and monitor feelings</div> <div>-Self development</div> <div>-Different treatment required</div>	<div><i>“Sometimes it’s a bit shaky but I realise and I have to be understanding and patient with him and I realise that ‘cause of what autism’s like. You have to be understanding of him and like you have to try and just like progress that little bit more in holding your temper than you normally do with normal kids with like conditions like that”</i></div> <div><i>(Participant two: lines 301-311)</i></div>	<div><i>Making allowances for autism</i></div>

Fig 2. Example of line and focused coded extract

2.7.2 Memo writing

Memo writing is integral to Grounded theory. This was utilised as a way of keeping track of the research process. As part of the constant comparative method, memos were written throughout the research process, as soon as interesting ideas and categories arose and were directed towards making comparisons. Memos were reviewed and revised throughout and used in the formulation and revision of theory. For an example of a memo see Fig. 3.

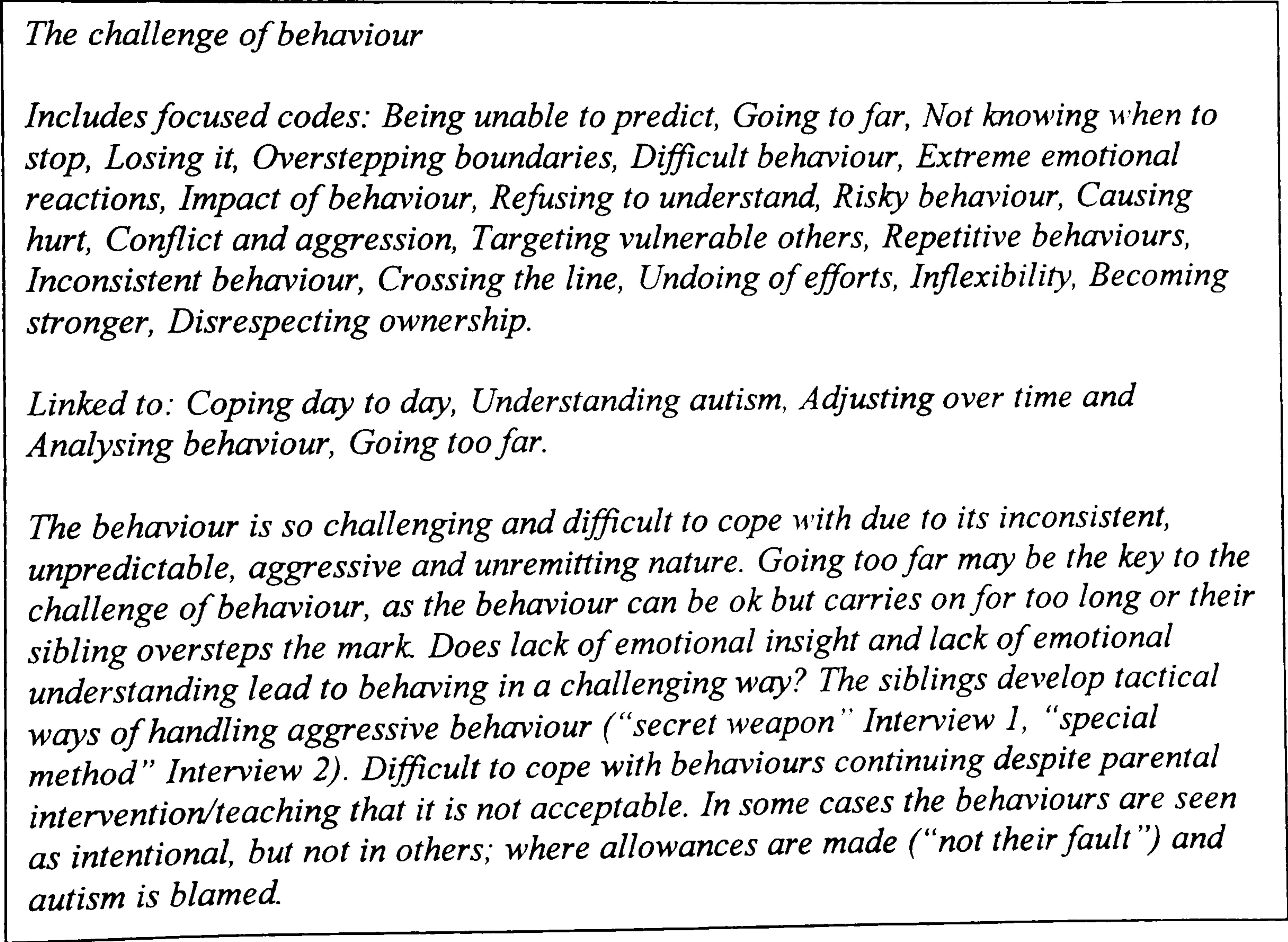


Fig. 3 Example of a memo detailing the category of “The Challenge of Behaviour”.

2.7.3 Theoretical coding and conceptualisation

Categorising then took place, which involved raising certain codes to categories. Similar concepts from the focused codes were grouped together and integrated into broader categories. Memo writing was used to raise focused codes to conceptual categories. This involved the researcher choosing the most representative codes and raising them to categories giving them conceptual definition and analytical treatment in individual memos, whilst remaining consistent with the data. This process was also aided by keeping a trail of category development (see Appendix 8 for an example of the category development trail). This involved typing up a list of potential categories following analysis of each interview and helped to determine saturation point. Following saturation of the categories, through further comparison of the memos and reference to the reflective diary and category trail, the core category emerged and was labelled. The core category of 'Deep Need for Relationship' was felt by the researcher to be central to the relationship between siblings where one child has autism and to adequately encompass the categories whilst also explaining variation.

2.8 Methodological rigour and quality measures

The researcher employed several measures to ensure quality, namely keeping close to the data, reflexive validity and peer review. The researcher aimed to remain close to the data throughout the research process to ensure the resultant account would be grounded in the participants' accounts, through constant comparison between data, codes and

categories and consistently returning to the interview transcripts and earlier understandings to review the emerging understanding and resultant theory's fit with the data. The researcher has taken steps to be transparent (Rennie et al., 1988) about the analytic procedures used and the understanding developed, through the use of memos and a reflective diary. Attending a qualitative support group throughout the research process, with other Trainee Clinical Psychologists and a Clinical Psychologist with a wealth of experience in using Grounded theory, allowed the enhancement of coherence through peer review.

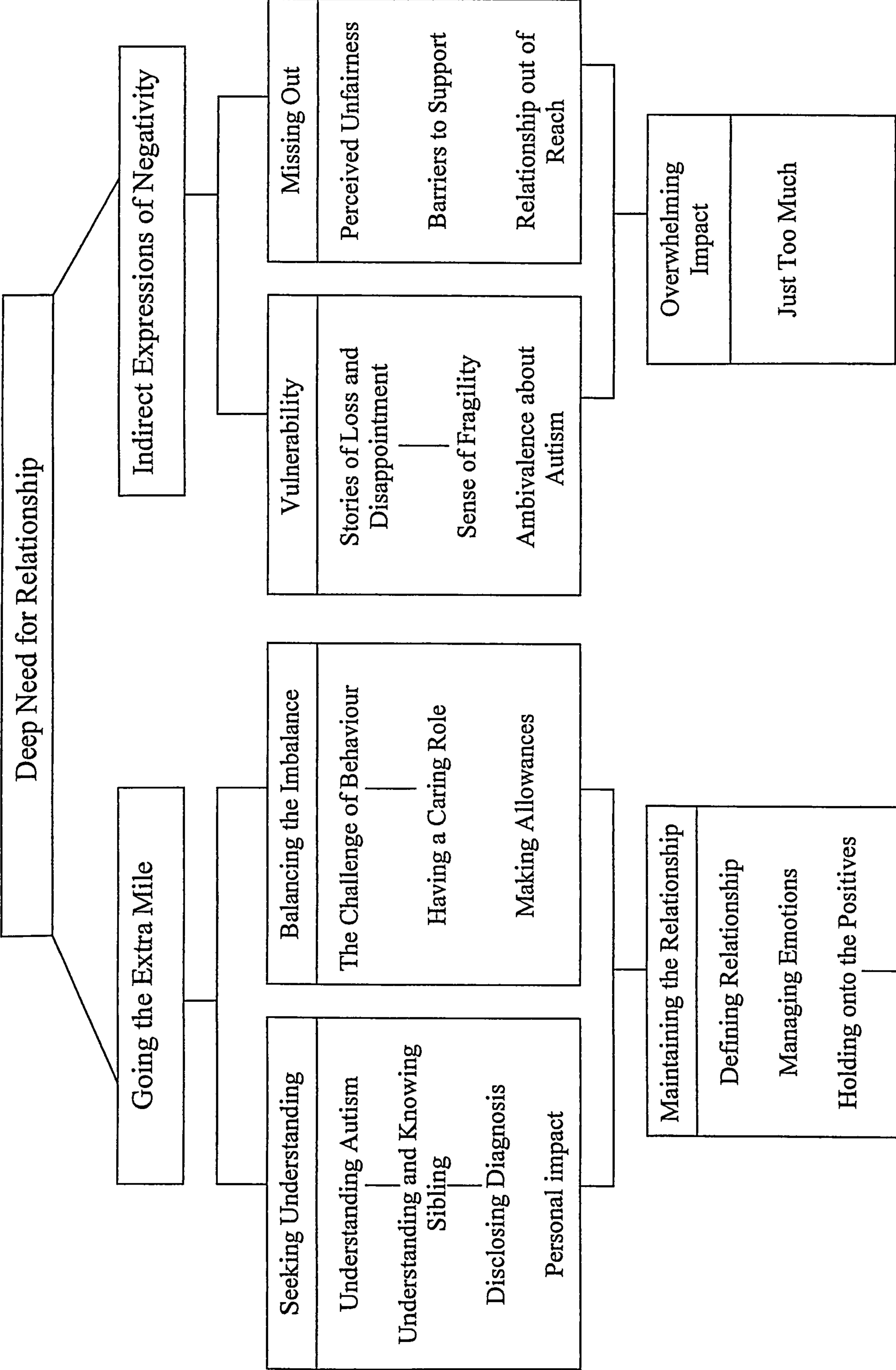
3.0 Analysis

3.1 Introduction

This chapter provides a detailed account of the analysis of the thirteen interview transcripts. The model, constituting a core category and six main categories is presented in diagrammatic form, summarising the analysis. A description of the core category is given and an outline of the six main categories relating to it, each illustrated by direct quotes³ from the interview transcripts⁴. Descriptions of how interview material relating to the emergent concepts was distributed across the participant's accounts are provided. Negative cases, where instances appeared in the data that did not seem to fit with the emergent theory, are discussed.

³ Quotes are indented, written in italics and followed by a reference to their transcript location (transcripts are provided as an addendum), in the following format: I(interview number), name of participant: Line number(s), e.g. I3, Phillip: 203-204 refers to a quote taken from the transcript of the interview with participant three, whose pseudonym is Phillip, lines 203-204. Interview numbers are used, rather than participant numbers due to interview twelve involving three participants. The transcript conventions used are provided in Appendix 9 and at the start of the Transcript Addendum.

⁴ Additional supporting quotes can be found in Appendix 10.



3.2 Core category: Deep Need for Relationship

This represents the participants'⁵ drive and desire to have a relationship with their sibling with autism, no matter how problematic they experience the relationship to be. 'Deep Need for Relationship' provides a link between all the main categories, even when apparently discrepant.

Christina described a strong desire to remain in relationship with her family, when asked what she would wish for:

“... for me and my family to always be closely relate and never never really fall out and like come apart and never never like ... don't care about anyone like for us to all care about each other like we do”. (I4, Christina: 706-709)

She also conveys the importance of making amends with her brother:

“... but its he he doesn't really mind we always make up ... and erm I always go and hug him and say sorry... That's when we kind of make up”. (I4, Christina: 298-304)

⁵ For clarity, the siblings without autism are referred to as participants whilst the siblings with autism are referred to as siblings.

3.3 Sub-category of core category: Going the Extra Mile

This refers to the participants' resolve to do what is necessary to make their relationship with their sibling work, they seem to take a step back and decide they are going to put in as much effort as is required to try to make the relationship work; making more effort than their sibling.

Phillip talks about actively putting extra effort into the relationship:

“Pull the extra tighter on the rope... have to go that one step further”. (I3, Phillip: 293-294)

3.4 Main Category one: Seeking Understanding

‘Seeking Understanding’ emerged as the first main category and first stage involved in ‘Going the Extra Mile’. This category represents a process in which participants need and want to understand their sibling. The majority of the participants talked about actively trying to understand their brother or sister, conveying a need for understanding:

“I realise and I have to be understanding and patient with him and I realise that ... 'cause of of what autism's like ... You have to be understanding of him”. (I3, Phillip: 280-285)

3.4.1 Sub-category one: Understanding Autism

Participants described coming to an understanding of autism. A process of capturing autism seems to take place. The siblings refer to what they have read in the literature and information they have accessed. This information is combined with parental explanations in the development of narratives about autism, which seem to help them to make sense of their sibling. Participants talked about what autism means to them and the spectrum of difficulties involved; going on to locate their sibling on the autistic spectrum, in terms of their level of difficulties. It may be that knowledge of their sibling's limitations in understanding the world around them fuels their need to find a way to understand their sibling. For some siblings, understanding autism seems to facilitate forgiveness and an increased tolerance to difficult behaviours, perhaps leading to an acceptance of autism.

Olivia captures her understanding of autism as follows:

“Well it’s something wrong with the brain really when I was younger I used to classify it as like a missing wire in the brain it’s something wrong in the brain”.
(I7, Olivia: 191-192)

The youngest participant, Noelle, describes autism as follows:

“Well that it well that their brain is like looking in a broken mirror ...because I read it in a magazine”. (I6, Noelle: 284-286)

When the extent of Phillip's knowledge is commented on, he says:

“Yeah I’ve read a lot of books on it”. (I13, Phillip: 251)

Although there was a range in the level of knowledge about autism, the majority of the participants demonstrated a good understanding of autism. In contrast, when questioned about her knowledge of autism Saskia responded that she knew:

“nothing ... Absolutely nothing... I don’t even know what it is”. (I10, Saskia: 522-533)

Therefore, Saskia represents a negative case, she may not have felt compelled to try to understand her brother.

3.4.2 Sub-category two: Understanding and Knowing Sibling

The participants seemed to use their understanding of autism to understand their sibling, through attending to their behaviours and coming to ‘know’ their sibling. The lower level sub-categories of ‘Analysing Behaviour’ and ‘Awareness of Difficulties’ denote the processes participants use to achieve this understanding. Their siblings' difficulties become their concern. There is evidence to suggest that they examine and pay close attention to their sibling's behaviour, make comparisons and attempt to normalise certain behaviours. Another theme involved in the participants ‘knowing their siblings’; is

having knowledge about their siblings' special interests, likes and dislikes. Several participants indicated the importance of ‘knowing’ their sibling in order to understand them.

Phillip in particular, was keen to achieve a deep level of understanding and knowing of his brother Jake, evidenced by asking the researcher:

“...How does he like feel when something goes like bad for him really really bad for him really really as in really bad for him? How does he feel like inside?”. (I3, Phillip: 321-322)

Olivia talked about Anna's particular likes:

“Anna really likes elephants... She has a thing about elephants and crocodiles ... And she has these animal DVD’s and she’s gets bored but when the gruesome parts come on she goes and stares at the TV”. (I7, Olivia: 163-168)

3.4.2.1 Lower level sub-category one: Interpreting Behaviour

There is a sense that the participants are highly tuned in to their sibling's behaviour. They notice something different about the behaviour they are seeing. Tending not to be critical of their sibling's behaviour; instead they compare their behaviours to those of others, for example, younger children. Consequently, some behaviours are normalised within a

developmental context, with explanations and interpretations offered. Some behaviours are justified in light of their understanding and awareness of their sibling's difficulties. They are adept at taking a step back, analysing behaviour and articulating the results of their analyses.

Olivia explains how she interprets her sibling's behaviour:

“We sometimes cut paper up together depends if she wants to, if I ask her she she’ll probably throw something at me or hold my hands (laughing) ... I take throwing as a no (laughing)”. (I7, Olivia: 80-83)

Sophie explained that she is able to interpret even subtle cues:

“Well erm one time when he like takes something of mine and he doesn’t own up to it and I know that he’s lying ‘cause I can tell by looking in his eyes”. (I2, Sophie: 293-294)

3.4.2.2 Lower level sub-category two: Awareness of Difficulties

All participants demonstrated an awareness of their sibling's difficulties. For example, talking about misunderstanding social situations, difficulties losing, problems coping with changes to routine and struggling with feelings. Analysis of their sibling's behaviours and reactions and awareness of their difficulties, seemed to impact upon their

views of how to treat their sibling and resulted in an ability to predict their sibling's reactions to difficult situations.

Lucy talks about being aware that Edward struggles to cope with losing:

“he can't lose on that we have to go through such an enormous paddy, so that's difficult”. (I1, Lucy: 268–269)

Phillip explains his understanding of his brother's difficulties:

“It's harder for him and we have to treat him like he's a little bit younger 'cause that's how he works and it works a bit different in his brain 'cause the whole universe works around him it's like that in his brain, it's like that really”. (I3, Phillip: 247-249)

3.4.3 Sub-category three: Disclosing Diagnosis

The category ‘Disclosing Diagnosis’ refers to the process participants go through in considering whether or not to disclose their sibling's diagnosis of autism to friends and peers. The perception of others is a key theme within this category. The siblings tended to be aware of, and sensitised to, other's perceptions of their sibling. Another key theme, is that disclosure may facilitate understanding: a move from knowing there is something different or ‘wrong’ to viewing difficult behaviours as part of autism. Disclosure may therefore assist others in embarking upon the same process of looking at behaviour.

understanding and accepting. Participants discussed their feelings about disclosing the diagnosis in terms of how they expected others to be able to cope with hearing the diagnosis, how difficult it is to explain and the possible benefits of telling others. Parental influences and levels of openness about the diagnosis seemed to impact upon the decision to disclose. Participants alluded to the complicated nature of autism and the potential difficulties in explaining their sibling's diagnosis.

Lucy and Noelle explain just how complicated it is to explain what autism is:

“It’s really hard to explain that your brother is because you can say my brother’s autistic but it’s really hard it could take days to explain what it actually means”.

(I1, Lucy: 611-613)

“Yes. She autism is a word that all my friends say what’s what’s autism and I say it’s like looking in a broken mirror and everyone says a broken mirror? And they say they don’t understand me”. (I6, Noelle: 292-294)

Stigma associated with autism was only directly referred to in one account; Christina refers to the idea of others finding out about the diagnosis without directly being told and the potential negative impact of this:

“Er sometimes I get a bit like anxious because I think that when I go to secondary school erm because Callum gets teased a bit because like they might find out that

I'm his brother or something I mean I'm I'm his sister or something and they might tease me or something". (I4, Christina: 668-671)

3.4.4 Sub-category four: Personal Impact

This category represents the personal development that seems to take place on a number of levels for siblings of children with autism. This involves developing a concern for others and an awareness of potential problems that can arise in interactions and relationships. The participants seemed to have a heightened awareness of others needs and sensitivity towards those who might be struggling. It is in the areas in which the participants seem to have enhanced abilities that their siblings are lacking: empathy, insight, sensitivity and awareness of the wider system. Furthermore, the siblings tended to be adept at pointing out their own and their siblings skills and achievements.

Lucy described an enhanced understanding of problematic situations:

"I can see what the problem is I can see where it's going ... I can see where the problem can go before people have even started arguing". (I1, Lucy: 683-685)

3.5 Main category two: Balancing the Imbalance

‘Balancing the Imbalance’ refers to the processes participants go through, in assessing their relationship with their sibling and their decision to compensate for their sibling's

difficulties in relating. The most difficult challenge to overcome is their sibling's behaviour. Processes of 'defining their role as sibling' and 'deciding to make allowances' for their sibling result in 'going the extra mile' towards maintaining the relationship:

“...you have to progress that little bit more pull the extra tighter on the rope so you like have to go that one step further and that's what it's like”. (I3, Phillip: 289-290)

3.5.1 Sub-category one: The Challenge of Behaviour

All participants expressed the challenging nature of their sibling's behaviour. The behaviour, witnessed and experienced is challenging and difficult to cope with due to being inconsistent, unremitting and often aggressive. The participants perceive their sibling with autism to be behaving in an appropriate or positive way until they go too far and they push or overstep boundaries; their sibling does not seem to know when to stop. Many participants rise to the challenge of handling difficult behaviours by developing tactical strategies.

Boundary-pushing is encapsulated by the following quote:

“Last night he was playing really happily with dad on his work phone...he was good at that and when he said ok then it's the last one after this and he kept on

trying to play it and play it so he can be fun but then he carries it on too far". (I1, Lucy: 215– 220)

Similarly, 'Noelle' describes a time when a joint game ended in aggressive behaviour:

"Well she's she's we were playing a game in the bath last night and we had this splashing the water out of the bath and it's called copy Olwen ... And I was very good at playing it but in the end Olwen donked me on the head". (I6, Noelle: 115-118)

3.5.2 Sub-category two: Having a Caring Role

The siblings tended to describe fulfilling many roles in order to 'Balance the Imbalance' and protect their sibling from any potential consequences of their behaviours.

Participants' roles in managing behaviour were described as: teaching, helping and protecting their sibling.

Christina describes taking on a peacekeeping role, encouraging understanding and harmony between her siblings:

"I kind of took charge ... so I went to look after Callum and Julian ... 'cause they were fighting a bit ... I said to Callum erm so say sorry to each other so they did and then I said erm now erm now you you're not you're not meant to fight to

over erm those things ... you shouldn't be mean to Callum and tease him and erm so they both kind of made up". (I4, Christina: 238-246)

She describes feeling proud of teaching her brother social skills:

"when the door bell rings he opens the door and then goes back into the living room and watches telly but I taught him to ... be polite and say hello so erm he went up to the door he said hello Erin are you OK have a good morning erm make yourself comfy and sit down and erm I was really pleased with him". (I4, Christina: 349-353)

3.5.3 Sub-category three: Making Allowances

This category refers to the participants making allowances for their sibling. The participants describe most aspects of interaction as being on their sibling's terms. They follow their sibling's lead, expressing that they want to do what their sibling likes, in response to recognising their social difficulties. Some participants felt that their parents made too many allowances for their sibling, but the majority often went out of their way to accommodate their siblings wants, likes and needs. This indicates that 'Making Allowances' plays an important part in maintaining the relationship and in some way compensates for the apparent lack of reciprocity. Again these mechanisms for 'Balancing the Imbalance' are developed in response to the need to relate to their sibling. All participants described putting their sibling first, accommodating their likes and at times

compromising their own needs. Almost all participants described interactions with their siblings as being on their sibling's terms.

Participants describe 'Making Allowances for Autism'. Autism is given as the reason for excusing certain behaviours exhibited by their sibling:

"I realise and I have to be understanding and patient with him and I realise that ... 'cause of of what autism's like". (I3, Phillip: 280-283)

3.6 Main category three: Maintaining the Relationship

This category encapsulates the maintenance processes participants utilise in fulfilling their deep need for relationship. The participants develop a narrative, to define their relationship with their sibling, which involves weighing up the positives and negatives of the relationship. They tend to actively manage their emotions as part of remaining in relationship with their sibling. The participants seem to focus on the positive aspects of their relationship, no matter how seemingly small or insignificant, as a means of holding onto hope of maintaining the relationship.

"... the things we do together they kind of build our relationship". (I13, Nathan: 79-80)

3.6.1 Sub-category one: Defining Relationship

This category refers to the way in which participants defined and described their relationship with their sibling. Mixed experiences were described in the majority of cases, with the minority of participants referring to either a special relationship or a highly problematic relationship. The presence of a sibling bond was apparent in all cases, regardless of how the relationship was classified. All accounts involved descriptions of mixed feelings about the relationship, in most cases strong loving feelings were described but the siblings were unanimously described as annoying and problems in the relationships acknowledged. Almost half of the participants asserted that their relationship has special qualities absent from other sibling or peer relationships. Participants described unique and better relationships with their siblings. These relationships involved having a more playful relationship, experiencing more intimacy and engaging in different activities.

In most cases, the relationships were referred to as being both good and bad, difficult but fun and nice but annoying:

“erm as a brother sometimes he is really really really really annoying and sometimes he’s really really really really fun to be with”. (I9, Mia: 154-155)

“... well there’s only two (words) that describe her when she’s playing with me, nice and nasty”. (I6, Noelle: 181–182)

Phillip talks about his special relationship with his brother:

“You can get really close to him in a relationship you can, as a really good friend because he opens up just that tiny bit more than the others. ... That’s what I find good about it ... he likes a bit more lively like he wants to play more he wants to become your friend more so you be able to get a bigger and better relationship really. (I3, Phillip: 208–215)

Only one participant directly referred to their sibling relationship as being predominantly difficult, describing it as:

“a weak relationship ... Un-getting on”. (I5, Kay: 184-187)

3.6.2 Sub-category two: Managing Emotions

Throughout the interviews, the management of emotions was described in different ways. Experiences of a variety of feelings about having such a sibling were described, as were various ways of trying to cope with and manage these feelings. Participants talked about feeling annoyed, happy, sad, frightened, hurt, angry or cross, upset, embarrassed, and threatened. Emotional management strategies involved attempts to monitor and control feelings, actively seeking emotional support from parents or significant others and using physical strategies to dissipate feelings.

The participants all put a great deal of effort into managing their emotions:

“A lot of my patience is used up on Edward I get to school after getting ready to go and if something happens on the way to school I’ll just go to school I really can’t do it today I just can’t face it today and I’ll be quiet in the morning and in the afternoon I’ll feel better”. (I1, Lucy: 738-742)

“(.) Well I can be understanding with Jake most of the time (.) that and sometimes I can control my temper quite good and be quite good most of the time”. (I3, Phillip: 169-170)

Times when the participants struggled to contain their feelings, particularly anger, were described in terms of uncontrolled release of pressure:

“The pressure’s all bottled up inside and then I just let it all out on Edward but I don’t tell anyone, just let it all out on Edward probably”. (I1, Lucy: 798-799)

3.6.3 Sub-category three: Holding onto the Positives

This category refers to the participants holding onto and focussing on the positive aspects of having a sibling with autism. Despite the negative aspects of how their sibling interacts with them, their treatment of them and the difficult situations that arise, they are able to

focus on the positives and willing to see and hold in mind the achievements of their sibling and their positive attributes.

Noelle describes how having a sibling with autism makes her feel unique:

“Well it it means something very special to me ... It means that I’m the only one at school with an autistic sibling”. (I6, Noelle: 298-300)

Participants described the importance of ‘significant moments’ (or ‘feel good’ moments) where their sibling for example does something unusual or responds to them in a different or special way, which may seem small and insignificant to those outside the relationship:

“Um at school because in assembly he’ll walk by and I’ll just be sitting down and he’ll just stop the whole line and just wave at me and that’s quite happy”. (I13, Nathan: 86-87)

“Anna came and tapped me on the shoulder for the first time and nobody thought it was special until she said but I was scared of coming down to my own living room”. (I7, Olivia: 141-143)

Times when their siblings had ‘flashes of understanding’; where participants seemed to be getting through to them were highlighted:

“‘cause when Anna throws something at me she did it again she really hurt me I screamed and Anna suddenly had a paddy because she understood finally that she actually hurt me ... She actually I stood there ‘you understand?’ (laughing)”. (I7, Olivia: 338-342)

3.6.3.1 Lower level sub-category: Sharing Activities and Having Fun

Key positive aspects focussed on by all the siblings, as part of ‘Maintaining the Relationship’, were ‘Sharing Activities and Having Fun’. The majority of the participants talked about games that they played with their sibling and having fun together. Joint play often involves physical games, playing on games consoles or inventing games to play together.

“Well when like when we have go a have a good time on the Xbox he kind of just giggles and it’s just really funny and it’s playful and I tickle him and it’s fun”.
(I13, Nathan: 61-62)

Noelle describes a game she plays with her sister:

“Well it’s a game where I’m an angel ... and I have to catch Olwen because she’s the devil”. (I6, Noelle: 240-241)

3.6.4 Sub-category four: Coping Day to Day and Adapting Over Time

This involved a two level process in which participants described coping with having a sibling with autism on a daily and longer-term basis. The participants indicated that having a sibling with autism has to be dealt with each day often utilising the strategies of ‘Managing Emotions’ and ‘Holding onto the Positives’. Strategies that helped the participants to contend with their siblings on a daily basis, using either internal or external resources, were described⁶:

“I’ll just go and talk to my mum or my dad if things get a bit difficult with Jake. They’ll like tell him to stop, they’ll deal with it”. (I3, Phillip: 295-296)

“Yeah so he I’m usually the one that he picks on. ...Yeah I try that’s why my mum treated me so I could be able to cope with all of with being the brunt of his behaviour”. (I2, Sophie: 281-284)

In some cases participants described a positive adjustment over time, which seemed to be facilitated by having taken time to understand and learn from their sibling and their behaviour. The participants described learning from experience to adapt their own behaviour and getting used to having such a sibling:

⁶ Only one participant mentioned accessing services for support (I5, Olivia: 120), a further two participants mentioned attending a support group for siblings of children with autism.

“we can live with each other and we don’t drive each other out ... he’s loving he’s very problematic but also you can live with it if you’ve grown up with it if you haven’t it’s it’s harder”. (I1, Lucy: 643-645)

3.7 Sub-category of core category: Indirect Expressions of Vulnerability

This category represents an important aspect of five of the participant’s accounts.

Participants felt that no matter what they tried, the relationship remained very difficult and their experience of it was negative. Their ‘Deep Need for Relationship’ however, meant that these children could not easily and openly express their negative feelings resulting in ‘Indirect Expressions of Negativity’:

“... does it get any easier?”. (I1, Lucy: 834)

3.8 Main category four: Vulnerability

There was a sense of the participants' vulnerability and that of their relationship with their sibling; alluded to through ‘Stories of Loss and Disappointment’, a ‘Sense of Fragility’ and the participant’s ‘Ambivalence About Autism’.

3.8.1 Sub-category one: Stories of Loss and Disappointment

Most of the participants described their pets as important members of the family⁷ and as a source of emotional support. In Lucy's case, her negative feelings seemed to be projected onto the family dog. Milly talked about wanting a pet but not being able to have one, perhaps as an expression of wanting something to love, play with and have a fulfilling relationship with. Participants also made reference to the distress felt when family pets die, possibly as a way of indirectly expressing their feelings of loss and disappointment about their sibling relationship.

Lucy talks about her admiration for the family dog, Bessie and her amazing capacity for tolerance:

“And with animals as well we are very lucky Bessie is an absolute, she's like a diamond in a lucky bag, she is an amazing dog ... she has only ever bitten once and that was for very good reason when she tried to protect us and Edward would do the most horrible things to her, he once put all of her toys in her water bowl and her chew got all soggy and it was a brand new chew and she was so upset about it... But she didn't go all mardy with him ... she just restarted with him from the beginning again and just built her confidence with him again, she didn't bite him, she didn't growl at him or anything she just stared at him and he feels sorry then because he knows he's done wrong and he'll grab hold of her tail and

⁷ 12, Sophie: 41 – 43.

she'll go round and she'll knock his hand out of the way and then she'll take her toy to him and say you play with this not my tail". (I1, Lucy: 422-434)

3.8.2 Sub-category two: Sense of Fragility

This category represents the theme of a sense of fragility, evident in several interviews. Participants seem to have a sense of fragility evidenced by talking about risks, the need for protection and showing concern for the safety of others. One participant in particular, alludes to ways of protecting herself from being hurt emotionally by her brother by detaching and distancing herself from him.

Sophie said the following when asked what she would wish for:

" ... and not be mugged in the street and all um shot or anything by bad people shot or actually robbed or anything erm the sort of car I might get when I grow up is sort of like erm a safe normal car that don't look too (can't hear) so that no-one robs it. I'm not going to get the sort where the roof goes up and down because they could just rip a hole in that and then get in the car". (I2, Sophie: 633-637)

Noelle explains that she tends to visit the school nurse often, which suggests that she needs regular help to 'feel better':

“I feel a bit strange when my mummy says I live in the welfare room because I always have to go to the welfare room (laughing) ... It’s the room with the nurse in and she she makes everyone better and (laughing) every day it seems like I have to go in there” (I6, Noelle: 221-226)

Furthermore, one of Noelle's wishes perhaps indicates a desire to return to a place of safety where she would not feel fragile:

"Well my different one would definitely be to to make a machine that would rewind your life ... So I could go back to being a baby ... Yeah. And then you can start your life all over again. When I was in mummy’s tummy". (I6, Noelle: 363-379)

Furthermore, three participants mentioned being bullied⁸ which could indicate their fragility and vulnerability.

3.8.3 Sub-category three: Ambivalence About Autism

This category encapsulates the participants' feelings about their sibling’s autism. They tended to express opinions about whether or not they would keep their siblings autism, if given a choice. Participants tended to weigh up the positives and negatives of autism and

⁸ 11, Lucy: 673, 15, Olivia: 118-124, I10 & Saskia: 330-331.

whether they wished it away or not seemed to depend on whether they externalised autism or saw it as an integral part of their sibling.

Milly described possibly keeping the useful parts of autism:

“I sometimes wish he didn’t have autism not all the time ‘cause autism can be useful”. (I8, Milly: 721)

Eight participants said that they would wish their sibling’s autism away⁹. With one participant saying that she sometimes wished her brother wasn’t there¹⁰. Several participants talked about wishing their sibling was ‘normal’:

“Well sometimes I do wish he was normal but apart from that I don’t really mind”. (I5, Kay: 338)

Interestingly, Phillip wished that Jake could decide for himself:

“That he could make his choice whether he wanted autism or not ... His choice that he’d have his own choice, that’d be my wish that he could have his own choice in what he wanted to do”. (I3, Phillip: 304-308)

⁹ ‘Mia’, ‘Saskia’, ‘Naomi’, ‘Olivia’, ‘Sarah’, ‘Joe’, ‘Riley’ and ‘Kay’.

¹⁰ “sometimes I wish he wasn’t there a little”. (I8, Milly: 401-402)

3.9 Main category five: Missing Out

‘Missing Out’ encapsulates the idea that the participants are aware that there are certain opportunities, activities and experiences they miss out on through having such a sibling. Furthermore, there are elements of the relationship that are absent, for example missing out on worry-free interactions with their sibling. In some cases, there seemed to be a realisation of missing out on what could have been, in terms of the relationship.

3.9.1 Sub-category: Perceived Unfairness

This refers to some of the participants seeming to feel a sense of injustice in their treatment, compared to that of their sibling and a sense of being overlooked by their sibling and their parents, at times.

Participants described being treated differently to their sibling by their parents:

“he normally swears and if I swear I get told off and sent to my room but if he swears you don’t my mum and my dad don’t do anything to it”. (I5, Kay: 166-167)

Lucy described limitations placed upon her freedom because of Edward:

“I wanted to go along...there was no way I was going to be able to go to a train club without Edward he would he just couldn’t accept that I was going to train clubs and he couldn’t go ‘cause they don’t let people children in who aren’t eleven”. (I1, Lucy: 758-762)

A couple of participants described being over looked due to the needs of their sibling:

“Oh well erm I do have a bit of sort of bit of jealousy ‘cause my mum does stuff for him like put all his clothes away and everything but I have to do it by myself. It’s especially annoying ‘cause I’m the youngest so (laughing) I don’t know”. (I5, Kay: 315-317)

3.9.2 Sub-category two: Barriers to Support

‘Barriers to Support’ refers to some of the participants missing out on potentially helpful support and the ways in which this happens. For example, a few participants said that they did not talk to anyone about their feelings about their sibling, tending to cope alone:

“When I do get upset about Robert I usually go into my bedroom to play with my teddies ... I go into bedroom and cuddle my teddies for a bit”. (I8, Milly: 683-686)

“[AND IF YOU DO EVER GET UPSET OR THINGS GET DIFFICULT WITH COREY, IS THERE SOMEONE YOU CAN TALK TO ABOUT IT?¹¹] Erm no ... Mum’s sometimes busy and dad’s at work ... No all I do is sit in my bedroom, listening to music singing to the radio”. (I10, Saskia: 560-566)

Having to keep their siblings autism a secret is a potential barrier to receiving support:

“[DO YOUR FRIENDS KNOW THAT COREY HAS DIFFICULTIES?] No I’ve not told ‘em ‘cause I’m not allowed to tell anyone because it’s kind of a secret. I’ve only told my best friend Skye”. (I10, Saskia: 567-569)

3.9.3 Sub-category: Relationship Out of Reach

This category represents the accounts of those participants who feel that their attempts at maintaining the relationship with their sibling have been thwarted to a point where they feel that the sibling relationship remains elusive to them. They seem to have lost hope that they will fulfil their deep need for relationship.

For Olivia a glimmer of hope turned into disappointment:

“but once in her life she said Olivia and I was right behind her and she couldn’t

¹¹ Upper case letters denote the interviewer's speech.

say it again ... I was really upset because she didn't say it again". (I7, Olivia: 234-237)

Her wish to communicate with Anna is powerful:

"It's just like I really don't want, I don't like her having autism if she could be a normal child and speak I would, I would (can't hear) if there was like an operation or something like on the news they said they've got half way to a cure to autism and and in the future hopefully they (can't hear) hopefully you can get a cure for Anna's autism that's my dream anyway ... Yeah and she could actually talk to me". (I7, Olivia: 224-230)

Kay indicates that she feels replaced and disregarded by her brother as he is "*locked in his computer game*"¹²:

"before he knew about computers and all the fun about them and things he used to like playing with me". (I5, Kay: 225-226)

3.10 Main category six: Overwhelming Impact

The sixth category 'Overwhelming Impact' encapsulates some of the participants' experience of feeling overwhelmed by their sibling and their frustrated attempts at

¹² I5, Kay: 103

staying in relationship with them. Although this category only emerged in three of the interviews, where it was present it was striking. These participants experienced the sibling relationship as being extremely difficult to cope with.

3.10.1 Sub-category: Just Too Much

In these relationships the extent to which the participants felt vulnerable and felt they were 'Missing out' meant that they found it very difficult to cope with their sibling relationship or lack of it.

Lucy talks about having to mentally prepare her self for interactions with Edward:

“Because you have to be you have, I can only do it when I know I have a lot of patience otherwise I just can’t, I can’t do it, it’s impossible” (I1, Lucy: 245-246)

Several participants seemed to acknowledge the overwhelming impact of their sibling on the wider family system:

“when Dad got over stressed (laughing) Anna just kept throwing Dad was nearly crying but he made me upset I was really upset so mum sent me up to my Nana’s but that wasn’t a good time”. (I7, Olivia: 100-102)

Finally, for participants who felt overwhelmed, there was evidence of continuing to hope for improvements or being resigned to having to get used to the situation:

“Does it get any easier?”. (I1, Lucy: 834)

“But I can get used to it”. (I7, Olivia: 126)

4.0 Discussion

This chapter focuses on a critical discussion of the analysis and the research process. A summary of the analysis is followed by a methodological critique, highlighting strengths and limitations of the study. The chapter then provides a discussion of the theoretical account, in relation to previous research. Clinical implications of the results are presented and suggestions for future research are identified.

4.1 Summary of analysis of interviews

The analysis indicates that children¹³ experience a deep need for a relationship with their sibling, despite the difficulties and challenges encountered. The interviews indicated that the children seem to have resources available to put into their relationship with their sibling, resources that are not easily diminished by difficult behaviour, problems in communication, lack of reciprocity, the demands the sibling places on wider systems or the demands placed on the siblings themselves. There seem to be areas in which the siblings can only make limited contributions to the relationship. The children bridge these gaps, motivated by their need to relate to their sibling.

The majority of participants reported mixed feelings about their relationship with their sibling, but the positives seemed to outweigh the negatives. Negative feelings were minimised in most cases and positive aspects of the relationship were focussed on and

¹³ For clarity, throughout the discussion, siblings without autism are referred to as children and siblings with autism are referred to as siblings.

upheld. The children appeared to utilise various strategies and processes in order to maintain the relationship. They sought to understand their sibling and balance the imbalance between their sibling's relationship resources and their own.

The findings revealed that whilst this was often successful, in some cases this was more difficult, resulting in a less positive adaptation, whereby the children's attempts to maintain the relationship were thwarted by their sibling and the relationship seemed fragile. The children's deep need for a relationship meant that they did not feel able to express their feelings of negativity directly; rather these feelings were indirectly expressed. In denying their feelings of disappointment and loss, and missed experiences, the resulting impact of having a sibling with autism was overwhelming. The participants felt that it was all too much and seemed to have lost hope that the situation would get any better or they would feel any differently.

The model explains how the processes the children used to learn to live with and manage having a sibling with autism may fit together. The model suggests a new dynamic to previous research on the impact of having a sibling with autism by demonstrating the processes which may lead to a positive adaptation or a more problematic adaptation. Furthermore, the model potentially accounts for the positive skew of some previous research studies in this area.

4.1.2 The reflective nature of the researcher

It is important to note the significance of the reflective nature of the researcher in the development of the model. Stiles (1993) explains that investigators internal processes are part of the investigations context and can represent an important source of information in their own right. During certain interviews, namely those where the participants tended not to directly articulate more negative feelings, tension was experienced between the demands of the roles of researcher and clinical psychologist (Grafanaki, 1996). It seemed that the children may have been struggling to articulate their negative feelings (Stiles, 1993) in a direct way, as the researcher was left with a sense of sadness, loss and disappointment both after the interviews and having analysed the interview transcripts.

The researcher felt it important to attend to her internal processes and interpret these in terms of the possibility of counter transference (Giami, 2001). It is possible that the researcher initially, subconsciously, prevented the more negative aspects of the sibling relationships being represented in the model as a reflection of the children's feelings of needing to block out their negative feelings in order to have a relationship with their sibling. It seemed that the children could have been using several defences against having negative feelings towards their sibling and their situation, feelings which are potentially unbearable due to their 'Deep Need for Relationship' with their sibling. The revisions made to the model based on giving credence to reflection on the researchers feelings seemed to capture the rich detail of the data and better address the subtleties and complexities of the sibling relationship.

4.2 Methodological critique

4.2.1 Strengths of the study

The current study involved a varied sample in terms of gender and age of participant and sibling, birth order, number of children in the family and severity of sibling's autism, which could be considered a strength of the study. The sustained substantial effort put into recruitment resulted in a good response rate and a relatively large sample for a qualitative study was achieved. This meant that the use of supplementary means of data gathering, such as, triangulation with parent interviews, was not necessary. The findings are therefore based purely on the perspectives of child siblings of children with autism, supplementing previous research.

A second strength of the study was the interview process, in terms of the apparent effectiveness of the semi-structured interview schedule and the interviewing skills used. The initial interview schedule revisions following the pilot study meant the interviews proved more effective in eliciting narratives by encouraging the children to provide detailed descriptions of relationship events. The addition of techniques from The Adult Attachment Interview (George et al., 1984) resulted in lengthy interviews in which participants talked directly and indirectly about their feelings about their sibling relationship. The 'warm up'¹⁴ seemed helpful in building rapport and encouraging the children to focus on their sibling relationship. All participants appeared able to articulate

¹⁴ consisting of using part of The Bene Anthony Family Relations Test and asking the participants if they wished to draw a picture of their sibling.

their experiences, even if in some cases this was in an indirect way. This evidences the researcher's skills in allowing the children to direct the interview, speak at length and also suggests that for some children they enjoyed the undivided attention given.

Spencer et al. (2003) assert that rigour in qualitative research is achieved through being 'grounded'. The researcher aimed to remain close to the data throughout the research process, through constant comparison between data, codes and categories. The researcher took steps to be transparent (Rennie et al., 1988) about the analytic procedures used and the understanding developed, through the use of memos and a reflective diary. Thus an accessible 'paper trail' was created of the entire research process (Henwood & Pidgeon, 1992). Substantial amounts of data were generated through the thirteen interviews; the varied perspectives and experiences described were given equal attention ensuring an inclusive theoretical account less skewed by the researcher's assumptions.

Hence the inclusiveness of the conceptual model is a further strength. Following completion of the analysis, an initial model was developed concentrating on the striking finding that the majority of children reported a mainly positive, yet difficult relationship with their siblings. However, upon closer analysis and a return to the original data, taking a more analytical stance revealed more indirect expressions of negativity with regards to the sibling relationship; evident in around a third of the accounts. The model was revised to incorporate less adaptive processes, which had initially been excluded due to their indirect expression. The revised model therefore indicated very few negative cases as it addressed and incorporated variance in the experiences. It was important that those

children whose attempts at maintaining the relationship were not successful, were not over looked. It was necessary to explicitly infer underlying psychological processes. The model developed is therefore, conducive to the clinical applicability of the findings regarding sibling relationships where one child has autism.

4.2.2 Limitations of the study

Methods of recruitment and the resultant sample may have affected study findings in several ways. As the participants were recruited through support groups and a newsletter, the respondent families were likely to consist of those who are in touch with other families with a child with autism. These families may be more adept at seeking support. Parental attitudes to and perceptions of their child's relationship with their sibling with autism may have affected the likelihood of asking their child if they wished to partake in the study. Several parents decided against their children taking part, as they thought that the interview might cause problems which weren't previously there, particularly for young children. The sample may have been biased due to the exclusion of children from families with parental anxiety about the impact of having a child with autism on their other children. One parent observed the interview, seemingly as a way of finding out about her child's feelings. For this participant, their parent's presence may have impacted upon their interview responses. In another interview, the participant requested that their mother remain in the room and proceeded to candidly discuss the negative impact of her sibling upon her. It is therefore unclear whether the participants felt constrained by the

presence of a parent or not. Some parents seemed to use the interview as a way of allaying their apparent anxieties.

A limitation of the procedure is that theoretical sampling was not conducted; due to time constraints it was not possible to code and analyse every interview before the subsequent interview took place. Theoretical sampling could have involved altering the latter interviews to confirm or refute the emerging themes, adding weight to the theoretical model, particularly in terms of gentle questioning about any indirect emotions expressed, perhaps encouraging more open articulation of negative affect and potentially achieving saturation of the categories relating to indirect expressions of negativity, which remained less saturated.

A further limitation of the study concerns the generalisability of the model and overarching theme or core category of 'Deep Need for Relationship'. As the exclusion criteria explicitly stated that the child with autism must live in the family home, those sibling relationships where the child has severe autism or severe behavioural problems are unlikely to have been represented in the study. It remains to be seen whether there is a 'Deep Need for Relationship' in these sibling relationships. Furthermore, due to the age limits on the sample of both the participating child and their sibling, the themes may only reflect that developmental period. It remains unclear how the findings might relate to future developmental processes.

Finally, due to the exploratory nature of the study the results cannot be described as conclusive. The research cannot claim the development of a comprehensive theory rather it provides a useful insight into a previously un-charted area of research into the impact of having a sibling with autism, focussing on child siblings' perspectives. The findings provide a starting point for further investigation.

4.3 Interpretation of findings

4.3.1 Confirmation of findings from previous research

The current study echoed the findings of some previous research examining the impact of having a sibling with autism (Kaminsky & Dewey, 2002; Fisman et al., 1996; Mates, 1990). More recent studies have tended to highlight the positive impact of having a sibling with autism, for example, showing children of siblings with autism to have higher than average scores on self-concept measures and enhanced interpersonal and caretaking skills (Mates, 1990; Howlin & Yates, 1990). Studies have also shown an absence of adjustment difficulties (DeMyer, 1979; Rodrigue et al., 1993; Pilowsky et al., 2004). Although negative effects including parentification (Mates, 1990) and anxieties about their siblings future (Pit-ten Cate & Loots, 2000) have been suggested, previous research has tended to show a general positive appreciation of the relationship when one child has autism (Kaminsky & Dewey, 2001; Howlin & Yates, 1990).

In the majority of cases, in the current study, positive aspects of having a sibling with autism were described and a positive yet difficult relationship was maintained. However, in other cases although positive points were acknowledged, a much more negative picture emerged. Therefore, both positive and negative aspects, less apparent in some previous studies, of having a sibling with autism were found. The current findings support those of Howlin's (1997) study on a sibling support group in which the majority of children highlighted both positive and negative parts of their sibship and one child described a very difficult relationship about which she could not think of a positive aspect. Notably, McHale et al. (1984) found positive effects including the children being less hostile, less embarrassed, more accepting, and more supportive than siblings of typical children, but with a wide range of problems of varying severity.

Some support is found in the current study for mediating factors suggested in previous research (Miller, 2001). Although the severity of the sibling's autism was not directly measured in the current study, children who described more aggressive and destructive behaviours, and fewer shared activities seemed to find it more difficult to maintain the relationship and to cope with their sibling. Knott et al. (1995) found that when siblings had lower social competencies and there were larger discrepancies in interaction and play levels between siblings, this negatively impacted the relationship; a finding also apparent in the current study. Although the children used many strategies to maintain interaction and share activities with their sibling, in some cases the relationship seemed out of reach due to their sibling rejecting their attempts to interact with them and being absorbed in their own world.

The current study also suggested that having other siblings acted as a buffer to some of the negative aspects of the sibship and led to more positive adjustment (McHale et al., 1986; Howlin & Yates, 1990). This could be accounted for by the social support offered by siblings and a sharing of the impact. It has been suggested that girls may experience more 'parentification' (Lamorey, 1999), however in the current study there is some indication that the male children seemed to take on a greater supportive role than their female counterparts. As identified by Mates (1990) this did not result in adjustment difficulties, rather it seemed to facilitate a more positive attitude towards the relationship. It is important to consider that, as the presentation of autism is much higher in males than in females, studies are likely to recruit more siblings with a brother with autism, as was evident in the current study, which could impact upon the results. Due to the exploratory and small scale nature of the current study this is an interesting potential avenue to research further.

Correlations have been shown between the quality of sibling relationship and knowledge and understanding about autism and also with children's coping abilities (McHale et al., 1986; Roeyers & Mycke, 1995). This was a striking finding of the current study, as represented by the main category of "Seeking Understanding". Children who talked about a positive relationship, with some describing a relationship better than that with their other siblings, demonstrated that they had sought to understand and gather knowledge about autism and had a good understanding of their sibling. Bagenholm and Gillberg (1991) stressed the importance of children having simple words of explanation to give to others about their sibling with autism. The development of these explanatory narratives is

likely to be facilitated by a good understanding of autism. The children in the current study used several methods of coping with the daily challenges of having a sibling with autism. Notably, the children talked about making allowances for their sibling's behaviour by attributing it to autism. This is supported by previous findings suggesting that quality of sibling relationship is partly a function of processes involving not only occurrence of daily stressful events but also the children's affective reactions to those events (Gamble & McHale, 1989).

A selection of key concepts in the model appear in previous qualitative studies. Sullivan (1979), in a retrospective qualitative study of adult siblings found the following themes: 'Better understanding of how to handle people', 'Proud to be able to teach sibling something', 'Coped through special talent of responding to the small but wonderful things', 'Reasons behind behaviours' and 'Acceptance over time'. Corresponding categories emerged in the current study: 'Personal Impact', 'Care Giving Role', 'Holding on to the Positives', 'Interpreting Behaviour' and 'Coping Day to Day and Adapting Over Time' respectively. This suggests that the model developed in this study may have some applicability over time¹⁵.

4.3.2 Development of previous research findings

The current study offers possible explanations for the absence of negative feelings about the sibling relationship in previous research (Pit-ten Cate & Loots, 2000). The theoretical

¹⁵ See section 4.3.4 for further discussion.

account explains the processes involved in managing having a sibling with autism and in doing so sheds light on reasons why some studies may not capture the more negative perspectives on such a sibling relationship. The model clearly encompasses a variety of sibling experiences and although the majority of the children interviewed presented mainly positive feelings about their relationships, some accounts had a much more negative flavour.

Feelings of sadness and loss were not directly expressed, rather they were alluded to in, and consequently inferred from, the children's stories of loss and disappointment. Stiles (1993) explains that people often tell stories when they have difficulty making a point. For example, in psychotherapy people tell stories when they do not seem to understand how they feel. Furthermore, individuals often cannot fully explain the point of a story they have told; the story may convey interpretations that are beyond their ability to articulate (Stiles, 1993). According to Lewis (1993) children may sustain an emotional state but not necessarily experience conscious awareness of that state. In addition, it should be noted that children are socialised to show their anger, distress, fear or anxiety more indirectly through subtle behaviours rather than direct actions (Blumberg & Izard, 1991; Harris, 1989), which could include 'half-hiding' negative feelings in stories. It was interesting that some of the children displaced their negative feelings and furthermore used family pets as a way of talking about their difficult feelings.

Children may feel compelled to hide their negative feelings to protect their parents, as they recognise the impact on the whole family, resulting in 'Indirect Expressions of

Negativity'. The accounts generated in the interviews may parallel this, further evidenced by several children playing down their negative feelings. The concepts of 'Holding onto the Positives', 'Managing Emotions' and generally 'Going the Extra Mile' indicate that the children tend to look on the bright side, perhaps encouraged to do so by their parents.

Parents may place emphasis upon their children coping with their sibling and adapting to their sibling as they are aware of the permanence of autism. This may take prominence at the expense of encouraging discussions where negative feelings could be normalised and validated.

As in Bagenholm and Gilberg's (1991) study, which also used semi structured interviews, the current study elicited negative and positive views of the relationship. Indirectly expressed feelings are likely to be missed in studies employing standardised assessment measures. The current findings support suggestions from clinicians working with siblings of children with autism that they may harbour concerns that go undetected by the standardised instruments used in most research (Glasberg & Belchic, 1996).

Retrospective studies in this area may lack reports of negative effects as adult siblings may look back with 'rose tinted glasses' and additionally, may have gone through a process of adjustment and acceptance over time. Furthermore, when interviewing children researchers may be less likely to pursue subtle inferences of negativity due to wanting to let the child lead the interview whilst trying to maintain a stance of 'empathic neutrality'¹⁶ (Patton, 1990) and also due to limitations in what they can do to help. This

¹⁶ Empathic neutrality refers to maintaining empathic engagement with participant's stories, but neutrality regarding the content of the material.

may be the case particularly when clinical psychologists are carrying out interviews in researcher role (Hutchinson & Wilson, 1994) and feel unable to help.

4.3.3 'Deep Need for Relationship' from an Attachment perspective

The core category of 'Deep Need for Relationship' was striking in its centrality to all the children's accounts. The children seemed compelled to relate to their sibling no matter what obstacles they had to tackle in the process. There is evidence to suggest that the type of social interaction shown by children with autism is significantly different to children with typical development (Dissanayake & Crossley, 1996). In addition, the nature of that interaction is qualitatively different (Kasari & Sigman, 1997), particularly in terms of lacking reciprocity. This was apparent in the current study in terms of interaction being on the siblings' terms, and the siblings wanting to be in control of interactions. In contrast to previous findings (Snow et al., 1987), all the siblings shared at least one activity with their sibling and talked about having fun with their sibling. The children, in their keenness to maintain a relationship, talked about accommodating their sibling's likes and compromising their own needs. In compensating for their sibling's deficits in social interaction, particularly reciprocal social interaction, and making allowances for their sibling's difficulties, they balance the imbalance. Human attachment relationships are regulated by a behavioural motivational system that develops in infancy (Bowlby, 1979). Research indicates that siblings can serve as attachment figures (Teti & Ablard, 1989). It may be that children feel compelled to relate to their sibling as part of being attachment-programmed individuals.

4.3.4 Adapting to having a sibling with autism

In gathering the perspectives of siblings while still children on their sibling relationship, this study has added to previous research findings, in terms of process of adaptation potentially being more complex than previously thought. The current study offers a tentative model, of adapting to having a sibling with autism. Previous research has shown that parents of a child with autism go through a process of adaptation akin to that of bereavement, loss or grief (Attfield & Morgan, 2007; DeMarle & Le Roux, 2001; Innocenti et al., 1992; Mahoney et al., 1992). There is evidence to suggest that parents adapt over time (Gray, 2006), which is likely to also be the case for siblings without autism. Children in this study described how they learnt to adapt over time through attempting to cope day to day and putting their efforts into maintaining the relationship. Research indicates that family member's roles undergo adaptive redefinition (Lamorey, 1999) when a child in the family has a disability. In the current study, children reported taking on the roles of supporting, teaching and protecting their sibling. Previous studies have shown that children take pride in being able to teach their younger siblings with autism (Bristol & Schopler, 1984; Sullivan, 1979).

As this study focussed on children aged between six and twelve¹⁷, there is a possibility that they are still adjusting to having a sibling with autism. In this study, the children seemed to vary as to how much they had come to terms with, or begun to accept their sibling and this seemed to be mediated by their level of understanding of autism.

¹⁷ with an average age of eight.

Different parallels with previous research may have been drawn depending on the age range and developmental stage of the children interviewed. In the current study, only the older participants mentioned concerns about their sibling's future and the impact of stigma. The current model may be representative of the experiences of children at a particular developmental stage. Revisiting these children in five years time might result in a theoretical account with a different focus. The children may have developed in terms of openly expressing negative feelings about their sibling due to having more tools with which to understand their sibling's disability (Lamorey, 1999). In addition, there is potential for the 'Deep Need for Relationship' with siblings with autism to impact upon the young person's ability to separate and make intimate relationships. A longitudinal approach may be necessary to accurately measure the process of adjustment involved in having a sibling with autism.

4.4 Clinical implications

In adding a different dimension to previous research on children's relationships with their sibling with autism, a number of clinical implications are suggested. The 'Deep Need for Relationship' shown by all the children indicates that children may not openly talk about the negative aspects of having a sibling with autism. There is therefore a need to monitor the impact, paying close attention to children's reports, looking out for indirect expressions of negativity and signs that they feel overwhelmed.

Importantly, the model detailing the processes siblings go through in managing their relationship with their sibling provides points at which intervention could take place and also ideas of how parents can help to facilitate positive adjustment. Although Rodger and Tooth (2004) suggested that while siblings have unique concerns they are no longer necessarily considered the vulnerable, at-risk population once described in the research literature, this may not be the case for all children for whom there is a risk of their emotional needs not being met. As these children often experience mixed feelings about their siblings, having opportunities to discuss what might be very confusing feelings and being reassured that such feelings are natural and understandable is essential (Howlin, 1988).

One of the most striking findings of the study is the children's commitment to actively seeking understanding about their sibling and their condition. A positive relationship seemed to be associated with understanding autism and their sibling's behaviour. In a few cases the siblings may not have had the diagnosis explained to them as they could not pronounce the word autism or describe it; however in the majority of cases the siblings seemed to have knowledge of their sibling's diagnosis and offered definitions of autism. There is potential to maximise on the children's tendency to become very psychologically minded in actively searching for explanations for their sibling's behaviour. Parents could help their children to understand their sibling's condition by facilitating the gathering of information about autism, through making appropriate literature available and again, taking time to openly discuss autism with their children. Simeonsson and McHale (1981) found positive benefits to open parental communication in promoting understanding and

adjustment in sibling relationships where one child has a disability. It is therefore important that parents of children with autism are furnished with appropriate information in order to be able to help their other children to understand the condition. Hence, there are implications for clinical practice in terms of fostering a culture of curiosity in families where a child has autism and encouraging families to develop and maintain a facilitative learning environment where autism can be embraced.

Some children talked about their sibling's autism being 'private' or 'a secret' and implied that they had not been encouraged to disclose their sibling's diagnosis to their friends and peers. This could potentially act as a barrier to children seeking understanding, adjusting to their sibling's autism and accepting their sibling, in terms of children thinking that their sibling's diagnosis is something that needs to be hidden and possibly result in hiding their feelings about their sibling. Furthermore, they may miss out on peer support. In other cases, seeking understanding seemed to help the children to develop a sense of their sibling's difficulties and facilitate the development of a rich detailed account of the sibling relationship. The researcher acknowledges that an interview reflects what interviewers and participants bring to the interview, impressions during it and the relationship constructed through it (Charmaz, 2006). The interview may therefore have facilitated development of these narratives. The fact that the children seem to find the development of these narratives helpful has interesting implications in terms of the potential value of using narrative therapy with those children who have adapted less positively to their sibling relationship. Narrative therapy would give these children a chance to vent their feelings in a safe environment without worrying what the receiver

will think, due to being outside of the family. Stories of loss and disappointment could perhaps be replaced with adaptive narratives about their brother or sisters autism.

Previous research has indicated that siblings of children with autism are often 'therapists' and educators of their siblings with autism (McHale et al., 1984). In the current study, the children talked positively about being able to help and teach their siblings skills. James and Egel (1986) found that with guidance brothers and sisters can become adept at encouraging social behaviours in their siblings with autism¹⁸. There are implications for these siblings providing an educational resource for their siblings with autism as part of positive adaptation. The children seemed to assume these roles of responsibility willingly. If as the literature and the current study suggests children feel more positive about the relationship when they have a defined role, parents could help to facilitate and also monitor this in case the responsibility becomes overwhelming.

The current research findings have implications for therapeutic input from clinical psychology for children and families affected by autism. There is a potential role for raising awareness of the issues highlighted by the current study amongst professionals involved in working with children with autism; particularly in terms of the children's indirect expressions of negativity, the range of adaptations and the processes which seem to lead to more positive adaptation. It is important for clinicians to be attuned to the varied subjective experiences of these siblings. Previous studies have highlighted positive effects of support groups for siblings of children with autism (Naylor & Prescott, 2004).

¹⁸ This is particularly important as children with autism may rarely have the opportunity to interact with other children without autism.

The current study indicates that support groups with a narrative focus could provide a useful way of helping children to seek understanding by providing psycho-educational input, normalising the range of feelings, allowing children to talk about their feelings with children in a similar situation, talking about making fair allowances for autism, acknowledging the deep need for relationship but also encouraging children to put appropriate boundaries in place when enough is enough, focussing on feelings of loss and disappointment, examining barriers to support, encouraging children to seek support when feeling overwhelmed, talking through coping strategies and maximising opportunities for sharing activities and having fun.

4.5 Future research opportunities

The present study informs potential areas for future research in several ways. Firstly, as was the case with the present study, further qualitative studies may encourage disclosure of both the positive and negative effects of having an autistic sibling (Taunt & Hastings, 2002) and give a rich account of the impact this may have.

Secondly, it would be useful to extend the study through conducting theoretical sampling. This would facilitate the gathering of data from older children, and allow for investigation of the applicability of the model to children and young people at different developmental stages. There was a sense of movement and shift over time in adaptation and coping, indicating different stages of adjustment. Furthermore, themes appeared in the older children's accounts that were less apparent in those of the younger children.

including the impact of their sibling on friendships. It would be beneficial for future studies to gain a spread of data across varying developmental levels, bearing in mind developmental transitions particularly the move to individuation in adolescence. Questions arise as to whether the deep need for a relationship persists into early adulthood. If so, there could be implications for the young person's individuation being problematic. Attfield and Morgan (2007) suggest that the impact of having a sibling with autism changes as both children grow older. Furthermore they explain that for younger children the focus of literature has been to help the sibling to recognise and understand why their brother or sister is different whereas publications for older siblings are less easily available. Theoretical sampling may therefore establish whether the theoretical account represents only the experiences of children aged between six and thirteen who have a sibling with autism, or whether the account encapsulates the experiences of older children and young people or alternatively if certain aspects of the model apply across different age ranges and corresponding developmental levels. Furthermore, it would be interesting to evaluate how the current theoretical account applies longitudinally, for example by interviewing the participants from the current study in ten years time.

Theoretical sampling may also help to clarify the impact of some of the potential mediating factors suggested in previous research and the current study, for example by interviewing children whose sibling lives away from the family home in a residential placement. This could illuminate whether the severity of autism has an impact on experiences and perceptions of the sibling relationship.

Thirdly, interventions based on the model developed in the current study, as suggested above, could be evaluated in future studies. Support groups are likely to recruit children with a range of perceptions and feelings about their sibling relationship. There may therefore be opportunity for children who feel they have to hide their negative feelings to have their feelings validated and normalised by other children who talk about their feelings more openly. Indeed, Naylor and Prescott (2004) found that in a support group for siblings of disabled children, although the siblings were initially reluctant to acknowledge negative feelings about their situation, they found a readiness to do so as the group progressed. Support groups based on the processes identified would need thoroughly evaluating in terms of outcomes. Particular attention could focus on whether indirect expressions of vulnerability lessen as children develop narratives to talk about their sibling's autism.

Fourthly, as suggested by one of the participants in the current study, further research could aim to gather perspectives and experiences of the sibling relationship from children with autism themselves. Although there would be various communication barriers to overcome, and possibly only children with less severe autism would be able to partake, this would add an extra dimension to research in this area.

Finally, the factors important for children in positively adapting to living with a sibling with autism found in this study may be evident in sibling dyads where there is another type of disability or aspect of 'difference'. Further research could investigate whether or

not the findings of the present study are unique to adaptation processes when a sibling has autism.

In conclusion, the current study has given insights into how children without autism adapt to having a sibling with autism. This exploratory study has shown that in these sibships there tends to remain a deep need for relationship despite the many challenges faced.

Several further avenues for future research are indicated which could potentially substantiate the preliminary findings and clinical implications of this study.

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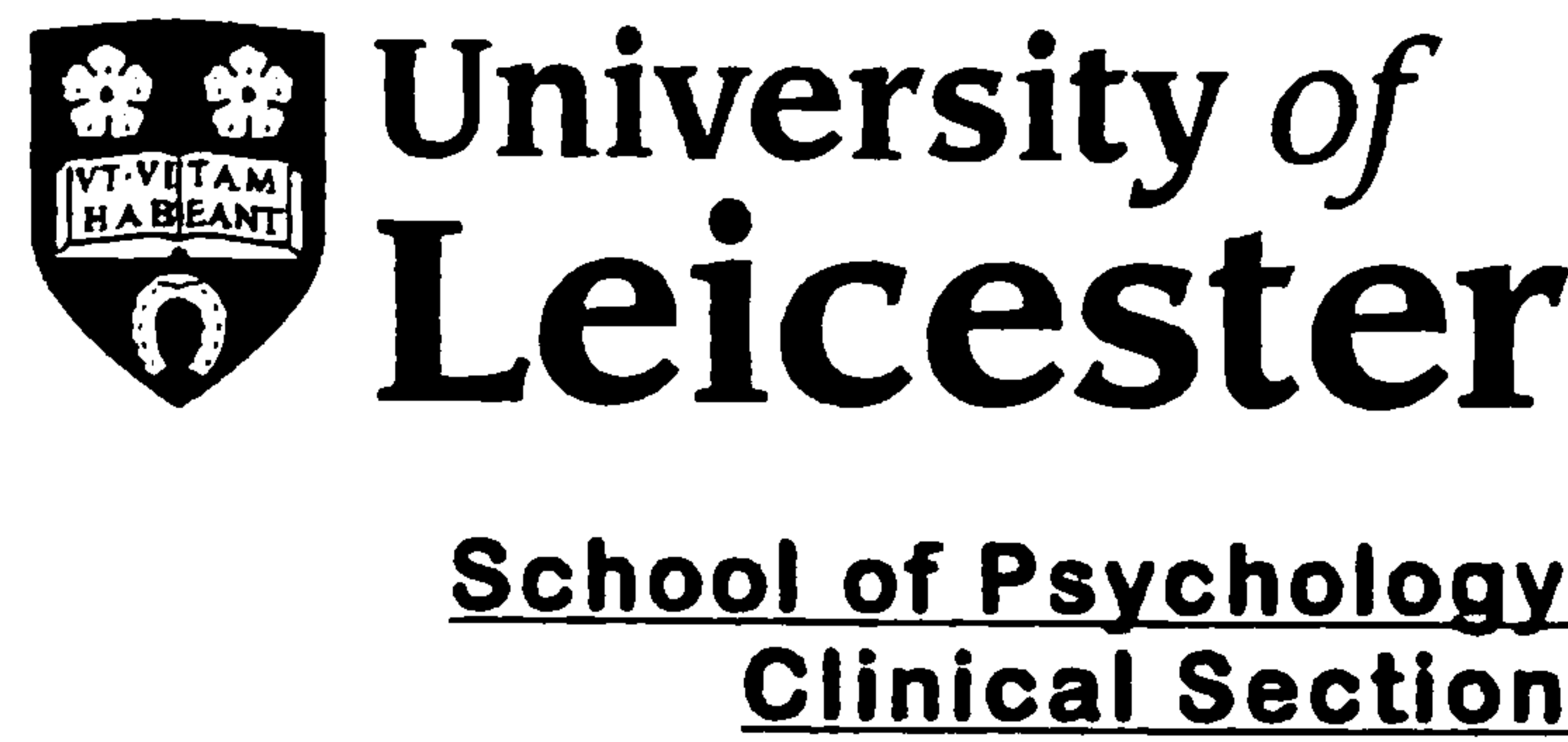
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Appendix 1 Demographic questionnaire



104 Regent Road
Leicester LE1 7LT · UK
Tel: + 44 (0) 116 223 1639
Fax: + 44 (0) 116 223 1650

Having a brother or sister with Autism:

A project looking at children’s experiences of their relationship with their sibling with autism.

Questionnaire for Parent/carer(s)

Now that you have read the information sheet and talked about the project with your child. If they have expressed an interest in taking part in the project, it would be really helpful if you could answer the following questions.

1. Could you confirm that at least one of your children has been formally diagnosed with Autism?

Yes, my child has received a formal diagnosis of autism ☐

No ☐

2. Could you confirm that your child who has Autism does NOT have any other difficulties (such as epilepsy.)

My child with Autism does NOT have any other difficulties ☐

My child has Autism has other difficulties also ☐

3. How many children do you have and what are their ages? and genders?

Please write their ages on the dotted lines and tick the correct gender box

Child one.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
Child two.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
Child three.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
Child four.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>

Child Five.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
Child Six.....	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>

Please put a P in the box next to the child who would like to take part in the project.

Please put a C in the box next to the child who has Autism.

4. Could you confirm that your child who would like to take part in the project does NOT have Autism or a history of any developmental difficulties?

My child who would like to take part does not have Autism or a history of any developmental difficulties ☐

5. Could you confirm that your child who would like to take part is aware of their siblings diagnosis of Autism

My child who would like to take part is aware of their sibling’s diagnosis of Autism ☐

6. Could you confirm that your child with Autism lives in the family home (i.e. they do not have a residential placement). ☐

7. Is your child who has Autism currently undergoing a specific treatment programme? or have they previously undergone a treatment programme
Please provide brief details below, including dates:

.....

.....

.....

.....

.....

.....

.....

.....

.....

8. Who lives in the family home and what is their relationship to each other?

.....

.....

.....

.....

.....

.....

.....

9. Are there any specific words or phrases used at home to talk about the difficulties your child with Autism has? What words does your child who would like to take part use to talk about their sibling with Autism’s difficulties? For example if you do not use the word autism, please write down the word or phrase you use instead.

.....

.....

.....

.....

.....

.....

Thank you for taking the time to complete this questionnaire. If you are unsure about any of the questions, we can discuss these when I come to see you.

Thanks again. Lucy.

Appendix 2 Child information sheet



**University of
Leicester**

School of Psychology
Clinical Section

104 Regent Road
Leicester LE1 7LT · UK
Tel: + 44 (0) 116 223 1639
Fax: + 44 (0) 116 223 1650



Can you help with my project?

Having a brother or sister with Autism:

**A project looking at children's experiences of their
relationship with their sibling with autism.**

Information sheet for participating child.

There are lots of children who have a brother or sister who has difficulties. I want to find out what it is like for children to have a brother or sister with Autism.

My name is Lucy Gillatt. I am from the University of Leicester. I am doing a project about children who have a brother or sister with autism.

I would really like to hear
your story about what it is
like having a brother or sister
who has autism.



I am going to be talking to other children like you, who have a brother or sister with autism. I am doing this because I want to know what kinds of things help brother's and sister's.

If you would like to help me with my project I will come to see you at home. I will ask you some questions about how you get on with your brother or sister and you can draw a picture. There will be a tape recorder, recording what we talk about. I will listen to the tape and write down the all the important things you have told me.

If you agree to take part, you can change your mind at any point. If for any reason you felt that you wanted to make a complaint, someone from Leicestershire Partnership NHS Trust would help you to be able to do this through the Trust complaints procedure.

Thank you very much for reading this.

I hope to hear from you soon! Lucy

Appendix 3 Parent and child consent form

CONSENT FORM FOR PARENTS/CARERS

A Project Looking at Having a Brother or Sister with Autism.

Interviewer: Lucy Gillatt. Based at: School of Psychology, Clinical Section,
University of Leicester, 104 Regent Road, Leicester, LE1 7LT

I have read the Information Sheet about this project.

☐

Myself and my son or daughter have met with Lucy Gillatt who
has explained the project. I have had the opportunity to ask questions.
I understand what my son or daughter will be required to do.

☐

I understand that the interview will be tape recorded.
I understand that the tape will be kept in a safe and
secure place and the information my child and I give
will be used for this project only.

☐

I understand that the information myself and my child
give will be treated as confidential unless
the researcher becomes concerned someone is at risk.

☐

I understand that myself and my child can change
my mind and pull out of the project at anytime, if I want
to. If I do, any information I have given can be
withdrawn from the study.

☐

I understand that taking part in this research will
not affect my child or my families care or treatment
in any way, now or in the future.

☐

I AGREE TO MY CHILD TAKING PART IN THIS PROJECT

☐

I confirm that I have explained the nature of this study,
as detailed in the Information Sheet, in terms which,
in my judgement the participant has understood.

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed, 1 for parent; 1 for researcher.



Having a brother or sister with Autism:

A project looking at children's experiences of their relationship with their sibling with autism.

CONSENT FORM FOR PARTICIPATING CHILD

Interviewer: Lucy Gillatt, Based at: School of Psychology, Clinical Section,
University of Leicester, 104 Regent Road, Leicester, LE1 7LT

I have read/had read to me, the Information Sheet about this project.

☐

I have met with Lucy Gillatt who has explained the project.

I have had the opportunity to ask questions.

I understand what I will be required to do.

☐

I understand that the interview will be tape recorded.

I understand that the tape will be kept in a safe and

secure place and the information I give will be used for this project only.

☐

I understand that the information I give will be treated as confidential unless
the researcher becomes concerned someone is at risk.

☐

I understand that I can change my mind and pull out of the project at anytime,
if I want to. If I do, any information I have given can be withdrawn from the study.

☐

I understand that taking part in this research will not affect my or my
families care or treatment in any way, now or in the future.

☐

I AGREE TO TAKING PART IN THIS PROJECT

☐

I confirm that I have explained the nature of this study,
as detailed in the Information Sheet, in terms which,
in my judgement the participant has understood.

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed, 1 for parent; 1 for child; 1 for researcher.

Appendix 4 Ethics confirmation



Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 9123344
Facsimile: 0115 9123300

17 November 2006

Miss Lucy A E Gillatt
Trainee Clinical Psychologist
University of Leicester
Department of Clinical Psychology
104, Regent Road
Leicester
LE1 7LT

Dear Miss Gillatt

Full title of study: Having a brother or sister with Autism: Children's experiences of the sibling relationship.
REC reference number: 06/Q2501/225

The Research Ethics Committee reviewed the above application at the meeting held on 03 November 2006.

It was noted that as this research will not be taking place within the NHS, and is not a clinical trial of a medicinal product for human use, it falls outside the remit of Research Ethics Committees as set out in the Governance Arrangements for NHS Research Ethics Committees (GAfREC).

However, the Committee was happy to review the ethics of the research on a voluntary basis and to offer the following opinion.

Ethical opinion

Discussions: The researcher confirmed the following:

- Researchers have been checked by the Criminal Records Bureau

The Committee gave the following advice:

1. The Committee felt that consent should be re-negotiated - to make sure the participant is happy, this could take place when the child is being interviewed
2. The Information Sheets should be re-written to clarify the following:
 - a. The wording in the parent information sheet is rather simple
 - b. The study title should be included
 - c. Researchers contact details should be included
 - d. Complaints mechanism should be included
3. Statement 1 of the Consent Form for Parents/carers should include the date and version number of the relevant information sheets
4. A Consent Form for the child to give formal Consent should be available
5. Expenses should be reimbursed

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Application		10 October 2006
Investigator CV	Field Supervisor	07 September 2006
Investigator CV	Educational Supervisor	
Investigator CV	Chief Investigator	07 September 2006
Protocol	1	07 September 2006
Peer Review		15 May 2006
Questionnaire: Parent / Carer(s)	1	07 September 2006
Participant Information Sheet: Child	1	07 September 2006
Participant Information Sheet: Parent / Carer	1	07 September 2006
Participant Consent Form: Parent / Carer	1	07 September 2006
Expression of Interest Form	1	07 September 2006
Diagram of research procedure	1	14 September 2006

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2501/225	Please quote this number on all correspondence
--------------	--

Yours sincerely


Dr Carl Edwards/Ms Linda Ellis
Chair/Co-ordinator

Enclosures:

Attendance at Committee meeting on 03 November 2006

Leicestershire Partnership **NHS**
NHS Trust

Research & Development Office
Daisy Peake Building
Towers Hospital
Gipsy Lane
Leicester
Tel: 0116-225-3743
Fax: 0116-246-3591
David.Clarke@leicspart.nhs.uk

DC/LEG/0446

23 November 2006

Miss Lucy E Gillatt
204 Bosworth Road
Measham
Swadlincote
Derbyshire
DE12 7LG

Dear Lucy

Re: Having a brother or sister with Autism: Children's experiences of the sibling relationship

Thank you for forwarding details of the above study for the consideration of the Trust Research Governance Review Group. This has now been reviewed and approved in principle, subject to confirmation of a favourable ethical opinion in due course. I am happy to confirm therefore that Leicestershire Partnership NHS Trust formally approves the study to proceed, subject to the following conditions:

- You abide by the conditions imposed by the REC
- All correspondence with the REC is routed through the Trust Research Office (including the obligatory progress/final report as detailed).
- The agreed protocol is adhered to.
- A summary of any findings is reported to the Trust/Clinical Service/Participants at the conclusion of the study.
- Any changes in the protocol, timescale etc. are notified to the R&D Office
- At the conclusion of the study, a final report form is completed.
- A copy of any subsequent publication is lodged with the Trust.
- That paperwork related to the study may be subject to audit at any time (this requires maintenance of a site file).

This letter also serves as confirmation that as Principal Investigator you are covered by the terms of the Trust's research indemnity for the duration of the project, and that the Trust is happy to confirm it's role as primary sponsor. Please sign and return the attached confirmation sheet without which Trust approval will be rescinded.

With my best wishes on the success of your study.

Regards,



Dr. Dave Clarke
Associate Director (R&D)

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 9123344
Facsimile: 0115 9123300

10 January 2007

Miss Lucy A E Gillatt
Trainee Clinical Psychologist
University of Leicester
Department of Clinical Psychology
104, Regent Road
Leicester
LE1 7LT

Dear Miss Gillatt

Full title of study: Having a brother or sister with Autism: Children's experiences of the sibling relationship.
REC reference number: 06/Q2501/225

Thank you for your letter dated 21 December 2006 confirming that you made the alterations based on the advice from the Committee

With the Committee's best wishes for the success of this project

Yours sincerely


Dr Carl Edwards/Ms Linda Ellis
Chair/Co-ordinator

Appendix 5 Parent information sheet



Can you help with my research project?

Having a brother or sister with Autism:

A project looking at children's experiences of their relationship with their sibling with autism.

Information sheet for Parents/Carers.

(Version 2, November 10th 2006: Information sheet, Expression of interest form and Consent form).

What is this project about?

This project is about exploring sibling relationships where one child has Autism and one child does not have Autism. I hope to talk to children aged between 6 and 12, who have a brother or sister aged between 4 and 16 who has Autism. I want to find out what it is like for children to have a brother or sister with Autism.

Who is doing the research?

My name is LUCY GILLATT. I am from the UNIVERSITY OF LEICESTER. If your son or daughter would like to take part, I will be the person who interviews them. If your child would like to take part I will come to talk to you and your child, so that you can ask any questions or discuss any concerns you might have about your child taking part. If after we have talked this through your child decides to take part we can arrange a day and time for the interview.

I think it is really important to find out from child sibling's about their experiences. I am very keen to hear their story. I am undertaking this project because it may help to find out about the best ways of helping siblings of children with Autism.

What will you have to do?

If you think that your child may like to take part, I would like you to complete the enclosed questionnaire about your family. The questions ask about how many children you have, their ages and how you talk to your children about Autism. Then, I would like you to talk to your child about the project using the information sheet enclosed. If your child would like to take part, I would like you to return the questionnaire and expression of interest form to me in the envelope provided. Once I

receive the information, I will contact you to arrange a date and time to come to see you and your participating child.

What will your son or daughter have to do?

I would like your child to take part in one interview. The interview will last for about 45 minutes. It is hoped that 10-12 children will be interviewed. In order to get a wide range of views ideally both boys and girls, of different ages will be interviewed.

What sort of questions will be asked?

The questions in the interview will ask about what activities your child does with their sibling with Autism, how they see their relationship and how well they interact with each other. **Whilst the experience of each child may be different, the aim of this research is to identify any common themes or issues that emerge that appear to be important to children who have a sibling with Autism.**

Where will the interview take place?

The interview will take place at your home, so that your child feels comfortable. Ideally, the interview will take place at a time when it is quiet at home.

What will happen with the information?

All the information will be confidential. However should the researcher become concerned that someone was at risk, confidentiality would be broken in order to ensure support was made available for the person at risk. Each interview will be tape recorded and transcribed, by a member of university staff. During transcription all identifiable information will be changed to ensure the anonymity of participants. All tapes and transcripts will be kept in a secure location that is locked and has restricted access. Tapes will be destroyed once they have been transcribed. All information held on computers will be password protected. Access to data will be restricted to the interviewer and supervisors of the project.

Consent for you and your child

Once you feel you have received all the information you need about the project, I will ask you and your child to sign a consent form. This means that you and your child understand what the project is about and agree to take part.

Withdrawing from the research

Your child can withdraw from the research at any point, even after you have given written consent. Any information collected at that point would then be removed from the study. **Whether your child takes part or not this will not affect any help or care your child or your family is receiving nor will it affect any help or care you may want in the future.**

What happens if your child becomes upset after the interview?

It is important to plan for every eventuality. If your child becomes upset during the interview process it will be stopped immediately and they will be able to choose whether or not to continue. I will talk to your child about their feelings and offer them a break. If the interview is stopped before the end, you and your child will be able to decide together if you want your child's interview data to still be included in the study or not.

After the research has finished...

Once everyone has been interviewed, the research will be written up and you and your child will have the opportunity to attend a feedback session. Alternatively, you may wish to receive a summary of the findings by post. The specific comments made during the interviews will be anonymised and will not be fed back to anyone. I hope that by gaining an insight into children's experiences of their relationship with their sibling with Autism will help to increase awareness of this very important area.

If you think your child may be interested in taking part...

- After you have read this sheet, if you think your child might be interested in taking part please complete the enclosed questionnaire and the following page and return them in the stamped addressed envelope provided, so that I can contact you to arrange a meeting to discuss this further.

Feel free to contact me if you would like to discuss the study or ask any questions:

Lucy Gillatt 07810 375707
laeg1@le.ac.uk

If at any point during the study yourself or your child, for any reason, felt that you were not happy with taking part in the study and wanted to make a complaint, someone from Leicestershire Partnership NHS Trust would help you to be able to do this through the Trust complaints procedure.

Thank you for taking the time to read this.
I hope to hear from you soon. Lucy.

Appendix 6 Expression of interest form

**A Project Looking at Having a Sibling with Autism.
Expression of Interest Form.**

My Name is:

My Address is:

.....

.....

.....

Tel No Date

The name of my child who would like to take part is:

Please tick the appropriate box:

My child is interested in being interviewed and would like to meet

YES ☐ NO ☐

with the researcher to discuss this in more detail.

Please contact me to arrange this by (please tick one)

TELEPHONE ☐ LETTER ☐

If you have any questions or worries about taking part, please write them down below.
This will help me to prepare for when I come and meet with you. Thank you!

Appendix 7 Interview schedules

Interview Schedule

The sibling relationship

Tell me about your brother/sister *sibling's name*

- Prompt: What is your brother/sister like?

Can you tell me a bit more about ...*sibling's name*

Could you tell me about how you get on with *sibling's name*

What do you like about *sibling's name*?

What don't you like about *sibling's name*?

Do you think *siblings name* likes you?

How would you describe yourself?

How would you describe *siblings name*?

What do you like about yourself?

What do you like about *siblings name*?

Interaction

Could you tell me what sorts of things you do with *sibling's name*?

- Prompt: What sorts of things do you like doing together?

What about your other brothers and/or sisters? Do you get on with them? What sorts of things do you like doing with them?

- Prompt: Do you get on with them?

Do you like them?

Family life

Do/does your parent/s spend a lot of time doing things for/helping *sibling's name*?

Do you go on holiday all together?

Impact of Autism and 'differentness'

Can you tell me what autism is?

- Prompt: What do you know about autism?

Can you remember when you found out that *sibling's name* has Autism?

Can you tell me about how you felt about this?

How do you feel about it now?

Do you have a best friend/some best friends?

Does *sibling's name* play with you and your friends?

What can't you and *sibling's name* do together?

Does *sibling's name* make anything difficult for you?

Does *sibling's name* ever make it difficult for you to do your schoolwork?

Does *sibling's name* ever make it difficult for you to bring friends home/have friends round (to play)?

Does *sibling's name* ever spoil your possessions?

-Prompt: computer/homework/things you have made

Does *sibling's name* help you with anything?

Is there someone you can talk to/somewhere you can go when things get difficult with *sibling's name*?

Do you have contact/know any other children who have a brother or sister with autism?

Do you go to any support groups? Attend any activities for sibling's of children with autism?

General questions

If you had three wishes for your sibling what would they be?

If you had three wishes (for you) what would they be?

Is there anything else you can tell me about how you get on with your sibling?

Would you like to ask any questions?

Revised Interview Schedule

Interviewer to elicit anecdotal accounts using open questions and follow up significant anecdotes using the prompts below:

- What do you mean by that?
- Could you tell me a bit more about that?
- Can you tell me about a time when that happened?
- How did you feel?
- What did you do next?
- What happened next?

Family

Can you tell me who is in your family? *(Interviewer to map the child's family)*

Are there any other people who are not in your family but who are important to you?

Tell me a little bit about your family *(interviewer to map relationships and ask questions about relationships between family members)*

Bene Anthony

Interviewer asks child to choose a figure for themselves and their sibling who has autism and place the 10 statements read out by the interviewer in one of the boxes or pass the statement back to the interviewer

Drawing

Interviewer invites participant to draw a picture of themselves and their sibling (older participating children may not wish to do this)

How would you describe you and *sibling's name* in the picture?

Prompt: Can you give me an example of that/tell me about a time when it was like that?

The sibling relationship

Can you tell me a bit about your brother/sister (*sibling's name*)?

Prompt: What is your brother/sister like?

Can you use 3 words to describe your brother/sister (*sibling's name*)?

How would you describe the relationship between you and *sibling's name*?

What 3 words would you use to describe your relationship?

(Interviewer to follow up each descriptor by asking for an example)

- Prompt: Can you give me an example of that/tell me about a time when it was like that?

What do you/don't you like about *sibling's name*?

Do you think *sibling's name* likes you?

What 3 words would you use to describe yourself?

What do you like about yourself?

Could you tell me what sorts of things you do with *sibling's name*?

- Prompt: What sorts of things do you like doing together?

How would you describe your relationship with your other brother(s)/sister(s)? *(Only ask if have other siblings and not already discussed)*

Do you have a good friend?

Impact of Autism and 'differentness'

Can you tell me what you know about autism?

Can you tell me about how you feel about *sibling's name* having autism?

What sorts of things do you like doing together as a family?

Prompt: Can you tell me about the last time when you all did that together?

Do you get angry or upset about your relationship with *sibling's name* sometimes OR what are the good things about your relationship with *sibling's name*?

Is there someone you can talk to/somewhere you can go if things get difficult with *sibling's name*?

General questions

If you had one wish for your sibling what would it be?

If you had one wish (for you) what would it be?

Is there anything else you can tell me about your relationship with your sibling?

Would you like to ask any questions?

Appendix 8 Example of category development trail

Interview eight – May 25th 2007

1. **Love for family**
2. **Getting on**
 - Getting on and fighting (L:35-6)
 - Getting on OK (L:207)
3. **Defining self**
 - Being naughty (L:45-7)
 - Pushing boundaries (L:49-52)
 - Helping role (L:124.139-40)
4. **Awareness of difficulties (L:346)**
 - Difficulty reading (L:124-5)
 - Knowing siblings limitations
 - Difficulty coping with feelings (L:233-5)
 - Daily struggle (L:346)
 - Anticipating future difficulties (L:405)
5. **Having fun (L:143)**
 - Pushing boundaries (L:154-8)
 - Joint activities (L:149-152)
 - Being fun (L:171)
 - Shared activity (L:73-4,218)
6. **Managing emotions**
 - Feeling annoyed
 - Feeling sad (L:375)
 - Feeling angry (L:371)
 - Getting upset (L:385-6)
 - Talking through emotions
7. **On his terms**
 - Being self-centred (L:144-5,192-4)
8. **Good and bad relationship/Annoying and fun (L: 163-4)**
 - Nice to be with (L:146)
 - Fun relationship (L:203-5)
 - Extremes of feeling (L:246)
 - Same sibling relationship (L:295-6)
9. **Empathising with sibling**
 - Feeling sorry about autism (L:164-7)
10. **Managing behaviour**
 - Distracting from homework (L:170-1)
 - Changing behaviour (L:173-7,240-1)
11. **Difficult behaviour**
 - Lack of awareness (L:189-95)
 - Needing intervention (L:251-3)
 - Being blamed (L:249)
 - Aggressive behaviour (L:371)
12. **Making allowances**
 - Learning lessons (L:222-3)

- 13. Loving relationship**
Comforting sibling (L:234-5)
- 14. Focusing on the positives**
Being playful (L:240-2)
Being calm (L:240-2)
- 15. Changing relationship**
Playing less games (L:289-90)
- 16. Importance of friends**
- 17. Acceptance**
Needing to accept autism (L:3329-30,379)
Accepting self (L:333-4)
Positive and negative (L:328)
Permanence of autism (L:329)
Happened for a reason (L:340-4)
Specialness of having autism (L:340-3)
- 18. Impact on family** (L:377)
- 19. Seeking support** (L:396)
- 20. Wishing autism away** (L:405)

Interview Nine – May 27th 2007

- 1. Recognising autism** (L:5-8,21-22)
- 2. Holding onto the positives**
Significant moment (L:451-2) Linked to underleaf
Change from usual behaviour
Responding to intervention
Recognising strengths (L:678-9,718-20)
- 3. Missing out**
Friendships filling the gaps
Appreciating similarities with friends (L:582-3)
Missing family activities (L:706)
- 4. Mixed feelings/mixed relationship**
Sometimes getting on (L:87-8)
Sometimes annoying
Wishing sibling away (L:434-7)
Nice relationship (L:440-1)
OK relationship (L:440)
Having fun
Enjoying being helped (L:498)
Loving relationship (L:535)
- 5. Role as sibling**
Helping sibling (L:94-5)
Helping others
Being needed
- 6. Coping day to day**
Invading space (L:109-112)

Annoying but manageable (L:399)
Adapting interactions (L:468-72,502-4)
Brunt of behaviour (L:644)
Avoiding getting hurt (L:632-3)
Coping alone (L:751-2)
Distracting self (L:751-2)
Unmet needs (L:157-9)

7. Managing emotions

Feeling fed up (L:114)
Playing down feelings
Blurting out emotions (L:547-51)
Feeling rejected

8. Lacking reciprocity

Being nice (L:226,205-6)
Physical affection (L:178-80)
Empathy,play,insight,understanding social situations,awareness

9. Challenge of behaviour

Lacking awareness
Hurting others (L:182-4)
Difficulty coping with losing (L:184-8)
Blaming others (L:184-8)
Exceptions to behaviour (L:228-9)
Taking possessions (L:406-8)
Putting up with it

10. Seeking to understand

Versus sibling lacking empathy (L:188-90,415)
Misunderstanding social situations (L:799-804)

11. Knowing sibling

Awareness of likes

12. Making comparisons/awareness of difference

Different priorities (L:378-80)

13. On his terms

Affection (L:517-20)
Giving permission (L:427-8)

14. Self in relationship to sibling

Comparing skills (L:405-1)
Positive view of self (L:592-3)

15. Wishing autism away (L:791-2)

Keeping the useful parts (L:791-5)
Positives and negatives of autism

Appendix 9 Transcript conventions

Transcript conventions

The following list details the conventions used in transcription of the following sixteen interviews. There are three transcripts of pilot interviews and thirteen transcripts of interviews proper.

Capital letters denote words said by the researcher

Lower case letters denote words said by the participant

/ denotes an interruption.

A pause of longer than three seconds is denoted by (.)

A pause of less than three seconds is denoted by a comma

Words said in quick succession have not been punctuated

(can't hear) denotes inaudible words or inaudible parts of the interview recording

Interruptions from individuals are denoted in italics

If the ending of the tape disrupts the interview, this has been noted in brackets

Any other details such as coughing have also been placed in brackets

All identifying details have been changed

Appendix 10 Additional supporting quotes

Appendix of supporting quotes

Main category one: Seeking Understanding

“Oh well I know they can't really control their anger and things like that and ... they've got problems in their comm- communication skills and ... they don't really erm they don't really understand things sometimes and that's sort of it”. (I5, Kay: 302-305)

“When he's running around the house, stealing my football running around the house with it and making me get a little bit frustrated at him and when he steals the football from outside and runs inside when he can't knows he can't win ... But I know I understand that 'cause I know about he can't like it's like he tries it hard- he finds it hard to know why he can't win that's why”. (I3, Phillip: 98-103)

Sub-category: Understanding Autism

“Erm just know that erm there's a large amount of autism and there's erm there's well there's he he well Brian's actually hasn't got that much autism but he still needs the benefit and there's other people who/ he's minor autistic/ yeah erm and there's other people who needs much more erm benefit than him”. (I12, Joe & Sarah: 817-821)

Sub-category: Understanding and Knowing Sibling

“after he took my Yasmin doll ... he was just looking at me like no I haven't got it but I knew there was something ... I knew he was up to something”. (I2, Sophie: 489-491)

Lower level sub-category: Analysing Behaviour

“Erm what Anna does she like bangs her head on the wall when she's cross but it she acts really weird I can't really describe it ... Um Anna will touch stinging nettles and she'll start crying and then she'll keep touching them over and over again she likes the feel of pain”. (I7, Olivia: 196 – 200)

“well he find it hard to make friends but once he got he gets friends he tries he finds a little bit hard to stick to 'em ... because he sometimes starts on 'em and doesn't realise it and he doesn't realise why they go and that's how he gets angry”. (I3, Phillip: 74 – 78)

“I know about Robert he likes he likes eating the same thing all the time and he doesn't like it when things break that's the main reason why he stopped eating bananas ... because it 'cause it broke and fell on the floor and that's the main reason why he didn't he doesn't eat them because it broke”. (I8, Milly: 601-606)

“And we don’t know whether it’s the texture he doesn’t like or what it feels like in his mouth”. (I1, Lucy: 156-157)

“...It’s what’s meant to happen for him ‘cause the world goes round ‘em so really I reckon they feel like like it should have gone their way ‘cause they feel like they’re in full charge”. (I3, Phillip: 325–336)

“It’s ok for for Gemma just thinks that he is a very annoying little boy because she has an older brother and a little brother um and Billy annoys her not as much as Edward”. (I1, Lucy: 553–555)

“stuff he acts more like a five year old than his ago so ...and five year olds are crazy and stuff at times and when they get angry they can be quite physical so because of his strength we do really struggle at that ...And even though he acts like a five year ago he talks like a fourteen year old or fifteen year old a teenager”. (I13, Sarah & Joe: 535-540)

“Yeah he’s he just ‘cause most thirteen year old brothers kind of tease their younger sisters ‘cause like they don’t like care about them sometimes but having an autistic brother it it seems much it seems like well he’s always there for you and like just thirteen year old brothers they they’re a bit mean to their younger sisters ...but Callum he’s never mean to me and he’s always like he’s like (.) if I treat him like a servant he probably wouldn’t mind”. (I4, Christina : 429-435)

“He walks around on his own a lot... he finds it hard to make friends” (I3, Phillip: 25-27).

“... and not to hurt people when they’re being rude to him or when he thinks they’re being rude to him ‘cause he thought there’s someone called Jadine in his class was being rude to him but she was actually she was actually being rude to somebody else”. (I8, Milly: 725-728)

Lower level sub-category: Awareness of Difficulties

“He’s erm (.) well he gets on most well my da- he gets on mostly with other people who he doesn’t really know and he isn’t confident with and he erm doesn’t normally get on with other people. He prefers playing with one person than a big group of friends”. (I5, Kay: 114-116).

“he gets a bit like upset and like goes a bit funny when he can’t win the game and stuff so he has to win”. (I3, Phillip: 64-5)

“he also gets um mardy if um ‘cause um the infant school they do milk or water or they do fruit um that’s at break time and he gets if there’s not milk he gets really mardy”. (I11, Naomi: 73-75)

“he doesn’t like to share it takes a lot he’s a lot better than he was but he’s still gets in a big paddy if he has to share, he doesn’t want to share”. (I1, Lucy: 142-143).

“And if he isn’t back in time for Pingu he will get very annoyed”. (I1, Lucy: 323)

Sub-category: Disclosing Diagnosis

“They they know about Edward and they’re interested to know how he’s getting on and you know we go to see them regularly and then there’s Auntie Sandy and Uncle Tony they don’t know about Edward but they know there’s something wrong” (I1, Lucy: 98-101).

They all know that there’s something different about him, about the way he behaves but I’m not sure if they know it’s autism or not” (I1, Lucy: 131-132)

“and Katie just knows that there’s something wrong but she doesn’t question it because she knows that I don’t like it”. (I1, Lucy: 556-557)

“I do find it I find it annoying sometimes when my mates ‘cause I have ‘cause we have to tell our mates and stuff about his autistic and stuff and some of ‘em don’t really understand that much and I can find them really annoying at times ... most of ‘em are really good”. (I12, Joe: 884-891)

Sub-category: Personal Impact

“he sang and he did it in front of the whole school and parents and things ... but the boy who was Macbeth didn’t really have didn’t really want to sing but Callum chose to do it”. (I4, Christina: 92-103).

“I mean before like he was like on my team at football and look at this over here (.) [showing trophy to interviewer] ... I let him in the team [interviewer reading details on trophy] Yeah we scrimmaged ‘em”. (I3, Phillip: 196-201).

Main category two: Balancing the Imbalance

“You have to be understanding of him and like you have to try and just like progress that little bit more in holding your temper than you normally do with normal like with kids with like conditions like that”. (I3, Phillip: 285-287)

Sub-category: The challenge of behaviour

“Then he went on about it a bit too much he over does it he doesn’t know when to say stop when you say stop you mean stop so...”. (I1, Lucy: 637-639)

“Olwen keeps on pulling my hair”. (I6, Noelle: 3-4)

“he kicks me”. (I9, Mia: 351)

“he just will not shut up only when he watching telly or playing on his Play Station”. (I11, Naomi: 112-113)

“when we have to do the dishes he’s always singing and I always have to tell him to shut up”. (I11, Naomi: 78-79)

“if like someone annoys him he tries to hurt people”. (I11, Naomi: 48-9)

“he whenever he doesn’t come first he hurts me he hurts everyone he hurts the people who comes first”. (I8, Milly: 169-170)

“he likes hurting people and things”. (I5, Kay: 195-196)

“he does like it but he doesn’t want to eat it”. (I1, Lucy: 153-154)

“he’s gone on this little starve thing and he doesn’t eat much any more and he doesn’t eat anything at school because he doesn’t like he just doesn’t want to and he doesn’t eat much at home”. (I5, Kay: 97-99)

“he can get cross about some things that other people wouldn’t get cross about”. (I4, Christina: 211-212)

“he can be really embarrassing because he has autis- autism”. (I4, Christina: 455)

“... he used to when he just he didn’t care who it was though he usually knew them and he’d just go up to them and kiss them ... Yeah ‘cause you wouldn’t just go up to someone and kiss them (laughing) but he just he’s only do it at school which was good”. (I13, Nathan: 69-73)

Sub-category: Defining Sibling Role

“Um when he gets upset, he really gets upset but that’s basically it ... Yeah but you’ve just got to say “Like Jacob we’ll go on the Xbox or something together” we’ll go on multi-player or something like that and he starts to cool down, he won’t cool down straight away as soon as you say something like that but then it will make it a bit easier then if you do the thing that you said you’d do then he’ll be a lot happier”. (I13, Nathan: 106-113)

“when people were like bully him he gets me he used to get me to go up to ‘em like he used he used to like ask me to like help him and stuff and I did ... Yeah I sort ‘em out”. (I3, Phillip: 103-109)

“Riley and Brian got into a fight once and it was quite like Joe had to hold Brian back I had to hold Riley back and I couldn’t hold Riley back because of how boisterous he was it was like that he had to get him in like a headlock or something just to hold him back”. (I12, Sarah: 999-1009)

Sub-category: Making Allowances

“he gets just a little bit confused sometimes”. (I3, Phillip: 85)

“I I I fell out with my a friend of mine who’s not my friend any more ‘cause he said rea- something really, really nasty about Brian”. (I12, Sarah: 945-946)

“I’m good at making new games up that he’ll enjoy”. (I13, Nathan: 126)

“Because you’ve, you’ve stayed there for a day and the next day it’s gone, everything you’ve taught him the day before so there’s live mode ... and I say ok Edward go to live mode “can’t remember where it is”. It takes so long. It’s taken ages for him just to learn how to hover over the bars and that shows you what their mood is and what they need for you so ... yeah but he likes it so much you see”. (I1, Lucy: 248-254)

“he had actually let me join in”. (I10, Saskia: 412)

“One time in English at my old school we were doing there was this thing written by an autistic child he was a child then but he’s an adult now, they found it funny because he said I couldn’t hear them even though they were shouting they found it funny I found that extremely horrible because I knew it wasn’t his fault and I I I really hated it”. (I1, Lucy: 559-563).

Main category two: Maintaining Relationship

Sub-category: Defining Relationship

“It’s ok it’s quite good um quite bad (laughs) it can it’s like is this person nice to me? They can be nice they can’t be nice it’s the same we’ve got a family relationship just a steady relationship we can live with each other but we can still feel like we could kill each other as well at the same time ... But also we can feel really happy as well so it’s up and down”. (I1, Lucy: 628-633)

“He can be nice and he can be very annoying”. (I1, Lucy: 310-311)

“Well she’s kind at times”. (I6, Noelle: 339)

“... mostly playing together and we’re mostly happy sometimes fight and sometimes upset and we’re both angry at each other sometimes”. (I2, Sophie: 481-482)

“Very inquisitive erm it can be bad sometimes but most of the times it’s good erm being able to play with him and have good fun with him”. (I12, Joe: 501-502)

“Brian and me just get on just get on really really well but he can be annoying at times. Erm well I don’t think sometimes it’s quite good like at the moment how he’s friends with me and other times it’s not very good”. (I12, Riley: 458-461)

“Erm well sometimes quite well and sometimes not very well at all”. (I6, Noelle, 177)

“He’s sometimes nice “. (I5, Kay: 77)

“Well sometimes he’s nice and sometimes he’s weird and horrible and hurts other peoples feelings sometimes”. (I11, Naomi: 103-104)

“Fun, um also annoying and bad tempered”. (I11, Naomi:112)

“he’s a bit nice sometimes. He can swear but I don’t really mind that because er when I’ve gone glum or anything he comes to help me or something or play with me and when I’m bored”. (I10, Saskia: 345-47)

“The thing I like about Anna ‘cause she can be really playful and lovely to me the bad things are she throws, she pulls, she spits”. (I7, Olivia: 107-108)

“Well annoying, erm (.) erm annoying and (.) he’s sometimes nice (.)”. (I8, Milly: 371-372).

“He does love me but sometimes not like me”. (I10, Saskia: 478)

“Nice kind person, brilliant brother ... great brother I’m close to him as a brother most of the time he’s not really that much angry at me he loses it a bit sometimes but he gets just a little bit confused sometimes but I know that it’s hard for him so really he’s just like a brilliant brother”. (I3, Phillip: 83-86)

“we don’t really often but we sometimes have some and erm if we do erm he’ll come into my room and he’ll say sorry and he’ll say like take this in my room I don’t want to fall out with you because you’re the best sister in the world”. (I4, Christina: 324-327)

“Just like a little but like three quarters of the way like to nearly perfect like just nearly to perfect a little bit shaky in some areas but nearly to perfect and like it’s just like a bit most of the time it’s quite nice relationship and it’s like he’s always like nice to me and I’m always nice to him because I mean like it’s just like a good relationship really”. (I3, Phillip: 122–126)

"older brothers they're kind of they sometimes tease their younger brothers or sisters but with Callum it seems like he cares a bit more and well he's not like them because he thinks that it's mean and he doesn't want to be mean really to me or Julian so he's always doing what me or erm Julian erm kind of says". (I4, Christina: 621-624)

Sub-category: Managing Emotions

"Very very cross with her". (I6, Noelle: 182)

"Well I wouldn't say angry I would say I get I would say I cry a lot not really angry I wouldn't say that way". (I9, Mia: 365-366)

"sometimes he makes me cry". (I2, Sophie: 359)

"Annoying, frustrating and annoying frustrating and erm (.) complicated". (I5, Kay: 141)

"Erm (.) well I'm sometimes fed up with Robert". (I8, Milly:102)

"sometimes he can be so so embarrassing that's probably worst thing about him ... he can be really really embarrassing sometimes but normally he's not really embarrassing". (I4, Christina:382-385)

"When er er we were playing on the play station together it was like playing football like right near the end of it three quarters of the way through and I was winning (can't hear) he turned it off because he didn't wanna to lose ... After nearly a full ninety minutes ... shaky ... Bit annoying". (I3, Phillip: 131-143).

"Today he's being annoying but not to the extent where I completely lose it so I can just live with it but I'll feel slightly annoyed". (I1, Lucy: 658-660)

"Erm well I've got a godmother ... and she's really nice to me and if there's something wrong I tell her". (I2, Sophie, 50-52)

"I've said to mum the other week oh I told her all of this and erm erm and dad and they said OK and we don't try to treat treat him any better than you and if we are just tell us again". (I4, Christina: 481-483)

"I can be very hot headed with Edward I can burst out at mum and dad if you know say I've had a bad day at school Edward has been a pain on the way home my homework isn't going right and I've also got a violin lesson tomorrow and I've got to practise but it's time to go to bed and their telling me to go to bed but I've still got work to do...I can just lash out and I'll regret it later bit I just feel so cross with him I can be hot headed as well". (I1, Lucy: 695-702)

Sub-category: Holding onto the Positives

"I like it when he tells jokes 'cause his jokes are really funny. And he's quite kind". (I11, Naomi:144).

"because he's very good at that he is very good at speaking clearly, very good at acting, doesn't mind being the centre of attention he likes it". (I1, Lucy: 167-168)

"And it was really good 'cause I got to hold Anna's hand while we were in with the dolphins and all that". (I5, Olivia: 254-255)

"Well she once, yesterday we went to the doctors and she held my hand". (I6, Noelle: 184)

"we arrived at this farm park we bought some food what we did I fed a lamb and Anna we put some on Anna's hand she sniffed it and nearly ate it but we put her hand underneath the lamb and the lamb ate it and I was like Anna you just fed a lamb ... and that was like really good". (I5, Olivia: 282-287).

"at school because in assembly he'll walk by and I'll just be sitting down and he'll just stop the whole line and just wave at me and that's quite happy". (I13, Nathan: 86-87)

"my doctor was really worried about me he thought I was going to have to have an operation...he really did try to be good then and he really did he really did love me then that's one of the times he was kind". (I1, Lucy: 651-565)

"Well he's very, he's quite cool and he won't spoil your games or anything like that he only he just comes up to me in the playground at school where I'm playing with all my friends and just say hello to all my friends and say hello to me and just say what we're going to do when we get home and then he goes off and does his own stuff". (I13, Nathan: 40-43)

"Um sometimes it feels upsetting 'cause he upsets me and sometimes most of the time I like it when he has autism 'cause he's always playing with someone and erm most times it's me and in the summer he always asks me first if I want to play with him 'cause erm I what I've been thinking is that it's the brunt of his behaviour of their behaviour is always the person they like to play with the most". (I2, Sophie: 587-591)

Lower level sub-category: Sharing Activities and Having Fun

"So and we'd play games like lion fights which it's not really fighting really hard it's just like play fighting and he enjoys that and we play lots of things really we just play on the Xbox and play games yeah". (I13, Nathan: 152-154)

“well sometimes we play with the Frisbee he and a friend and erm sometimes play football sometimes play on our bikes”. (I2, Sophie: 228-229)

“He’s always played with me in primary schools. He likes playing with me”. (I3, Phillip: 220)

“the thing I play with Ethan usually is erm is a game called Kerby when one person goes in one side of the road and I go on the other ... we have to try and throw the ball to make it hit the kerb and bounce back at you”. (I2, Sophie: 245-249)

Sub-category: Coping Day to Day and Adapting Over Time

“It’s hard but I cope with it”. (I3, Phillip: 70-71)

it’s quite hard ‘cause he’s got autism but you get used to it after a while”. (I12, Sarah: 845-846)

Main category four: Indirect Expressions of Vulnerability

Sub-category: Stories of loss and Disappointment

“‘Cause Sugar died because she died of sickness ... she she had black coat around her and because she died we had a McDonald’s but I didn’t eat it because I was too sad and then we went to a disco but none of us would dance and then we had some sweets but none of us ate ‘em ... mum actually had to watch her die ... so did dad but we was at school when it happened ... She had to get electrocuted and died”. (I10, Saskia: 25-35)

“because they are getting older they like to escape to places because their whole lives they have been stuck in those two rooms”. (I1, Lucy: 452–454)

“when I’ve got a tidy room she messes it up”. (I6, Noelle: 4)

Sub-category: Sense of Fragility

“when he grows up he doesn’t have a difficult life like people winding him up and getting to him and him hitting them ... and I wouldn’t like that I think he would die”. (I2, Sophie: 625–629)

“once they get into a fight one of ‘em’s one of them’s gonna one of these days one of them’s gonna have to go end up going into hospital”. (I12, Sarah: 1006-1008)

“I get there’s this girl that picks on me at school ... I’ve got a hospital appointment some time about how I feel (can’t hear) ... Yeah I’ve basically been getting bullied for nearly three years now and when I have like a bad day at

school and come and get my first steps at home and then I have mostly a bad time at home so I just go and lock myself in my bedroom". (I5, Olivia: 118-124)

Sub-category: Wishing Autism Away

"I suppose it's a mixture of him not having autism and at the same time still having it because it's part of him and it's what makes him so good at some things". (I1, Lucy: 802-803)

Main category five: Missing Out

Sub-category: Perceived Unfairness

"I wish that sometimes I could just go out on my own with my friends and obviously mum and dad would worry but they'd it one of the problems is not that they don't trust me but 'cause of Edward would want to but they can't let him out on his own". (I1, Lucy: 812-815)

"I didn't get to spend much time with mum and dad on my own without Edward". (I1, Lucy: 792-794)

Sub-category: Relationship out of Reach

"Play on Play Station erm (.) oh (.) you mean like recently or for like? oh sometimes I do this sort of like Lego and things like that but then and I don't build them with him any more because it makes a mess and I always have to end up tidy it up we some well I don't I can't think of anything". (I5, Kay: 279-282)

Part 3

Critical Appraisal

1.0 Critical appraisal

1.1 Origins of the study

The idea for this research project arose from my previous clinical experience, special interests and personal experiences of family relationships. My special interest in learning disabilities and communication disorders has led me to work with children, young people and adults with autistic spectrum disorders and their families over several years. Through this, I developed an interest in the impact of autism on family relationships and a curiosity about the impact of overcoming communication barriers within relationships. In deciding upon a research topic, I was keen to learn more about how children perceive and adapt to 'difference' and disability and cope with potentially challenging relationships. My choice of project was also influenced by my strong belief that children's voices, often missing from research, should be heard.

Reflection on my personal experiences of conflict in and the dynamics of family relationships and also the positive impact of my own sibling relationship influenced my area of study. Re-examining my undergraduate dissertation, which considered father-daughter relationships, I am struck by how both projects evolved to explore family relationships, a connection I only became aware of upon revisiting my dissertation when writing up the current study. This highlights a personal emphasis on the importance of quality in relationships, which fuels my clinical interest in family relationships and led to the development of the current research project. My approach to clinical practice is also

influenced in this way, with psychoanalytic ideas used to inform my understanding of the therapeutic relationship, which I feel often impacts upon outcomes of therapeutic intervention.

1.2 Early stages of the research process

In preparation for conducting the study, a brief literature review was undertaken to inform and provide understanding of existing research in the area and to develop an initial research proposal. This confirmed my interest in the impact of autism on families. I felt that exploring children's experiences of their relationship with their sibling with autism qualitatively, would bridge some of the gaps in previous research. The potential clinical usefulness and feasibility of the study in terms of the likelihood of being able to recruit participants was confirmed, through consultation with clinicians in the field. These discussions motivated me to consider the most appropriate ways of conducting research with children.

A more comprehensive literature review was delayed until data analysis was complete, in order for emergent theories to be grounded in the sibling's accounts rather than influenced by previous research findings as recommended by proponents of grounded theory methodology. I was keen to demonstrate fidelity to the model by postponing the literature review, even though it felt daunting as I tend to prefer working in a sequential way; writing up parts of academic assignments in order. However, I did enjoy the challenge of working in a different way. As the initial literature review was carried out in

my first year of training, I felt that the findings of previous research were not at the forefront of my mind as I embarked upon the study.

Grounded theory methodology based on that of Charmaz (2006), was chosen for a number of reasons. The literature review had highlighted a dearth of studies exploring the perspectives of child siblings on their relationship with their sibling with autism; hence an exploratory approach was thought to be appropriate. Grounded theory was used at undergraduate level, and suited my analytical view of research. I was conscious of the time constraints of carrying out a doctoral level research project whilst undertaking other academic assignments and being on placement, and as such I was keen to choose a methodology which I had some experience of. I envisaged that Grounded theory would provide a meaningful way of constructing children's perceptions of their relationships with their siblings with autism and add an extra dimension to, and expand upon theories on the impact of a having such a sibling.

In defining and operationalising my research proposal, although I had originally hoped to interview children of all ages, I was advised by clinician's in the field to limit the age range of my sample, based on assumptions that children of different ages and developmental stages would have very different experiences of the sibling relationship and different concerns. I felt resistant to this as I thought that there would be commonalities in the children's experiences. However, as an inexperienced researcher I felt that I should heed this advice in order to seek to make the results of the study more manageable, whilst remembering the exploratory nature of the study. Furthermore, I was

advised to develop a 'Plan B' in case I was unable to recruit enough participants; triangulation using interviews with parents was suggested. By this stage I felt determined to achieve my research sample and committed to putting across the opinions of child siblings who had been overlooked by previous research studies. I was surprised that I had cast myself in the role of advocate at this early stage. My experience of working with people with learning disabilities had taught me that there is often an additional and integral role of advocate when working with vulnerable individuals. On reflection I felt that this is likely to be the case for all individuals in a less powerful position, in this case, children. I decided to step back from my apparent attachment to my study and reflected upon my perhaps unrealistic optimism. It was helpful to anticipate potential difficulties in order to prepare for them.

At this point I felt that decisions needed to be made upon an epistemological standpoint, however research supervision encouraged me to delay this until data had been gathered and to let the data direct an appropriate stance. The children seemed to use the interviews to construct their perspectives on the sibling relationship and perhaps as a process to develop narratives about that relationship. An affinity is felt with constructionist perspectives, as they place value on the experiences and perspectives of individual's.

1.3 Achieving the sample

Achieving the sample presented the first unanticipated challenge to conducting the study, as I had been over-optimistic in estimating how many support groups would need to be

approached. At this stage it was extremely helpful to discuss experiences of recruitment with fellow trainees' in the Qualitative Support Group. Feedback indicated that small numbers of participants tended to be recruited from each support group, which motivated me to begin networking. Information packs were sent out and I attended several support groups to present my research. Indeed, only a few participants came forward from each group and I became concerned that I would not achieve my sample in time.

An alternative recruitment strategy of advertising in a newsletter for families of children with autism was instigated. As 'Link-Up' is distributed quarterly, unfortunately the first advert was placed just before Christmas, perhaps the busiest time of year for families, even more so for families including a child with autism (as changes to routine can be problematic). A limited response was received and it was necessary to wait a further three months for the second advert to be published. After I had undertaken eight interviews, several families came forward, all of whom were very keen to partake. I felt that I could not turn them away, possibly as I was so keen to hear their stories due to enjoying the previous interviews. Further families came forward after data collection was complete. This highlights a difficulty in carrying out research with children who are part of families who lead very busy lives, as research studies are likely to have time limited data collection periods, indicating systemic limitations in involving children in research.

1.4 Data collection

Prior to carrying out the initial pilot interviews, thought was given to how my clinical training and experience, particularly in conducting assessment interviews, would impact upon my research interviews. I was aware that complete removal of my clinical psychologist 'hat' would not be possible, and that distressing stories could be heard. I anticipated that I would feel 'helpless' to offer help or support. This caused some anxiety. Reflecting on my responses to the youngest participant Noelle, I tended to refrain from asking follow up questions in response to descriptions of having been physically hurt by her younger sibling. During interviews such as this, tension was experienced between the demands of the roles of researcher and clinical psychologist (Grafanaki, 1996). It felt uncomfortable to hear such distress and not respond as I would in a clinical situation. I feel that I made attempts to compensate for being unable to intervene by emphasising the positives of their relationships at the end of the interviews and signposting to support, perhaps stepping out of the 'neutral' researcher role.

Anxiety was also felt following completion of the pilot study, as the interviews had not generated rich accounts of the sibling relationship. The children's responses were limited and the interviews relatively short. My anxieties were allayed by the successful revisions of the interview schedule apparent upon carrying out the interviews proper. The revised schedule maximised children's natural storytelling abilities. This process highlighted the complexities involved in interviewing children and the potential benefits of carrying out

pilot interviews in order to refine and maximise the effectiveness of interviews in eliciting rich data.

Carrying out the interviews was perhaps the most enjoyable stage of the research process. I thoroughly enjoyed meeting and interviewing each participant and particularly enjoyed hearing their imaginative descriptions of autism. I was impressed by their resilience and capacity to put so much energy into their relationship with their sibling no matter how challenging maintaining the relationship proved to be. I was overwhelmed by the families' keenness to help with my project, many parents and children expressed that they wished to take part so that the research would help other families with children with autism. All participating children were willing to talk and appeared to give faithful, honest accounts of their sibling relationship.

I was impressed by the warm welcome offered to me by all the families and the fact that they gave up their time so willingly despite busy schedules. The positive responses I received from the children and their families proved to be key in maintaining my motivation through what was an enjoyable yet time consuming and at times emotionally demanding process.

1.5 Data analysis

Reflecting on the data analysis stage of the research process, I realise that I was over optimistic in my estimations of how long this would take. There were several barriers to

effectively and efficiently beginning the analysis, which lengthened the process. Firstly as the interviews tended to take place quite soon after each other, thorough analysis did not take place in between each interview. Secondly, I found it difficult to say no to participants who were keen to be interviewed resulting in a large amount of interview data, which I initially felt overwhelmed by. Thirdly, although grounded theory had been used before, this was six years previous, causing significant time to be spent re-familiarising myself with the method. Finally, I felt concerned about getting the analysis 'right' and doing justice to the children's accounts. Research supervision was particularly helpful in giving me the courage to immerse myself in the data and commence coding.

Despite, the analysis being a pain-staking process, a great sense of achievement was felt once all the transcripts were coded and it was exciting to see emerging themes in the data. I felt satisfied that I had remained close to the sense of the speaker by giving equal attention to all transcripts and utilising my reflective diary. The emergence of 'Indirect Expressions of Negativity' indicated the effectiveness of my interviewing skills in identifying aspects of the sibling relationship absent from previous research studies.

1.6 Developing the model

Developing the theoretical account and model presented challenges, as limited time was available to let go of the analysis and my attachment to and sense of responsibility for representing the participants' perspectives. Consequently the step from analysis to the development of the model felt like a large leap. This could explain the emergence of a

simplistic initial model; a model which essentially did not include the negative aspects of the relationship expressed by some of the children. Again, this could have been due to my difficulty in acknowledging the negative impact expressed by the children due to the limitations of my role as researcher as discussed previously. In my defense, expressions of negativity did tend to be subtle and were inferred from stories of loss and disappointment. The children may have struggled to articulate their negative feelings (Stiles, 1993) in a direct way. It is possible that I initially, subconsciously, prevented the negative aspects of the sibling relationships being represented in the model reflecting the children's feelings of needing to block out their negative feelings in order to have a relationship with their sibling.

The new revised model captured the rich detail of the data and it seemed that the subtleties and complexities of the sibling relationship had been addressed through the chosen methodology (Denscombe, 2003). I was struck by the psychodynamic focus of the final model, in terms of the children using several defences against having negative feelings towards their sibling and their situation, feelings which are potentially unbearable due to their 'Deep Need for Relationship' with their sibling.

1.7 Dissemination of findings

I am committed to disseminating the findings of the study in the way that will help children who have a sibling with autism. I hope that siblings of children with autism will benefit from their families' consideration of the study and clinicians working with

families of children with autism will incorporate the results of the analysis into their clinical practice. I am keen to provide feedback directly to the children and families who partook in the study, through an information sheet summarising the findings. I feel I have an ethical obligation to do so and hope that this will be a suitable way of thanking the families involved for their time, effort and enthusiasm. I hope that relaying the results back to the participants will allow for catalytic validity, which refers to the potential for research processes to reorient, focus and energise participants; producing positive change and empowerment through hearing their experiences being described (Guba & Lincoln, 1989). I also hope to return to the support groups that assisted with recruitment to feedback the findings. I will be submitting a paper on the sibling relationship where one child has autism to be considered for publication in a relevant journal as soon as possible following completion, and would hope to send copies of the published article to the participants. This will give me a sense of great satisfaction and hopefully empower the participants further. In addition, I have been invited to include my findings in the 'Link-Up' newsletter.

1.8 The research journey and the supervisory process

The research journey was challenging and involved mixed emotions ranging from fear, when I seemed to lose my way, to elation, when something fell into place. Whilst planning how the study was to be conducted and recorded, I sought to consider: my tendency to be over optimistic with the time, my thoroughness, my difficulties in committing pen to paper and my need for deadlines, based on reflecting on previous

academic assignments. It was helpful to discuss the above in research supervision and anticipate potential problems in completing the current study. Setting regular deadlines with my research supervisor encouraged me to break the research process into smaller, more manageable stages making the process less daunting. My progress was slower than anticipated, which felt frustrating at times. I was able to seek support from my peers when the process became difficult, furthermore accessing the Qualitative Support Group provided a sounding board for any worries, queries or concerns.

Supervision facilitated the laying bare of all aspects of the research process, fathoming out and incorporating any nuances in the data. Supervision was particularly useful in the later stages of writing up the research, the stage I struggled with the most. I found my research supervisor invaluable in maintaining my motivation, providing helpful advice and guidance and in creatively helping me to plan the write up. I did not experience any barriers to supervision and found the supervisory relationship to be supportive and containing.

1.9 Ensuring quality in qualitative research

I felt that the purpose of the study was to develop valid and grounded theory that speaks to the issues and concerns of those studied (Strauss & Corbin, 1998) and felt it important to preserve the diverse perspectives of the participants; giving a fuller understanding of the phenomenon of having a sibling with autism (Madill et al., 2000). It was felt that using triangulation with data from other sources would undermine the value of the

children's perspectives and their accounts of the sibling relationship. I hoped that 'grounding' of the study was evident without this quality check. Attending a Qualitative Support Group throughout the research process allowed the enhancement of coherence. Original transcripts were peer reviewed and the subsequent model discussed and debated, in order to ensure a convincing theoretical account (Stiles, 1993).

1.10 Reflexivity

Participating in the Qualitative Support Group was also an effective means of addressing reflexivity in terms of ensuring that the findings emerged from the data and were not solely based on my preconceived ideas or beliefs about sibling relationships where one child has autism. Stiles (1993) explains that the investigators initial expectations and internal processes are part of the investigations context and can represent an important source of information in their own right. This was evident in that the sense of sadness I felt having analysed certain participant's accounts, and my feelings about the initial model being too simplistic encouraged me to return to the original transcripts to investigate issues of loss and disappointment further and consequently resulted in a more inclusive model. Keeping a reflective diary was very helpful for keeping track of my internal processes and remaining open to the data, however, I am aware that it would have been impossible to prevent my background, experiences and beliefs from influencing the research process to some degree.

In reflecting on the model, some of the processes resonate with my experiences of family relationships in terms of making attempts to try to understand family conflicts and difficult dynamics in relationships. I recognise that historically I felt the need to 'Go the Extra Mile' in relationships and thought that 'Making Allowances' was required to maintain relationships no matter how difficult. My perspective on this has changed over time due to increasing age and maturity, in terms of feeling that I could break relationship bonds if a friendship or relationship becomes too challenging. This leaves me curious as to whether the children in the study, with increasing age, would feel confident to say enough is enough, if their relationship with their sibling with autism became too much. Furthermore, I acknowledge that wanting to understand relationships has been a theme in my life. I am aware that my personal experiences may have impacted upon my interpretations of emergent themes in the analysis.

1.11 A learning experience

1.11.1 Personal awareness

Stiles (1993) asserts that qualitative researchers often address topics that are personally significant and thus involve them in self-examination, significant personal learning and change. The research journey has been a learning experience in terms of my personal awareness in a number of ways. Firstly, as mentioned above, the origins of my interest in family relationships have been clarified and contextualised through carrying out this study.

Secondly, I have learnt a lot about factors impacting upon the way I work. Notably, in writing this critical appraisal, the impact of fearing negative evaluation of written work on producing academic assignments has been brought into my awareness. I have always struggled to commit pen to paper, often delaying the writing up of assignments, having completed the practical investigations or information gathering at a much earlier time. I endeavoured to break the reoccurring habit of needing pressure to write in undertaking this thesis. I was aware my working style was not conducive to the conducting and writing up of a doctoral level project due to its grand scale and the need to have drafts written in time for perusal by supervisors. As mentioned earlier, interviews were completed in a relatively short space of time and setting deadlines helped to spur me on to complete stages of the research to a degree, however, true to style, much of the write up was completed at the eleventh hour. This highlighted my anxieties about doing things thoroughly and properly and the fear of not achieving this.

In the final stages of the project, the research was felt to be dominating other aspects of life. During low points I felt unconfident that I would be able to produce work of a doctoral standard. At these times my family, friends, fellow clinical psychology trainees, research supervisor and most importantly my partner provided well needed support and encouragement. In writing up the research report I felt pressure to accurately convey the analysis in a meaningful way that would be most useful for families of children with autism, clinicians working in the field and the siblings without autism themselves. Writing the research report therefore, presented significant challenges for me, exacerbated by my working style leaving me little time to let go of the analysis.

In contrast, writing the critical appraisal has been an enjoyable task, free from the concern of 'getting it right', perhaps due to being a reflective piece. The critical appraisal has allowed me to reflect on the lengthy research process, assessing the personal and professional development which took place along the research journey. I am left with a great sense of achievement in having completed a potentially clinically applicable project overcoming diverse challenges along the way.

1.11.2 Research learning outcomes

The research process has facilitated the development of my knowledge and skills in various ways. Insight has been gained into the complexities of carrying out research with children and the impact of the family context on involving children in research. I have become aware of the realities and constraints of, and high level of effort and commitment required to carry out clinically relevant research. Notably, I have also gained insight into the challenges faced by Clinical Psychologists in attempting to balance carrying out research with the clinical commitments of the role. The importance of having effective and regular supervision in sustaining the motivation and confidence to conduct a sizeable research study has been recognised.

A range of key research skills including research design, selection of appropriate methodology, organising data collection, carrying out grounded theory analysis and interpretation of findings have been built upon, which will be transferable to future projects. In particular, I have developed skills in effectively interviewing children about

emotive areas, a skill transferable to my clinical practice. My self-awareness has increased. I have developed an in-depth knowledge of a specific area of research which I am keen to continue to build upon in my clinical practice and perhaps through carrying out further research projects. Finally, I have become aware of the range of complex processes involved in children adapting to having a sibling with autism and how the strategies children use to deal with the daily challenges of having a sibling with autism impact upon their experiences and perceptions of the sibling relationship.

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