HOW DOES HAVING A SIBLING WITH AUTISM SPECTRUM CONDITIONS

IMPACT ON ADOLESCENTS' PSYCHOSOCIAL ADJUSTMENT?

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ABSTRACT

The rationale for this study was based on the paucity of current literature about adolescents whose siblings have autism spectrum conditions (ASCs). This sparse research has revealed mixed results, some of which appears to suggest that there may be negative psychosocial outcomes for adolescents whose siblings have ASCs, and some of which indicates that these adolescents are able to adjust relatively well. Furthermore, most of the limited literature around the adaptation of adolescents whose siblings have ASCs is quantitative in its methodology. This study proposed the use of qualitative methodology to discover what experiences adolescents could reveal about having a sibling with ASCs and how these experiences might impact on these adolescents' psychosocial adjustment.

There were four main aims of the study: (1) to explore the experiences of adolescents whose siblings have ASCs; (2) to explore how these experiences might impact on these adolescents' psychosocial adjustment; (3) to assess for possible implications for service delivery; (4) to generate a theoretical account of the pertinent factors influencing adolescent psychosocial adjustment, with a view to identifying possible areas for future research.

Photo elicitation methodology was used to help gather data alongside semi-structured interviews conducted with 11 adolescents between the ages 12-18 years whose siblings were diagnosed with ASCs. Grounded theory was employed to analyse the data. Four main themes were identified from the data: experiencing ASCs in daily life; adolescent psychological factors; social impact of ASCs on interpersonal relationships; adolescents' perceptions of siblings with ASCs. From these themes, a theoretical model was developed to demonstrate what adolescents identify from their subjective experiences as being crucial factors for adaptive psychosocial adjustment to living with a sibling with ASCs. The initial conclusions illustrated by the theoretical model suggest that adolescents feel most able to cope with and adjust psychosocially to living with a child with ASCs when they experience open and collaborative channels of communication with parents; supportive social networks that include friends, peers, family, extended family; positive perceptions of their siblings, including realistic hopes for their siblings' development; knowledge and understanding of ASCs and a perceived sense of self-efficacy in being able to manage their siblings in times of distress. Negative hypothesis testing was subsequently employed to assess the validity of the theoretical model. This scrutiny of the theoretical model

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highlighted the complexities relating to how each of the participant's accounts fitted with the proposed model. In light of this, whilst the theoretical model derived from this study can be helpful for providing an overview for some of the factors that appear to feature in how adolescents adjust psychosocially to living with a sibling with ASCs, it is ambitious to claim anything beyond this given that there are any number of factors specific to an individual's circumstances that will also influence how an adolescent adjusts psychosocially to living with a sibling with ASCs. This raises several clinical and research implications.

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LIST OF ABBREVIATIONS

ASCs: Autism Spectrum Conditions

DSM: Diagnostic and Statistical Manual

APA: American Psychological Association

RPI: Resistance to Peer Influence Scale

SES: Socioeconomic status

CBCL: Child Behaviour Checklist

FES: Family Environment Scale

PCSC: Perceived Competence Scale for Children

PCSA: Pictorial Scale of Perceived Competence and Social Acceptance for Young Children

MAS: Marital Adjustment Scale

DAMP: Impaired Attention Motor Control and Perception

IPA: Interpretative Phenomenological Analysis

GP: General Practitioner

CAMHS: Child and Adolescent Mental Health Services

CHAPTER 1: LITERATURE REVIEW

An overview of Autism Spectrum Conditions

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000) defines autism spectrum conditions (ASCs) as lifelong pervasive developmental disorders characterised by impairments in the 'triad' of social interaction, social communication, and development of imagination (APA, 2000). Previous epidemiological research suggested that the prevalence for pervasive developmental disorders was consistently rated at about 1 per 1000 persons (Bryson, Clark, & Smith, 1988; Sugiyama & Abe, 1989). Contemporary research suggests that the prevalence of autism is much more common—perhaps due to improved recognition and better diagnostic assessment procedures—and is now believed to be around 1 per 100 (Baird et al. 2006). Autism and Asperger's syndrome represent the two most widely recognised of the pervasive developmental disorders (APA, 2000).

Children with ASCs tend to have a restricted, repetitive, and rigid pattern of interests and activities and find it difficult to understand links between information from past and present events, to make sense of experiences, to plan ahead, and to predict future events (Wing, 1996). The combined difficulties arising from the impairments associated with ASCs makes autism a serious, lifelong, and disabling condition. Without the right support, it can have a profound and sometimes devastating effect on individuals and families. Autism presents difficult and pervasive challenges for families such as physically aggressive behaviours and self-injury (Gray & Holden, 1992; Wolf, Noh, Fisman, & Speechley, 1989).

In light of the challenges associated with living with a family member diagnosed with ASCs, this thesis is concerned with how adolescents might adjust psychosocially to living with a sibling with ASCs. This study focused on adolescent siblings because

adolescence incorporates a number of important psychosocial developmental issues, such as the development of identity and peer group relationships (Erikson, 1980), each of which is discussed in turn. According to Erikson (1980) the term 'psychosocial adjustment' describes how an individual adapts psychologically (i.e. internally and externally) to the demands of given tasks or experiences, as well as socially (i.e. within the familial context and within broader systemic networks, such as school and the community).

As the focus for this study was adolescent siblings of children with ASCs, this chapter begins by reviewing some of the key tasks and developmental considerations of adolescence, such as identity formation and understanding the intricacies of the development of peer groups. Special attention is also given to highlighting the theory around ways of coping with regard to understanding the types of coping strategies that might be adopted by adolescents.

This chapter then reviews other relevant literature beginning with a brief overview of the literature on sibling relationships. Due to the relatively limited literature on the psychosocial adjustment of children living with siblings with ASCs this review also incorporates a parallel discussion of the lifelong issues faced by siblings of children with chronic illness and disabilities. This wider exploration of the literature on the impact of chronic illness and disability on siblings in general alongside the current evidence on ASCs is with a view to making sense of what may be common across conditions and to highlight the specific challenges for adolescents living with a sibling with ASCs.

This chapter then explores the literature related to experiences of adolescents who have siblings with ASCs in order to uncover how these experiences might impact on the psychosocial adjustment of these adolescents, with a view to considering the possible implications for service delivery and areas for future research.

This chapter concludes with an appraisal of some specific methodological issues encountered in the research on siblings of children with illness and disabilities and, accordingly, presents the aims and a clear rationale for this study.

Adolescence

Adolescence represents a complex developmental period of significant physiological and psychological change. There are several transitions across emotional, intellectual,

cognitive, and social domains that incorporate key developmental tasks, such as the development of identity, the establishment of peer groups, and the development of ways of coping to meet the demands of these tasks. Such demands can include trying to establish and maintain a positive self-image; preserve good interpersonal relationships with family and friends; and gain a sense of direction to help plan for a growing sense of independence (Carr, 2006).

The adolescent time frame has been defined by some as between 13 and 20 years (Carr, 2006) or from as early as age 10 to as late as age 25 on the growing understanding that children are reaching puberty earlier in life and adolescents are now remaining longer in the family home (Mueller & Prout, 2009). One of the pervasive features across definitions seems to be the understanding that children gravitate towards desiring a greater sense of autonomy throughout adolescence in preparation for adulthood.

The age range for this study was confined to 12-18 years as it encompasses several important psychosocial adjustment processes (Erikson, 1980). Within this period, relationships with parents and peers change as adolescents move to high school and begin to make the transition towards adulthood so increasing their autonomy and engagement in the community (Smetana, Campione-Barr, & Metzger, 2006). Adolescents begin to face dilemmas around the process of establishing group identity through relationships with peers. Due to the rapid succession of the changes that occur during the adolescent phase of life, Leffert and Peterson (1996) suggest that adolescence provides much potential for positive growth but also an increased risk for developing adjustment problems.

Development of Identity

According to Erikson (1980), one major task of adolescent life is the development of a sense of identity. Marcia's (1980) identity status paradigm attempted to make the concept of identity formation amenable to research. Marcia (1980) delineated four identity statuses: achieved, moratorium, foreclosed, and diffused, with a specific status held being determined by the adolescent's abilities to explore identity and to commit to self-chosen goals. With identity diffusion there is no firm commitment to personal, social, or vocational beliefs. Such adolescents can have low self-esteem, adjustment difficulties, or be serial fun-seekers. With foreclosure status, adolescents tend to subscribe to their parents' or others' beliefs with regard to vocational, religious, or political values. If an adolescent reaches a

moratorium status, he or she tends to experiment with a number of roles before settling on an identity. These roles can be negative (delinquent) or non-conventional (dropping out) but are each a particular status that is reached in the individual's journey to forming a stable identity. Where adolescents achieve a clear identity after attaining a successful moratorium status, they tend to develop strong affinities with specific vocational, political, religious, and social beliefs as well as good psychosocial adjustment in adulthood. Such adolescents have realistic life goals, high self-esteem, a strong sense of independence, and are more resilient to stress. If this sense of identity is achieved following a moratorium in which many roles have been explored and tested, the adolescent can avoid the problems that occur with identity diffusion, such as being aimless, or feeling trapped which can be a problem with the foreclosure identity status.

Since the formation of the identity paradigm, Berzonsky (1989) has criticised it for paying limited attention to the processes underlying identity development. According to Berzonsky (1990), self-identity is a self-theory and therefore an integrated, conceptual composition of assumptions and constructs all relevant to the self. Thus, in the interest of remaining effective, self-constructs require monitoring, evaluation, and revision as appropriate across the lifespan, particularly so through adolescence. To this end, individuals differ in the manner in which they undergo these supervisory processes whilst developing their identities (Berzonsky, 1997). Berzonsky (1989, 1990) proposes three categories of self-theorising. These include (1) the informational style (associated with a stronger desire to explore that involves actively seeking out, processing, and evaluating information relevant to the self); (2) the normative style (associated with a lesser orientation to explore and more closely characterised by being concerned about the expectations of others, e.g. parents); (3) the diffuse-avoidant style (typically defined by individuals who pay limited attention to their futures, have scant regard for the long-term consequences of their behaviour, make emotion-focused decisions, and have a tendency for procrastination until consequences determine a course of action). Berzonsky (1989, 1990) posits that individuals can adopt all three styles but that they tend to develop a preference for a particular style, which may vary from one identity domain to another.

A recent study of adolescent well-being and identity style (Phillips & Pittman, 2007) sought to extend the findings of previous researchers with respect to the significance of identity style and its relationship with well-being, particularly that of the pronounced

inverse association between a diffuse-avoidant orientation and well-being (Adams et al, 2001; Jones, Ross, & Hartman, 1992; White & Jones, 1996). Phillips and Pittman (2007) recruited two samples of participants from the general population, the first a predominately white sample with an age range of 11 to 20 years and the second an ethnically diverse sample with an age range of 12 to 20 years. Both samples were well balanced between males and females. Each sample was administered a series of questionnaires consisting of measures of identity style, self-esteem, hopelessness, delinquent attitudes, educational expectations, and optimism/efficacy. Self-esteem and delinquent attitudes were chosen as measures of current well-being, whilst future outlook was assessed by levels of hopelessness, educational expectations, and optimism/efficacy. Although the study was limited by a one-time measurement and can therefore not provide any real insights regarding developmental trends with respect to the use of identity styles, the results of the study indicate a strong association between identity style and other psychosocial variables. Consistent with previous research (Adams et al, 2001; Jones et al, 1992; White & Jones, 1996), the study's findings suggest that there is a particular relationship between a diffuse-avoidant orientation and various indices of well-being, indicating that individuals with a diffuse-avoidant identity style have a decreased sense of well-being and appear to have a less hopeful perspective of what the future might entail when compared with individuals with an informational or normative orientation; perhaps because those individuals with a diffuse-avoidant identity tend to bear the hallmarks of a lack of exploration, lack of commitments, procrastination, inability to delay gratification, and a failure to think about and plan future goals (Phillips & Pitman, 2007). One final point of intrigue raised by the study is the disparity between females being more likely to be information-oriented and males showing a more diffuse-avoidant style. This is in line with previous research on gender-differences in identity during early and middle adolescence (Jones & Streitmatter, 1987; Streitmatter, 1988).

Identity is believed to be shaped by an individual's reaction to and interaction with context (Berzonsky, 1997). Therefore, family circumstances are likely to play a large role. Thus, the development of identity is interesting when considering how adolescents living with siblings of ASCs might be influenced in their identity formation. This consideration makes it important for this study.

Peer group conformation

Another overlapping and important factor during the journey through adolescence is how an individual is able to interact with his or her peer group. This is worthy of further consideration here as it has yet to be explored within the context of adolescents who have siblings with ASCs. That is, the potential impact on peer group interaction for an adolescent with a sibling with ASCs is unchartered territory.

As children make the transition from childhood into adolescence they become more independent from their parents and begin to place greater emphasis on relationships with peers. Peers do not replace parents as much as to expand children's social arena (Lashbrook, 2000). Friends are made on the basis of similar attitudes and behaviours, and appear to foster further similarity once friendships become established (Berndt, 1996a). According to Erikson (1980), an adolescent's sense of identity forms between 12-to-18-years of age. During this period, adolescents begin to discover their personal sense of self and to see themselves as individuals. A crucial prelude to identity formation for adolescents is the sense of belonging to or feeling and being accepted by a chosen group.

Erikson (1980) purports that adolescents between 12-and-18 years are faced with the dilemma of group identity versus alienation. The adolescent is required to negotiate the complexities of becoming affiliated with a group so that a sense of belonging is experienced, whilst potentially sacrificing personal goals and one's sense of individuality in the process. The alternative is perhaps to feel alienated from peers, experiencing limited networks of social support. This is problematic also for responsible parents who need to strike a balance of not being overly-restrictive of their children whilst also being supervisory of them to monitor for the onset of potential negative behaviours such as substance abuse and criminal activity.

The positive and negative effects of peer influence during adolescence is a well researched area (e.g. Arnett, 2007; Berndt, 1996b; Fergusson, Vitaro, Wanner, & Brendgen, 2007; Gifford-Smith, Dodge, Dishion, & McCord, 2005). Special attention has been given to researching the curvilinear pattern in susceptibility to age-related peer influence during adolescence. This curvilinear pattern relates to a sharp correlation between young adolescents having increased susceptibility to peer influence up until mid-adolescence at which time the effects on susceptibility to peer pressure appear to plateau with increase in age (Brown, Clasen, & Eicher, 1986). A few studies have examined peer influences from the

pro-social perspective (Ellis & Zarabatany, 2007; Barry & Wentzel, 2006; Robertson, Stein, & Baird-Thomas, 2006) or a neutral behaviour perspective (Allen et al., 2006; Walker & Andrade, 1996) but these studies have tended not to focus on age differences. Most studies have focused on the negative effects and deviant behaviour that can result from peer influence. In such studies, a curvilinear relationship between age and susceptibility to peer influence is reported as being strongest during mid-adolescence (Brown et al., 1986; Steinberg & Silverberg, 1986). More recently, Steinberg and Monahan (2007) also found a linear relationship between age and resistance to peer influence. These authors used a new questionnaire (the Resistance to Peer Influence Scale; RPI) which presents adolescents with 10 neutral peer influence situations. Each item offers the participant a choice of two acceptable responses. One group reflects highly resistant people, while the other group represents people that are more easily led by their peers. The results of the study indicated a linear increase in resistance to peer influence during adolescence, particularly so between the ages of 14 and 18.

The most recent study of peer resistance investigated age and gender differences in the trajectory of resistance to peer influence. Sumter, Bokhorst, Steinberg, and Westenberg (2009) recruited 464 children between the ages of 10 and 18, with a gender balance of 52% girls and 48% boys. These children were administered the RPI and informed that the study was on peer relations and personality. The results of the study showed that older adolescents were found to report more resistance to peer influence, with a steady increase in resistance to general peer influence with age. These findings are consistent with those of Steinberg and Monahan (2007) and the study by Walker and Andrade (1996), suggesting that over time adolescents develop more autonomy from their peers and become more confident in their own stance. This developmental progression can perhaps be understood as a consequence of increasing psychosocial maturity. Studies researching psychosocial maturity have shown that adolescents gain more responsibility, greater self-awareness, and better impulse control as they reach young adulthood (Greenberger & Sorensen, 1974; Loevinger, 1993; Weinberger, 1997) and, hence, are less likely to be susceptible to follow the lead of others without thinking.

The results for gender differences showed that girls reported more resistance, especially in the period during mid-adolescence. This finding also corresponds with previous research in psychosocial maturity, which has indicated that girls mature faster

than boys during mid-adolescence, and that boys tend to catch up by late adolescence (Cohn, 1991).

Although Sumter et al.'s (2009) study did not include young adults, therefore precluding the possible observation of what point during development the increase of resistance to peer pressure stabilises, Steinberg and Monahan (2007) suggest that resistance to peer influence reaches adult levels around 18 years and does not increase after this age.

Positive peer relationships as well as good friendships with siblings have been found to enhance psychosocial functioning by increasing a sense of self-worth and healthy coping skills, (O'Dougherty, Wright, & Masten, 2005) as well as possibly reducing psychosocial risk and vulnerability (Agrawal, Hauser, Miller, & Penn, 2003), thereby building resilience and the ability to cope which appears to be an integral part of children's differential reactions to growing up with a disabled sibling (Gamble & McHale, 1989) and therefore worthy of further consideration here.

Development of coping

Coping has been defined by some researchers as cognitive and behavioural efforts to conquer, alleviate, or manage the internal and external demands created by stressful events (Folkman & Lazarus, 1980). Coping skills refer to active or passive behaviours and strategies people use to work through stressful experiences (Carver, Scheier, & Weintraub, 1989). Emotion-focused coping strategies focus on trying to regulate or eradicate unwanted emotions associated with stressful events, whereas a problem-focused approach aims to reduce the effects of stressful events by attempting to actively solve the problem (Carver et al., 1989). These coping strategies incorporate a range of specific methods, including confrontive, distancing, escape-avoidance, and self-control (see Folkman & Lazarus, 1988).

The process of coping incorporates several tasks that relate specifically to psychosocial functioning. According to Moos (1982) there are four such tasks involved in the process of coping which involve striving to (1) regulate negative thoughts and feelings in order to try and retain a positive outlook for the future; (2) preserve a fulfilling self-image and sense of self-efficacy; (3) maintain healthy relationships with family and friends; (4) prepare for what lies ahead. Lazarus and Folkman (1984a) have also suggested that

emotional responses are mediated by the cognitive appraisals individuals assign to specific situations and that coping responses are regulated by this dynamic process of appraisal.

Coping in children and adolescents

Children develop better problem-solving skills and ways of channelling emotions as they mature cognitively and emotionally (Carr, 2006). In their review of age differences or changes in coping responses to stress, Skinner and Zimmer-Gembeck (2007) identified specific transition periods for coping. These transitions included 10-12 years; 12-16 years; and 16-22 years. These authors identified that the most rapid periods of development of coping occurred at ages 5-7 and 8-12 years. The salient findings of this review suggested that children develop increasingly sophisticated coping techniques, such as problem solving and distraction, as they reach middle childhood. By adolescence, the ability to regulate coping responses and to determine who to seek for help in specific situations has also developed (Skinner & Zimmer-Gembeck, 2007).

Coping strategies in children remain poorly understood and are not well studied from a developmental perspective (Glasberg, 2000). The difficulties in researching children's and adolescents' coping strategies arise from a lack of clear theoretical framework to facilitate investigation of coping in children or adolescents (Ryan, 1989) and because the majority of studies have failed to account for the child's cognitive and emotional growth in relation to the development of coping strategies (Houtzager et al., 2004). These difficulties also pertain to the literature on coping in families where there is a child with autism. To this end, the process of coping is an interesting consideration within the context of managing the tasks of adolescence and the additional demands that may arise for adolescents as a result of living with a sibling with ASCs. This chapter now provides a brief overview of the sibling literature, to contextualise the general nature of sibling relationships with respect to a wider discussion of the literature around siblings of children with chronic illness, or developmental disabilities, or ASCs specifically.

Sibling literature

Of all human relationships, sibling relationships typically last the longest (Orsmond & Seltzer, 2007). A combination of nurturance and conflict in the sibling relationship facilitate experiences that promote the development of emotional understanding, self-regulation, and a sense of belonging that fosters comfort (Brody, 2004). During childhood siblings can argue and fight and act as play partners and sources of support through daily contact. Children's satisfaction with their sibling relationships is somewhat due to their ability to communicate reciprocally (Stoneman & Brody, 1982) which provides a sense of social meaning in the context of being 'a brother' or 'a sister'. Through ongoing interaction and communication, children that are able to acquire and perform roles that are mutually pleasing for siblings are best placed to develop high quality sibling relationships (Brody, 2004). Sibling relationships that allow for healthy exploration of similar and differing opinions around a range of discussions provide the foundations for peer and adult relationships (Cox, Marshall, Mandleco, & Olsen, 2003; Harris & Glasberg, 2003).The various influences encountered through patterns in sibling relationships within the general population make for a potentially complicated and uncertain trajectory of those relationships. Thus, the additional factor of the presence of a disability or chronic illness in a sibling can further influence the life course trajectory of the sibling relationship.

Siblings of children with a chronic illness

Chronic illness, defined as a "medically diagnosed ailment with a duration of 6 months or longer, which shows little change or slow progression" (Williams, 1997, p.312), has long been considered to have an adverse impact on the behaviour and psychological functioning of the ill child (Cohen, 1999). However, a review of the current evidence suggests that the impact is less certain.

An early review in this area concluded that siblings of children with chronic illness were a population at risk for adjustment problems, anxiety, and low mood (McKeever, 1983). A review by Hannah and Midlarsky (1985) found that siblings of children disabled by chronic illness were at risk of experiencing psychological difficulties but also suggested that there were potential advantages of growing up with an ill sibling, such as greater compassion, findings which are corroborated by more recent reviews of children with siblings with chronic physical and cognitive disabilities (Faux, 1993), and siblings that have undergone bone marrow transplants (Packman, 1999).

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More recently a meta-analysis by Sharpe and Rossiter (2002) of the literature pertaining to the siblings of children with a chronic illness sought to resolve some of the discrepant findings across reviews. On the basis of the findings from traditional literature reviews Sharpe and Rossiter (2002) anticipated a negative effect for having a sibling with a chronic illness, hypothesising a number of methodological and substantive issues. For example, these authors predicted (1) more recent studies would show fewer negative and more positive outcomes than earlier studies, (2) more negative effects would be found for parental reports than sibling self-reports, and (3) there would be larger effect for internalising (e.g. anxiety and depression) over externalising (e.g. aggression) behaviours. In line with traditional quantitative reviews of the relevant literature (e.g. Faux, 1993; Packman, 1999; Williams, 1997), Sharpe and Rossiter (2002) found a small but statistically significant and negative overall effect for having a sibling with a chronic illness with an effect size of -.20. These authors also found that fewer negative findings were yielded by recent studies compared with earlier research. Some suggestions for this reduction are improvements in the quality of life for children with chronic illnesses (Jackson, 2000) and the development of effective psychological interventions for children with chronic illnesses (Kibby, Tyc, & Mulhern, 1998), which may independently or combinatively moderate any adverse impact on the siblings. Parental reports were also found to be more negative than child self-reports, perhaps because children may not perceive any negative effects or may deny such effects until adulthood, or because they are relatively less distressed compared to their parents who may be overly sensitive to negative perceptions.

Also consistent with the previous relevant literature (Howe, 1993; Rossiter & Sharpe, 2001), Sharpe and Rossiter (2002) found larger negative effects for internalising behaviours, such as social withdrawal, than for externalising behaviours (e.g. angry outbursts). These authors suggest that this behavioural response might occur because the frustrations that may arise from parental inattention or caretaking responsibilities are difficult for the healthy child to externalise, perhaps through aggression, given the precarious health status of the ill sibling. The authors suggest that this can be explained by assuming that siblings of children with chronic illness take on an elevated caretaker role (Boyce & Barnett, 1993), which manifests in the sibling displaying an increase in internalised behaviours as a response to the inflated caretaking demands (Gold, 1993).

Sharpe and Rossiter (2002) carefully conclude that family dynamics are a complex and intriguing set of relationships, particularly so when a child is born with or develops a chronic illness. Families experiencing childhood chronic illness need to adjust to care-giving demands which will invariably incorporate physical and social environmental factors, elevated stress levels, and potential anxieties.

Siblings of children with developmental disabilities

The impression when reviewing the literature around the psychosocial adjustment of siblings of children with developmental disabilities is one of contradiction and confusion. Comparison studies in which one child has a disability and those where all children were described as developing typically have failed to arrive at any consensus regarding the psychological ramifications for children who have a sibling with a developmental disability. A large proportion of the research in this area has been developed on the premise that having a sibling with a disability will be problematic for children (Ross & Cuskelly, 2006). As these investigations have continued, more researchers are beginning to acknowledge that having a sibling with a disability may also be a positive experience for a child (Hastings, 2007). Investigators have focused their research on several sibling outcomes, including self-concept, behaviour problems, and locus of control and self-efficacy. The findings of these outcomes are now summarised.

There appears to be a consistent finding that self-concept of children is unaffected by having a sibling with a disability and that perceived competence between groups of children who do and do not have a sibling with a disability is similar (Burton & Parks, 1994; Dyson, 1996; Hannah & Midlarsky, 1999; McMahon, Noll, Michaud, & Johnson, 2001; Singhi, Malhi, & Dwarka, 2002).

Studies show mixed results in the investigation of whether children of siblings who have a disability show increased behaviour problems, either through externalising (e.g. aggression) or internalising (e.g. anxiety). Whilst several investigators have found no group differences in behaviour problems (Benson, Gross, & Kellulm, 1999; Hannah & Midlarsky, 1999; Lynch, Fay, Funk, & Nagel, 1993; Stores, Stores, Fellows, & Buckley, 1998) other researchers have found signs of increased internalising and/or externalising problems (Cuskelly & Dadds, 1992; Coleby, 1995; Nixon & Cummings, 1999). The differences in

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findings from these studies might be accounted for by the inconsistencies in measures, the wide age ranges in recruitment both of individuals with disabilities and of their siblings, and the variety of disabilities and associated challenges experienced by siblings.

In a similar vein, the limited evidence base on locus of control and self-efficacy suggests that a child can have mixed experiences in living with a sibling with a disability. Burton and Parks (1994) found that a sample of 30 college-age students (18-23 years) from low socio-economic status (SES) who were male and female siblings of children with a variety of developmental disabilities had a higher internal locus of control compared with peers living with non-disabled siblings; this was linked to improved perceptions of self-concept, self-efficacy, and psychosocial well-being. Grissom and Borkowski (2002) found no differences between adolescent siblings of children with disabilities to a comparison group in terms of self-efficacy. The complex interactive effects of age, gender, ordinal position of the sibling within the family, family socio-economic status, and type of disability are likely to have influenced the findings of these respective studies with regard to locus of control and self-efficacy. Moreover, the interplay between these variables obscures the effects and makes it difficult to decipher what enables one child to adjust better psychosocially than another.

Notwithstanding the misgivings associated with the above findings, a child's development may not be determined purely by a sibling's disability. A model of family adaptation purports that family adjustment in the presence of a child with disabilities incorporates personal and psychosocial factors beyond the potential risks incurred by the disabled sibling (Crnic, Friedrich, & Greenberg, 1983). For example, factors such as family social support (Ferrari, 1984), family functioning, and levels of parental stress associated with the child with disabilities (Dyson, Edgar, & Crnic, 1989) have been found to have a significant influence on the development of children who have a disabled sibling. This relationship between psychosocial functioning and family psychological correlates was further examined by Dyson (1999).

Dyson (1999) examined how the psychosocial functioning, defined by her as self-concept, behaviour adjustment, and social competence, of a family and its psychological correlates (parental stress, family social support, family relationships) alter with time in children who have siblings with disabilities. Here it is helpful to bear in mind that, historically, the process of psychosocial adjustment includes three common stages (Fortier

& Wanlass, 1984). Most models describe an initial period of shock and/or denial which is followed by significant distress and concludes with acceptance of one's situation, similar to those experienced during the grief associated with one's imminent death or the loss of a loved one (Kubler-Ross, 1969). According to this linear, developmental approach to adjustment, the appearance of later stages is predicated on the resolution of earlier stages.

In a longitudinal study spanning four years, Dyson recruited 71 school-age children and adolescents, divided into two groups: (1) 37 children and adolescents with disabled siblings of a younger age and (2) 34 children and adolescents with nondisabled siblings. The mean age range of the groups was similar: 13.7 years and 13.6 years, respectively. The disabilities included mental retardation, physical and sensory disabilities, developmental delay, and learning disabilities. The two groups were matched on SES but there were more than twice as many males to females in each of the two groups. The majority of participants were white American. Parents and children were asked to complete a set of validated questionnaires, including the Piers-Harris Children's Self-Concept Scale, the Child Behaviour Checklist (CBCL), the Family Support Scale, the Questionnaire on Resources and Stress Short Form, and the Family Environment Scale (FES) at the beginning of the study and again four years later. These questionnaires were designed to assess self-concept, problem behaviours, social competence, family support, the impact of a family member with developmental disabilities, and family functioning.

The results of the study indicated that where families had social advantages, such as higher household income and better support systems that incorporated early support, children with siblings with developmental disabilities did not differ from children with nondisabled siblings on measures of self-concept, behaviour adjustment, and social competence. These findings showed a moderate degree of stability in scores between groups over the four year period, with most children appearing to have increased stability in behaviour adjustment and social competence and less stability in self-concept, although children with siblings with disabilities showed greater stability in self-concept than children with nondisabled siblings.

The study also yielded a relatively stable relationship over the 4-year period between children's psychosocial functioning and family psychological factors, regardless of their siblings' abilities. That is, family psychological factors such as family social support, family functioning, and parental stress were differentially related to children's psychosocial

functioning at each time point in varying strengths. This suggests that family psychological factors might play more of a significant role than a family member with a disability in determining psychosocial outcomes. In particular, positive psychosocial functioning was strongly linked with positive family relationships and the emphasis that families placed on personal growth which may be a reflection of how these children might have developed a social construction in relation to their siblings' disabilities. In addition, in such families all members are likely to feel valued which mediates the potential impact of other factors, such as parental inattention and increased care-giving demands on sibling outcomes.

Dyson (1999) acknowledges that the inclusion of several disabilities (mental retardation, physical and sensory handicaps, developmental delay, and learning disabilities) in the study that also ranged in severity from mild to profound may have warranted further analysis to establish the potential effect of type of disabilities. The relatively small sample size for a quantitative study precludes any meaningful analysis. The potential interactive complexity of several variables makes it difficult to understand what factors are likely to be important and how these factors might impact at an individual and a family level. This is one of several methodological issues that thus far consistently flaw the research in the area of children with siblings who have disabilities. Before addressing these methodological issues comprehensively, this chapter now turns to one of the central tenets of this research study.

Siblings of children with autism spectrum conditions

Studies specific to siblings of children with ASCs have traditionally focused on the psychosocial and emotional adjustment of children whose siblings have ASCs. The majority of this research is quantitative and has yielded inconsistent results. This section now examines the existing literature around the adjustment of siblings of children with ASCs.

Relatively few studies have investigated the psychosocial adjustment of siblings of children with ASCs and relatively little is known about the trajectory of such sibling relationships. Some studies have reported that having a sibling with ASCs increases the risk for a host of adjustment problems that result in emotional and behavioural difficulties, such as social withdrawal, aggression, anxiety, and low mood (Bagenholm & Gillberg, 1991; Cox et al., 2003; Gold, 1993; Gupta & Singhal, 2005; Mascha & Boucher, 2006; Rodrigue, Geffken, & Morgan, 1993). Other studies have revealed positive aspects of having a sibling

with ASCs, such as positive self concept (Kaminsky & Dewey, 2002; Mates, 1990), improved skills in caring (Mates, 1990), enhanced empathy and compassion (Sharpe & Rossiter, 2002), and personal maturation (Mascha & Boucher, 2006).

The methodological issues which perhaps influence these differences in findings are explored in the next section. However, a salient issue in the research on siblings is that it has tended to adopt parents as respondents under the assumption that they will be able to accurately report on their children's perceptions of growing up with a sibling with ASCs. Moreover, whilst siblings of brothers and sisters with ASCs are not routinely offered anything by psychological services, it is interesting to note that research has invariably focused on questions that explicitly or implicitly suggest that having a brother or sister with ASCs will inevitably be stressful and lead to emotional and behavioural problems.

The study by Rodrigue et al. (1993) compared 19 siblings of severely autistic children with 20 siblings of children with Down syndrome and 20 siblings of developmentally typical children on perceived competence and social and behavioural adjustment. The mean age ranges of the participants (the siblings) in these groups, respectively, were 10, 11, and 9 years. The children with autism, Down syndrome, or typical development were matched on the basis of mental age, rather than chronological age, to guard against a possible confound of disability and adaptive behaviour. Their mean composite age equivalent as determined by the Vineland Adaptive Behaviour Scale was 2.8 years for the autism group, 3.9 years for the Down syndrome group, and 3.8 years for the developmentally normal group. Perceived competence was measured by either by the Perceived Competence Scale for Children (PCSC) or the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (PCSA) depending on their chronological age. Social and behavioural adjustment was measured by the CBCL. In addition, the Marital Adjustment Scale (MAS) was used to assess both mothers' and fathers' level of marital satisfaction.

The results of the study indicated that siblings of children with autism did not differ significantly from siblings of children with Down syndrome or typical development on measure of social competence or self-competence. Although siblings of children with autism had more internalising and externalising behaviour problems when compared to the other siblings in the study, their average scores on these dimensions of the CBCL fell within the normative range. Only sibling age and marital satisfaction were significantly

associated with sibling adjustment. Siblings older in age correlated with higher rates of internalising and externalising behaviour problems in siblings of children with autism, and higher marital satisfaction was related to higher levels of self-esteem in siblings generally. Overall, the results suggest that having a brother or sister with developmental disabilities is not necessarily a risk factor for poor psychosocial functioning. Rodrigue et al. (1993) do not raise any limitations of their study but their cross-sectional design does not capture temporal changes, which is an issue given that adjustment is a process.

A study by Kaminsky and Dewey (2002) investigated the relationships between feelings of loneliness, social support and psychosocial adjustment. The authors recruited 90 typically developing children and adolescents between the ages of 8 and 18 years from three groups: (1) individuals with a sibling with autism, (2) individuals with a sibling with Down syndrome, (3) individuals with siblings without any diagnosed disability. Each group contained 30 participants and were matched for gender, birth order, and approximate age. Children were asked to complete the Social Support Scale for Children, the Loneliness and the Social Dissatisfaction Questionnaire. Parents were asked to complete several measures including the CBCL, an adaptive behaviours questionnaire, and a demographics questionnaire which asked for information on family size, birth order, presence of other disabilities in the home, family income, and family make up (e.g. two-parent).

The study found siblings of children with autism not to be at increased risk for adjustment difficulties or loneliness and to be as socially competent as controls. Kaminsky et al. (2002) suggest that the results of their study may be due to the high number of participants' families attending support groups, which may facilitate healthy psychological adjustment. The results also suggested that higher social support was associated with lower levels of loneliness, although social support and loneliness appeared to be unrelated to psychosocial adjustment. Better psychosocial adjustment was associated with a greater number of siblings in the family. Possible explanations for this finding may be that having other non-disabled siblings in the family reduces the pressure in terms of their present and future responsibilities towards their sibling with the disability and also provides a source of social support (Kaminsky et al., 2002).

The authors highlight that 80% of the siblings were older than the child with autism, therefore limiting the applicability of the findings to siblings who are younger than the child with autism. A further limitation of the study relates to the trend that the gender

distribution of children diagnosed with autism is predominately male. In line with this trend, the results of the study were based on many more siblings in the autism group reporting on their relationship with a brother rather than a sister. A consideration for future investigations would be to examine adjustment of siblings in same-sexed versus opposite-sexed dyads.

Another study by Bagenholm and Gillberg (1991) reported that the siblings of children with autism have high levels of loneliness and problems with peers, which is significant given that the literature suggests that children and adolescents who experience social isolation and poor peer relations are susceptible to adjustment problems later in life (Coie & Dodge, 1983; Rubin & Mills, 1988). The Bagenholm and Gillberg (1991) study recruited 20 siblings of children with autism, 20 siblings of children with intellectual disability, and 20 siblings of typically developing children between the ages of 5 and 20-years. The results showed that siblings of children with autism were generally more negative in their accounts of their relationships, reported more problems with their siblings' behaviour, and expressed greater concern for their siblings' future. This research derived quantitative data from semi-structured interviews. Although, the aim was not to yield the detail that can be found in verbatim interviews, this approach may provide some explanation for the marked differences to the findings yielded by the study of Kaminsky et al. (2002) in that it might have tapped into information and knowledge held by the siblings that did not emerge through the conventional quantitative investigation of Kaminsky et al. (2002).

Sociodemographic factors, such as family size and gender, have also been investigated in terms of their influence on the psychosocial adjustment of siblings of children with autism. Some studies have indicated that family size (Ferrari, 1984; Mates, 1990) and the gender of the sibling (Gold, 1993; Mates, 1990) were unrelated to sibling adjustment. The Ferrari (1984) study incorporated two comparison groups of siblings of boys with diabetes and siblings of typically developing boys, thus excluding potential differences in gender, and included only 16 siblings whom had a variety of pervasive developmental disorders. The Mates (1990) study did not include a comparison group. Conversely, Gath (1973) reported that siblings of children with intellectual disabilities who came from two-child families were more at risk for maladjustment than siblings from families with more than two children. Overall, this literature highlights the inconsistencies

in findings which may be due to relatively small sample sizes, the diversity of the comparison groups, and sociodemographic differences in family constellations.

A recent study by Macks and Reeve (2007) also compared the psychosocial and emotional adjustment of siblings of children with autism and siblings of non-disabled children, with a focus on examining differences between self and parent reports, as well as various demographic factors, including SES, number of siblings, birth order of siblings, and gender of sibling. Participants comprised 51 families with an autistic child and 36 comparison families with typically developing children. In both groups the non-disabled child was aged between 7-17 years. All participating children were asked to complete the Children's Depression Inventory and the Piers-Harris Children's Self Concept Scale; parents completed the Behaviour Assessment System for Children-Parent Rating Scales.

Macks and Reeve (2007) found that siblings of children with autism appeared to have a more positive self-concept than did siblings of non-disabled children and were much more likely to have a positive view of their behaviour, intelligence, and school performance compared with siblings of non-disabled children. The authors suggest that this may be because siblings of children with autism are perhaps more mature than their peers, leading to improved behaviour, better social skills, and improved scholastic performance. The results of this study also indicated that parents of children with autism appeared to view the siblings' social and emotional adjustment more negatively than parents who did not have any children with autism. This finding can be explained perhaps because parents' attention is focused on the autistic child which might interfere with an accurate view of the sibling's social and emotional functioning or because parents project any frustrations or stress that they may have because of their child with autism on to their non-disabled child (Macks & Reeve, 2007).

Macks and Reeve (2007) found that multiple demographics, including being male, coming from a family with low SES, only having one sibling, and being older than the child with autism affected the psychosocial and emotional adjustment for siblings of children with autism; it became more difficult for the non-disabled sibling as the number of demographic risk factors increased, thereby increasing the risk for social, emotional, and scholastic difficulties. Despite limitations of the study, such as small sample sizes and the fact that the families recruited for the experimental group had community resources available to them, the authors suggest that their findings may help to explain a lack of

consistency among past studies. Thus, it is feasible that those studies that have yielded positive findings of children with autism on their siblings were using samples that were not exposed to multiple demographic risk factors. Conversely, those studies that have indicated negative influences of children with autism on their siblings may also in part be attributed to the recruitment of samples of children experiencing multiple demographic risk factors.

Another factor that might complicate research in this area is the understanding that the symptoms of ASCs change over time (Seltzer et al., 2003; Shattuck et al., 2007). As specific impairments of social interaction, communication, and behaviour associated with ASCs tend to become less severe over time, it is possible that relations between siblings where one has ASCs could also improve concomitantly (Seltzer et al., 2003; Shattuck et al., 2007). Moreover, it is likely that there will be changes in how siblings adjust to having a brother or sister with ASCs as they pass through developmental stages.

Research has shown that adolescents find the greatest sources of support with friends and parents (Lempers & Lempers-Clark, 1992; Smetana, Campione-Barr, & Metzger, 2006). Seltzer, Orsmond, and Esbensen (2009), following on from findings from previous research that suggested adults who adopted problem-focused coping strategies had closer relationships with their siblings with ASCs (Orsmond & Seltzer, 2007), investigated sibling relationships and well-being in adolescence and adulthood where one sibling had ASCs. As part of a longitudinal study, these authors examined differences in sibling psychological well-being, coping skills, and social support. Recruitment included siblings from families of 406 adolescents and adults who had experience of living in the presence of one sibling with ASCs. Whereas adolescent siblings participated in a 45 minute telephone interview, adult siblings were required to complete a list of questionnaires designed to measure sibling relationship quality, psychological well-being, coping skills, social support perceptions, and behaviour problems in the brother or sister with ASCs. Seltzer et al. (2009) found that, in similar ways to adolescents, adults perceived having positive relationships with siblings despite having decreased contact with their siblings. Adolescents appeared to use less problem-focused and more emotion-focused coping strategies than adults, reflecting typical age patterns (Skinner & Zimmer-Gembeck, 2007). Adolescents appeared to use problem-focused strategies in the face of problem behaviours in their sibling with ASCs as a way of buffering the potential negative effects of these problem behaviours. Greater social

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support from parents and friends was reported by adolescents than adults and adolescents from larger families reported greater positive affect and rapports with their sibling with ASCs; research has indicated that this can be explained by adolescents having more evenly shared caring responsibilities which reduces pressure during an already demanding stage of life (Howlin, 1988).

Given that the limited literature about siblings of adolescents with ASCs is predominately quantitative and has produced mixed results, it is worth considering the findings of the handful of qualitative studies in this field. Qualitative research does not have a focus on outcomes and can therefore perhaps shed some light on the inconsistencies in the literature as it lends itself to an exploration of the different perceptions and adjustment of siblings of children with ASCs.

A study by Dellve, Cernerud, and Hallberg (2000) investigated 15 sisters between the ages of 12- and 18- years who had a brother with impaired attention motor control and perception (DAMP) and/or Asperger's syndrome. The authors used grounded theory to analyse the data and found that siblings who possessed increased knowledge and understanding of their brother's disability tended to be less embarrassed in relation to their disabled brother and showed greater acceptance of their brother's circumstances. Whereas some siblings reported having a sense of responsibility and wanting a close, personal relationship with their brothers, others described trying to distance themselves from the family to gain more of a sense of independence. These results are best considered within the context that the sample was a mixture of siblings of children with different diagnoses and included only girls, which is an important consideration in terms of gender differences in adaptation (Sarafino, 2002) as boys may have reported different responses to their sibling than those reported by girls.

A further investigation by Mascha and Boucher (2006) recruited 14 siblings (age range of 11 to 18 years; mean age 14.7 years) from 11 families in which there was a child with a diagnosis of either autism or Asperger's syndrome (age range of 7 to 20 years; mean age 10.6 years). Using content analysis, their preliminary findings suggested that having a brother or sister with ASCs had positive effects, such as increased maturity and enjoying the company of their sibling with ASCs, for the majority of the typically developing children but that negative reactions were also evident, often in relation to their siblings' aggressive, uncontrolled behaviour, and the embarrassment that such behaviour caused. These

authors point out that their research left several factors that were unexplored, including the effects of relative age, gender, family structure, and the affected child's/teenager's place on the spectrum. However, these limitations are understandable within the context of a qualitative study.

The most recent qualitative study in this field investigated the perceptions and experiences of siblings with a brother with ASCs (Petalas, Hastings, Nash, Dowey, & Reilly, 2009). These authors used Interpretative Phenomenological Analysis (IPA) in a bid to capture the essence of the different accounts of participants. Although twenty-two typically developing siblings between 5- and 17-years with a brother formally diagnosed with ASCs were interviewed, the study included a subsample of eight biological siblings (age range 9-12 years; mean age 11.19 years) with a brother with ASCs. The foci for the interviews were (1) siblings' knowledge and perception of their brother's ASCs and (2) siblings' perceptions and experiences of their relationships with their brothers with ASCs. The average length of interview was 21 minutes, with a range of between 14.13 and 42.51 minutes.

The data analysis yielded a number of salient dimensions of experience from the siblings' accounts. Siblings had differing attitudes toward their brothers with ASCs, with some wanting things to change with their brothers and others expressing a positive acceptance of their brothers' circumstances. Some of the siblings' accounts also highlighted a sense of tension and ambivalence toward their brothers, although positive perceptions of their brothers were also recorded in each interview; positive perceptions included feeling proud of their brother with ASCs and feeling as though they had gained through their relationships with their brothers. The study also highlighted how the siblings found it helpful and supportive to openly communicate their thoughts and feelings by sharing their experiences with other typically developing siblings of children with ASCs. Finally, the accounts from the siblings in this study also showed evidence of processes that appear to be associated with resilience, such as developing a greater appreciation of people who are different and making positive sense of disability (Bayat, 2007).

The restricted age range helps to condense the findings from the children's accounts to facilitate an understanding of how children in middle childhood might experience living with a brother with ASCs. However, the small sample size and in particular the brevity of the average length of interview mean that it is imprudent to

generalise the findings of the study to other children and adolescents of brothers with ASCs. Different findings may also have been reported by siblings living with sisters with ASCs. Thus, methodological issues appear to be an integral difficulty within qualitative research as much as with quantitative studies.

Siblings of persons with disabilities: Methodological challenges

This section highlights the methodological challenges that lie ahead for researchers of siblings of persons with all types of disabilities. The author recognises that this study will not address some of these methodological challenges. However, in identifying and highlighting the recurrent problems within the research in this area, there is good rationale for returning to the salient issue of exploring what it is that adolescents consider significant to their psychosocial adjustment when living with a sibling with ASCs. That is, this question has never really been answered to the point where there exists a clear theoretical framework on which to base further research.

Stoneman (1993) has reported that research on siblings of children with disabilities is generally "theory-free". The existing research on sibling disability has tended to conceptualise the ideal sibling relationship involving a child with a disability as one which does not appear to harm the typically developing child (Stoneman, 2005). But this conceptualisation has not produced much in the way of useful or valid information with regard to developing a cohesive theoretical model of the important factors that contribute to the process of psychosocial adjustment to living with a sibling with ASCs.

Another approach to the concept of sibling relationships has been to compare siblings of children with disabilities and siblings of typically developing children, essentially making the "average" sibling relationship in the general population as the point of reference. Yet, this also proves methodologically problematic. Zigler and Hodapp (1986) encourage researchers to consider carefully that sibling group differences cannot necessarily be attributed to a child with a disability on the basis that siblings and their families could differ in other ways that could plausibly account for the group differences. One example of such a difference is that families in poverty are more likely to have a child with a disability (Fujiura & Yamaki, 1997) and, consequently, disability is not randomly distributed in the population; it is therefore important to match control groups on SES, for example. In addition to the neglect of these population differences, the comparison-group

sibling studies have created a literature fraught with conflicting and confusing findings, not least because the dimensions of chronic illness, disability, intellectual disability, and pervasive developmental disabilities are frequently interchanged and conflated within the literature.

The evidence base in relation to the psychosocial adjustment of siblings of persons with any type of disability is inconclusive and there appear to be several methodological shortcomings which contribute to this lack of consensus. An initial observation is that the majority of research in this area is quantitative. Most investigators, however, have examined only small samples (average of 20-50 per group) when conducting sibling studies. This makes it difficult for researchers to tease apart the subtle and interacting variables that any two siblings feature. For example, compared to the child with disabilities individual siblings can be older or younger, widely or narrowly separated in age, be step or half siblings, have their own form of disability, and be of the same or different gender. Siblings can also be part of larger or smaller families, of varying SES status, and ethnicities.

Families also often have more than one nondisabled sibling, yet researchers tend to concentrate their investigations on the sibling that is reported to have the closest emotional relationship to the brother or sister with disabilities. To comprehensively expand the study of sibling relationships over the life span, methodological approaches need to incorporate the study of more than one sibling of the individual with a disability, the sampling of older and younger siblings, and analysis of the contributions of age span, gender, and the size of sibling group on both childhood and later life outcomes.

Another issue that requires further attention is the lack of appropriate measures for evaluating sibling experiences and relationships when one child has disabilities. This particular problem concerns the dual relationship when one sibling has disabilities. From one perspective, like all sibling pairs, siblings and their brother or sister with disabilities will have varying levels of closeness, power, warmth, affection, and rivalry (Forman & Burhmester, 1985). On another level, however, there may be other feelings or experiences that may be unique to siblings of a person with disabilities. For example, issues of shame, over-protectiveness, or pride are all associated more with siblings of individuals with disabilities (McMillan, 2005; Swenson, 2005) but tend not to be tapped by commonly used sibling measures. To this end, the significance of the quality of the sibling relationship as a factor in the process of psychosocial adjustment remains inadequately explored.

A final issue pertinent to this study concerns the unbalanced portrayal of research in children who have siblings with disabilities. Traditionally, research has concentrated on the pursuit of negative psychosocial outcomes for this population. Even reasonably recent research has described this type of family research as "less negative" than previously assumed rather than focusing on the positive findings (Helff & Glidden, 1998). Researchers often begin their papers by describing the potential risks posed by having a child with a disability as a sibling and draw tentative conclusions when their data yield positive findings. The challenge for researchers must be to recognise these biases and to set them aside in the context of conducting robust research. One way of working toward that outcome is to communicate with the siblings of people who have disabilities, taking a non-value laden approach rather than assuming some experiences are good and others bad.

Rationale for this study

Our knowledge on siblings of children with disabilities remains limited to the extent that the literature appears inconclusive with respect to the overall impact on psychosocial development. Researchers of children who have siblings with disabilities have experienced "scientific inertia" (Stoneman, 1990) as they continue to pursue areas of inquiry that have already been investigated. This approach does little for increasing our future understanding of research literature focusing on siblings of children with disabilities. Disability as a construct fails to explain sibling outcomes or to establish why siblings differ. This area of research needs guiding theory, developed initially as part of an exploratory stance that helps to identify the issues of importance from the sibling perspective. Such investigation lends itself to a grounded theory approach to help conceptualise the experiences through which siblings influence each other and through which parents, families, and larger communities influence sibling relationships in the context of disability.

To do this, it is necessary to acknowledge that this can be achieved most effectively with a developmental perspective, as posited by Orsmond and Seltzer (2007) in their review of siblings of individuals with ASCs across the life course. This study chose adolescence as its point of reference from a developmental perspective because the majority of studies on siblings of children with ASCs have tended to group together siblings spanning the childhood and adolescent years, obscuring differences between these stages of life. Adolescence is also a developmental stage that is strongly associated with major

tasks, such as the formation of identity and peer groups, which are important factors to psychosocial adjustment and well-being (Phillips & Pittman, 2007), and therefore of added interest within the context of having a brother or sister with ASCs.

Research aims

This study advocated the use of grounded theory to achieve the following aims:

(1) to explore the subjective experiences of typically developing siblings of children with ASCs;

(2) to explore how these experiences might impact on these adolescents' psychosocial adjustment;

(3) to assess any possible implications for service delivery;

(4) to generate a theoretical account of the pertinent factors influencing adolescent psychosocial adjustment, with a view to identifying possible areas for future research.

A more elaborate discussion of grounded theory and the rationale for its use in the context of trying to identify siblings' views for this study is provided in the following chapter.

CHAPTER TWO: METHOD

This chapter introduces the methodology of qualitative research and reasons why grounded theory was the preferred choice of approach for this study. This explanation includes discussion of the principles associated with grounded theory and reference to the author's position. A description of the study design, ethical considerations, participant selection, and recruitment procedure is also presented. Thereafter, a summary of the data analysis and issues of credibility and quality are provided. Prior to this the author provides an insight into the personal interests and motivations for conducting this research.

Personal interests and motivation for research

The researcher places a high personal value on attributes of humanity, such as kindness and honesty, believing that these attributes feed into an individual's ability to maintain personal integrity. The researcher has developed professional awareness and understanding of the clinical features associated with a diagnosis of ASCs, and has since developed a certain fascination with the brilliant ability of people diagnosed with ASCs "to be seemingly who they are". That is, there appears to be honesty, if at times blunt in approach, to the ways that people with ASCs communicate that perhaps has been misunderstood by society as it becomes increasingly entrenched in doing or saying the 'right' thing across contexts. A tiring business!

The researcher should add that he has had no personal experience of living with a sibling with ASCs; however, it is likely that this facilitated an open, curious, and explorative approach to the analysis.

A Qualitative Approach

A particular advantage of qualitative research methods is that they can be flexible and open-ended, facilitating a process of data collection that potentially enables participants and researchers to challenge existing assumptions about the meaning and relevance of concepts and categories (Charmaz, 1995).

There is no single qualitative method and different interpretative approaches accomplish different aims. One example of a qualitative approach to data analysis is

interpretative phenomenological analysis (IPA; Smith, Jarman, & Osborne, 1999). IPA aims to explore the participant's experience from their perspective and the meanings that people attach to experiences, whilst recognising that the researcher's phenomenological analysis will always be an interpretation of the participant's experience. The nature of IPA is to take a phenomenological approach to capture the quality and meaning of participant and researcher experiences, resulting in the researcher identifying and integrating themes into meaningful clusters.

Another option that could have been applied to this research question is Q methodology (Brown, 1980). Q methodology facilitates the systematic study of subjectivity regarding a person's viewpoint, opinion, beliefs, and attitudes (Brown, 1993). In a Q methodological study, participants are presented with a sample of statements about a specific topic. Participants are required to rank order the statements according to their preference or judgment relating to their personal point of view. This process is termed Q sorting and is considered to reveal the subjective viewpoints of participants (Smith, 2001).

It is feasible that IPA or Q methodology could be conceived as being appropriate analytical approaches for this study. However, the researcher was keen to explore the experiences and perceptions of siblings living with children with ASCs whilst adopting an investigative process that remained open and curious to the data that emerged in the participants' accounts. To this end, the researcher did not intend to test a hypothesis but to set out to develop on how existing theory could account for the research situation as it was.

Grounded Theory

This study aimed (1) to explore the subjective experiences of typically developing siblings of children with ASCs; (2) to explore how these experiences might impact on these adolescents' psychosocial adjustment; (3) to assess any possible implications for service delivery; (4) to generate a theoretical account of the pertinent factors influencing adolescent psychosocial adjustment, with a view to identifying possible areas for future research. Because previous research is limited in these areas and existing data has often been provided by parental reports, the suggestion here was that a grounded theory approach could help to explore the important experiences of living with a sibling with ASCs as told by the adolescents who participated in the study. To this end, the intention was to

draw out important information identified by the adolescents that might help to guide further focused research into children and adolescents who have siblings with ASCs.

Grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was chosen ultimately because the principal aim of the study was to investigate the experiences of a group of participants who have siblings with ASCs and to explore how these experiences impact on their psychosocial well-being. Grounded theory retains a focus on pursuing an exploratory process which is devoid of a rigid investigative framework and therefore not led by a search for specific outcomes. The end goal was to interpret the data with a view to deriving a theory grounded in adolescents' accounts of their experiences of having a sibling with ASCs within the wider context of their lives. Grounded theory also fits well with the researcher's philosophy about qualitative research in relation to how social processes might develop through a socially constructed language.

Grounded theory was developed by two sociologists (Glaser & Strauss, 1967) on the basis that there was a need in qualitative research to make sense of large amounts of unstructured data. The main focus of the grounded theory approach has been concerned with the study of social processes involving local interactions and meanings as related to the social context in which they occur.

Grounded theory has also been used previously for studying the experiences of siblings who have a brother or sister with a chronic illness (e.g. Charmaz, 1990) and more recently in investigating issues of awareness of disability following acquired brain injury (Yeates, Henwood, Gracey, & Evans, 2006). Grounded theory analyses can provide health professionals with alternative understandings of client's beliefs and behaviours than those readily available in clinical settings. The consideration here is that the use of grounded theory can be extended to the discovery of the individual experiential accounts of children who have siblings with ASCs, principally for two reasons as highlighted by Henwood and Pidgeon (1992). Firstly, these authors suggest that an over-reliance on theory testing and verification can neglect strategies for systematically generating new theory, which is relevant for domains of new inquiry or where new theories are required to replace old paradigms. Secondly, there is a need for research to be sensitive to people's own understandings as perceived from their own frames of reference, or from within their own socially situated worlds. These issues point to ways in which psychologists can fully benefit from conducting qualitative research.

Grounded theorists begin with general research questions, with the idea of building comprehensive theoretical systems from purposively sampled sets of relevant cases (Henwood & Pidgeon, 1995). Grounded theory aims to systematically move away from textual data gathered by interviews to a meaningful and organised theory of the participant's experience which combines all the variables and complexities represented (Henwood & Pidgeon, 1992).

Grounded theory principles approach data collection and analysis concurrently so that sampling is adapted as the data begin to emerge into theory (Strauss & Corbin, 1990). Theoretical sampling is a means of constructing tentative ideas about the data and progresses to theoretical saturation whereby gathering fresh data does not appear to reveal any new theoretical insights (Strauss & Corbin, 1990). Potter (1998) compares the process of grounded theory analysis to the operation of a sophisticated filing system where themes arising from the data collection are cross-referenced and categorised in a range of ways, involving coding, categorising and interpreting the material (see analysis section).

A social constructionist version of grounded theory (Charmaz, 1990) was proposed here specifically because it encourages the process of categorisation of the data to be dialectical and active, as opposed to one of passive observation by the researcher. Thus, the social constructionist perspective promotes an active researcher whose decisions shape both process and product throughout the research (Gouldner, 1971). The researcher is encouraged to be as creative as possible in generating theory, whilst being aware that complete objectivity is unfeasible (Charmaz, 1995). Observations by the researcher are bound by individual beliefs, perspectives, and pre-existing concepts, making it impossible for theory to simply emerge from the data. However, holding one's perspective in relation to the material allows the reader to understand how the researcher interacts with the data.

In this way, grounded theory necessitates developing, refining, revising, and transcending concepts within the discipline. Because a social constructionist stance elicits a fresh look at existing concepts, their revision and refinement is obligatory and therefore amenable to a study such as this where an initial literature review around the area of interest has been mandatory. Moreover, grounded theory emphasises the idea of theory being developed as an iterative process from data to theory rather than from

predetermined hypotheses, which renders it particularly suitable for use in a field where the existing knowledge is limited, confusing, and generally "theory-free" (Stoneman, 1993).

The Methods

Ethical clearance and considerations

Ethical approval for this study was received from the Leeds East Research Ethics Committee (see appendix 1); Research and Development approval was granted by NHS Wakefield District and by Leeds Teaching Hospitals Trust (Reference number: 10/H1306/30). Parents and participants were informed fully of how they would be involved in the research process with a view to being in a position to give their informed consent to proceed. Specific attention was given to the photo elicitation method that was used in this study (see 'Materials' section). For example, participants were advised not to place themselves at risk when making choices about taking photographs (i.e. not to go out in the dark; not to take pictures of random people or strangers; not to take pictures of illegal acts). Participants were also encouraged to provide information about the nature of the study and to request permission should they wish to take photographs of their friends or family members. At this stage participants were also informed that the photographs would become their property and that the researcher would view them only during the interview. Moreover, to ensure anonymity and confidentiality were preserved participants and their parents were guaranteed that photographs would not be used as a means of disseminating any findings from the data analysis. Consideration was also given to the emotional well-being of participants and for the potential for participants to become upset during the interviews; this was discussed in an initial contact meeting with parents and adolescents prior to obtaining their written consent to participate in the study. Consent was obtained from at least one parent and each adolescent. The limitations of confidentiality in relation to any disclosures by adolescents of material that might be considered harmful to themselves or others were also carefully explained. A strategic plan to inform the relevant general practitioner (GP) was in place should any of the participants have needed a subsequent referral to child and adolescent mental health services (CAMHS). Interviews were designed to be sensitive and empathic for participants and a number of warm up questions were asked to acclimatise participants to the interview process. Participants

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were interviewed alone on the understanding that they and their parents were in agreement to this process. There were occasions where a parent was present for the interview either because they or their child had expressed a preference for this to happen. Participants were advised that they could stop the interview at any point if they felt uncomfortable or distressed.

Setting

All participants were recruited from the CAMHS department of Wakefield District Community HealthCare Services, which provides services for 0-18 year-olds. All interviews were conducted in the home environment of the participants.

Design

A grounded theory approach was employed as part of a qualitative design. Photo elicitation methods, using participant generated photographs with the interview process, described in detail in the 'materials' sub-section of this chapter, were used alongside a semi-structured interview schedule (see appendix 2) to collect data from adolescents who had a sibling diagnosed with ASCs. The decision to use photo elicitation derived from the desire to utilise methods that could engage with young people and allow participants some level of control in the interview discussion (O'Kane, 2000). The responses to broad questions around the context of the photographs within the initial interviews with the adolescents, as concepts developed and themes emerged, informed the development of a flexible, semi-structured interview schedule which gave maximum opportunity for adolescents to explore their experiences of living with a sibling with ASCs.

Recruitment

Inclusion criteria

Participants were selected for inclusion in the study if they fulfilled all of the following criteria:

(1)   If they had a brother or sister diagnosed with autism or Asperger's Syndrome.

(2)   They were between the ages of 12-18 years.

(3) Their brother or sister had attended and received the diagnosis of ASCs from NHS Wakefield District Child and Adolescent Mental Health Services (CAMHS) or they had attended CAMHS themselves.

Exclusion criteria

Participants were excluded from the study if they were non-English speaking. The reason for this is because the chief investigator is English speaking only and obliged to become immersed in the data; time and financial constraints meant that it was unfeasible to recruit interpreters for this particular study.

In addition, participants were excluded from the study when it was considered that an interview might be detrimental to well-being. This was discussed with the parents and with the adolescent before making a decision to proceed. There was one occurrence where it was mutually felt by parents, the adolescent, and the chief investigator that an interview would have been inappropriate because of the risk of perpetuating and exacerbating some current psychological difficulties.

Selection process

Initially, a locality based member of staff reviewed files of children and adolescents diagnosed with ASCs held within NHS Wakefield District CAMHS and then contacted the parents of potential participants to enquire about their level of interest in the study. Where parents and adolescents were interested the member of staff requested permission for their contact details to be passed on to the author. At this stage the author made contact with parents and arranged mutually convenient times to visit for an initial introduction with a view to providing parents and adolescents with information sheets about the study (see appendix 2), answering questions about the study, and obtaining written consent (see appendix 2) should participants agree to take part in the study.

Participants

Adolescents aged 12-to-18 years living with siblings with a diagnosis of ASCs, including step/half siblings, were recruited for this study. In line with the grounded theory approach, recruitment was guided in principle by theoretical development with regard to maintaining a balance of participants aged between 12-to-15 years and 16-to-18 years and all participants that agreed to participate were interviewed. Due to time constraints this study

was able to recruit 11 participants; a further 3 families were approached and offered the opportunity to take part but declined because either parents and/or adolescents considered there to be a risk of distress occurring either during or after the interview. Participants included 6 males (age range between 12 and 18 years; mean age of 14.6 years) and 5 females (age range between 12 and 16 years; mean age of 13.6 years). All of the participants had siblings who had received diagnoses of ASCs from the multidisciplinary assessment team within NHS Wakefield District.

Material

The study used visual methods as a precursor and informative guide to maintain initial openness alongside a topic guide which incorporated some broad areas. The specific method identified for this particular study is photo elicitation, initially proposed by Collier (1957) as a valid method for eliciting longer and more comprehensive interviews whilst mitigating against the fatigue and repetition of conventional interviews. Photo elicitation simply incorporates the inclusion of photographs within research interviews (Harper, 2002) and helped to set a discussion with participants alongside broader topics defined in relation to the study aims. These topics developed as the interviews progressed. Photo elicitation has operated in a variety of subject areas including, social and family organisation (Guschker, 2000), the investigation of the impact of children on family dynamics (Steiger, 1995), and the examination of the social identity of children and adolescents (Hethorn and Kaiser, 1999). The idea of using photo elicitation in this study was moulded around the philosophical perspective of Harper (2002). That is, that photo elicitation can lead to deep and interesting conversation that also inspires collaboration as the researcher and the participant can discuss a photograph together to try to make sense of something. To this end, the aim was to elicit participants' perspectives in a way that reduced the potential power imbalance between researcher and participant thus enabling participants initially to choose and control what they wanted to depict—referred to as 'autodriving' (Clark, 1999). The autodriving approach of photo elicitation allows participants an opportunity to be less inhibited in the research process, fostering shared recall and promoting an egalitarian activity (Prosser, 2008). A further strength of autodriving is that the participants' photographs can provide projective and iterative stimuli which can reveal a narrative of participants' experiences. This can be helpful to the

researcher in terms of identifying or refining interview questions (Becker, 1975). That is, the researcher can be mindful of the influence of photographs in generating topics for discussion and assessing how these transpose, or not, to the questions incorporated within the interview schedule. This also fits neatly with the grounded theory principle of guarding against missing or closing down points of discussion prematurely.

Procedure

At the initial introduction visit and upon agreement by parents and adolescents to participate the researcher provided a disposable camera for each participant, giving the simple instruction to take 10 photographs of any area of their life that he or she regarded as significant. The researcher gave the participants the option of developing the film and being reimbursed at time of interview or arranging for the researcher to collect the camera and process the film before returning at a later date to conduct the interview. The majority of participants decided to process the film themselves and be reimbursed.

At the interview visit, the researcher reacquainted himself with the participant and their parents and generally chatted for a few minutes and confirmed that all parties wanted to go ahead with the interview. Before beginning the interview, researcher then asked the participant to line up the photographs on a table for convenience. The researcher then engaged the digital audio equipment and asked participants to talk about the photographs in whichever order they preferred. Discussion around the photographs frequently overlapped with questions on the topic guide in the interview schedule but, if not, these topics were introduced at relevant points during the interview process. Interviews lasted for between 46 minutes and 83 minutes with a mean time of 53 minutes. With the exception of 3 participants who requested their mothers' presence during interview, all participants were comfortable being interviewed alone. After each interview the researcher took time to write notes and personal reflections (e.g. feelings around how the interviews had proceeded; perceptions of how the adolescents had experienced the interviews; specific comments identified by adolescents about the interviews, such as "It's been really useful to get the chance to speak about what I have to say about having a brother with ASCs").

Analysis

All interviews were recorded and transcribed verbatim. The data were managed manually through the use of paper-based filing systems for recording coded segments. The decision to analyse the information manually was for two reasons. First, the author had experienced difficulties previously when using Nvivo (version 6; QSR, 2002) qualitative data analysis software. Second, the author was keen to guard against some of the criticisms associated with computer-based packages, such as the data becoming part of a forced and artificial framework which would have impeded creativity (Charmaz, 1995). The researcher recognises the benefits of these packages, however, in allowing creativity and flexibility once fully informed of the underpinnings of qualitative research.

Transcripts were read repeatedly to immerse the researcher in the data. Thereafter, the analytic process encompassed five steps:

(1) coding line-by-line

(2) focused axial coding

(3) selective coding

(4) theoretical sampling

(5) memo writing

Line-by-line coding of the first four transcribed interviews enabled the researcher to retain a proximity to the data whilst maintaining a neutral stance. This began by the researcher writing labels for the concepts in the margins of the transcript page (see appendix 3 for an example of a worked transcript analysis). Focused axial codes were then developed. This process involved using the most significant and frequent earlier codes to sift through large amounts of data. Selective coding was then deployed to synthesise codes into overarching themes which contained sub-categories that most accurately conceptualised and represented the data in meaningful ways. This process facilitated the emergence of theoretical insight (Strauss & Corbin, 1990). Constant comparison was used here as it is the most common method of analysing the coded data. The process of constant comparison compares categories obtained from individual and different interviews for similarities, differences, and general patterns (Glaser & Strauss, 1967); it is a recursive process of sampling and analysis which develops throughout the data collection. Analysis of the

relationship between categories is done as the definitions of the categories are developed and modified as more material is consolidated. This will result in some categories merging and others being separated, allowing for a more refined understanding of the full diversity and complexity of the data. This process also involved refinement of codes which included some being merged or removed to capture the truest meaning and to identify relationships and patterns between categories (Charmaz, 1995). Initial categories were descriptive but these evolved to being conceptualised more analytically throughout the iterative process. Theoretical sampling took place after the first four interviews through the exploration of exceptions and contradictions identified through initial analysis and with a view to exploring the experiences of participants in the latter stages of adolescence. Thereafter, interviews were conducted in pools of two, three, and two respectively which facilitated a reflective and reflexive process of data collection. Time constraints dictated that a maximum of eleven participants were interviewed. Although there appeared to be no obvious new categories emerging from the data after this number of interviews, it is unlikely that theoretical saturation was reached definitely. There is some evidence however to suggest that theoretical saturation can be occur after around twelve interviews (Guest, Bunce, & Johnson, 2006); Crouch and McKenzie (2006) also recommend that the interviewer is likely to remain fully immersed in the data if less than twenty interviews are conducted. Finally, memo writing occurred and transcended throughout the data collection and analysis as a means of assisting the iterative process and in helping to define patterns and relationships between categories (Potter, 1998).

Quality and credibility checks

The researcher incorporated a number of relevant quality checks throughout the data analysis in order to maintain research integrity. Debate continues with regard to issues around quality and credibility checks in qualitative research. For example, some researchers have suggested a list of ten quality checks for qualitative research (e.g. triangulation, coherence of the interpretation, self-evidential quality for the reader; see Elliott, Fisher, & Rennie, 1999). However, Reicher (2000) purports that not all of these quality checks are commensurate with the epistemological and ontological underpinnings of all qualitative methods. The checks for this study included credibility (how well the researcher's interpretation corresponds with others' descriptions and experiences);

auditability (the extent to which another researcher can follow the decision making process throughout the analysis); consideration of self-evidential quality for the reader (being consistently reflective about the research aims and the potential for clinical knowledge to contaminate data interpretation).

Credibility was addressed by being careful to ensure that ambiguous statements from participants during interviews were clarified; this process became more robust as interviews progressed and as specific themes emerged from the data. Regular meetings with supervisors helped the researcher to reconsider personal inferences attached to the data and to be aware of how such interpretations might shape the data and the choices made around theoretical sampling (i.e. younger versus older adolescents). The most influential meeting for learning about the data analysis occurred following the fourth interview. At this stage supervisors emphasised the importance of remaining open to all possibilities with the data, in line with the grounded theory approach. Through training in supervision the researcher developed analytic techniques and was able to move from descriptive coding to conceptualising themes emerging from the data. Although inter-coder reliability was not systematically attained, this process ensured that emerging themes were justified and firmly grounded in the data. To consolidate further confidence that themes were credible and grounded in the data, the researcher also attended a qualitative peer support group which catered for cross analysis of anonymised interview transcripts to monitor for coding irregularities and for interpretative discrepancies.

The researcher was able to maintain auditability by keeping a clear record of information and personal insights that helped to inform the decision making process. This created a transparent and comprehensive interpretation of the researcher's thinking around the data analysis. Personal assumptions based on clinical knowledge of ASCs were reflected on prior to data collection (e.g. "I bet it's difficult to have a sibling that sometimes just doesn't seem to want to be around you") so that the researcher was best placed to remain open and unbiased during the interviews. The recording of these personal reflections was also an essential aspect of memo writing which was an influential part of the development of ideas.

During the data analysis, the researcher was helped by supervisors to retain a focus on the research aims to ensure that these were being followed. There is a possibility that this may have narrowed the coding process whilst working through the transcripts; it

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is also helpful, however, to acknowledge that the researcher might otherwise have been distracted by the endless potential for coding and comparison (Lyons & Coyle, 2007).

CHAPTER THREE: FINDINGS

This chapter aims to give a credible interpretation of the information yielded from the interviews with participants. In doing so, this chapter focuses on presenting the themes identified within the data; further discussion and exploration of these interpretations is saved for chapter four.

Quotation conventions

The quotations used to illustrate the interpretations of the data have been modified only for the purposes of maintaining confidentiality and where it was deemed necessary to retain clarity for the reader. These quotations are indented, italicised, and enclosed within quotation marks. Explanations have been provided where colloquialisms have been included. Identifiable information has been removed, including names of places, friends, pets, and family members.

Table 1. Quotation conventions

Text description	*Convention*
Participants' quotes	In italics and between quotation marks
Short pause	..
Long pause	...
Missing Information	[word in italics]

Although all identifiable information has been removed, pseudonyms for participants have been provided to assist with the fluidity of the results and to help the reader to feel more acquainted with the data. The list of pseudonyms and relevant demographic data are illustrated in table 2.

Demographics of Participants

Table 2. Demographic information

Participant	Age/gender	Total children in house	Diagnosis of sibling with ASCs	Age/gender of sibling with ASCs	Ethnicity
Michelle	12/female	2	Autism	7/male	White British
Martin	14/male	2	Asperger's	10/male	White British
David	13/male	2	Autism/Learning disability	10/male	Asian Pakistani
Peter	12/male	2	Autism	14/male	White British
Carole	12/female	2	Asperger's	9/female	White British
Debbie	13/female	2	Autism	9/male	White British
Matthew	15/male	8	Autism	8/male	White British
Davina	16/female	3	Autism	10/female	Asian Pakistani
Mark	16/male	4	Asperger's	17/male	Mixed: White British/Black African American
Sophie	15/female	3	Asperger's	9/female	*Mixed: White British/Unknown
Tony	18/male	3	Asperger's	9/female	*Mixed: White British/Unknown

* - In these cases information regarding the ethnicity of the fathers of the participants was not held within CAMHS.

Overview of findings

Four overarching themes emerged from the data analysis. These included 'experiencing ASCs in daily life', 'adolescent psychological factors', 'social impact of ASCs on interpersonal relationships', and 'adolescents' perceptions of siblings with ASCs'. These themes also incorporated a number of sub-categories (see table 3) which facilitated discussion of the main issues underpinning each theme. Themes were found to interlink and combined collectively to help synthesise the data. This provided grounding for contextualising how adolescents adjust psychosocially to having a sibling with ASCs.

An important consideration regarding the findings is the influence of the photographs in relation to the themes and the sub-categories that emerged from the data analysis. Some of the discussions generated during the interviews were directly related to specific photographs. There were also numerous examples where the photographs were a facilitation rather than a prompt for certain types of discussion. References are made where quotations illustrated in this section were inspired by photographs directly or indirectly. The remaining quotations illustrated within the findings section were generated by general conversation initiated by the researcher in the context of the interview schedule.

Table 3. Overarching themes and sub-categories

1. Experiencing ASCs in daily life

Issues of responsibility
Seeing life as an increased challenge
Living life on tenterhooks
Adjusting to siblings' ASCs

2. Adolescent psychological factors

Managing emotions through coping strategies
Working through the demands of adolescence
Developing a sense of personality

3. Social impact of ASCs on interpersonal relationships

Relationships with sibling
Experiences of other internal family relationships
Relationships with extended family
Animal lovers: searching for meaningful attachments
Friendships with peers

4. Adolescents' perceptions of siblings with ASCs

The meaning attached to diagnosis
Aspiring for successful sibling development

Theme 1: Experiencing ASCs in daily life

This theme illustrates how adolescents felt about their experiences of living with a sibling with ASCs as part of everyday life. The theme focuses on the complex issue of how adolescents perceived their roles of responsibility in relation to the care of their siblings; the challenges that adolescents struggled with as a result of having a sibling with ASCs; how adolescents reported living life on edge as a result of having a sibling with ASCs; and how adolescents learned to adjust to and interact with their siblings. Notwithstanding the variance in the ages of participants and the differences in time frame since respective siblings had received a diagnosis, all participants were able to reflect deeply upon their daily experiences of living with a sibling with ASCs.

Issues of responsibility

The role of being a guardian for their siblings was a frequent topic within the adolescents' accounts. All adolescents felt an element of responsibility for their siblings. This manifested in different ways and was consistent regardless of the age of the adolescent in relation to their sibling. For example, adolescents that were younger than their siblings with ASCs were inclined to reverse the roles of little brother to big brother to protect their older siblings.

Peter: *"...he'll come a far distance from home like say [place] and he'll be like "Can we go home, yet? Can we go home, yet?" and I have to ride him out back up home to make sure he's safe."*

Other adolescents who were older than their siblings but towards the younger end of adolescence expressed an eagerness to be allowed more responsibility for helping out but that their parents failed to see the potential benefit of their input.

Michelle: *"...it's annoying because I do know how to calm him down but then mum and dad are telling me that I don't. It's annoying."*

Older adolescents were sometimes given the responsibility of minding their younger siblings in the absence of parents. This role was a significant challenge for adolescents, as they not only had to look after their siblings but also think carefully and responsibly before doing anything that they wanted to do on a personal level.

Davina: *"Like if my mum's not here, I'll have to be here to look after her [sister with ASCs] and stuff. Like you can't leave her alone so I've always got to think about her before I do anything."*

This sub-category of adolescents having a sense of increased responsibility as part of living with a sibling with ASCs has an interface with the sub-category of life being more of a challenge for adolescents.

Seeing life as an increased challenge

All of the adolescents described how their lives were put under some form of additional pressure by their siblings, specifically because of the behaviours associated with ASCs. Some adolescents found life tough living with their siblings, particularly when their siblings demonstrated challenging behaviour. Though the adolescents appeared aware of the difficulties that their siblings faced in life because of their ASCs, these adolescents expected to witness the repercussions of their siblings' frustrations.

Martin: *"Ah, [name] is autistic and he struggles to understand day-to-day things so he's like a can of pop that's been shaken all day so that when he gets home from school he's ready to pop. And it gets poured out on to us and he has a meltdown."*

Michelle: *"..at times he'll say "I'm gonna kill you". Like, one minute he's alright and the next he's just kicking off."*

Because these adolescents felt that 'meltdowns' (a term used by four of the adolescents to describe episodes where their siblings would have a significant outburst of shouting, screaming, kicking, punching) were inevitable, a sense of eternal pressure was experienced which resulted in their being a continual sense of feeling on edge for these adolescents. In some cases, adolescents found it too difficult to look beyond the negative impact of their siblings' ASCs, which had specific and significant impacts for some individual adolescents. The following excerpt was generated by a discussion around a photograph of an adolescent's bedroom; it illustrates how this adolescent was unable to have his bedroom the way that he would have liked, highlighting the difficulties in having their wishes or desires prioritised or actualised because of the additional attention and effort required to address the siblings' needs.

Martin: *"Mmm the room is like this because of [name's] meltdowns and appointments and that there's not enough time in the day to redecorate the wallpaper and stuff."*

Several adolescents experienced further emotional upheaval because they found that some of the specific behaviours associated with their siblings' ASCs (e.g. being kept awake until the early hours of the morning; asked questions constantly for hours; and having toys and personal belongings taken and broken) were so overwhelming and difficult to tolerate.

Peter: *"Just like... [pause] times what I've had in... out... I just euhh... It's hard to explain this one like other month what I just... it got on my nerves that much I... I actually cried myself to sleep."*

Photographs of the same feature (a bedroom, for example) initiated a variety of discussions. This adolescent spoke about how it was difficult to share a bedroom with her sister with ASCs.

Sophie: *" it's hard when [name]'s either being really annoying or when she's screaming or something.*

The adolescents reported that there was frequently an underlying current running through their minds that they were aware of the possibility that their siblings with ASCs could react to a given situation in an unpredictable fashion, making for an 'edgy' existence.

Living life on tenterhooks

The adolescents reported that trouble could erupt unpredictably with their siblings with ASCs. The adolescents appeared to have an understanding that their siblings could have increased sensitivity to even a simple misunderstanding that caused confusion. This made the adolescents feel that they had to have a heightened awareness of the sensitivity of their siblings with ASCs.

Tony: "*Sometimes it can ba... backfire big time, and she'll have just... cos you say somat and she won't get it...and it'll just spark something off.*"

Michelle: "*He's really loving when he wants to be. Like, for no reason he'll just come downstairs and hug mum and then he'll say "I love you" to mum and everything. And then other times he'll say "I'm gonna kill you". Like, one minute he's alright and the next he's just kicking off cos like he can't watch a DVD or he's got to go to bed or he can't do what I'm doing cos I'm older.*"

Some adolescents could remember times when the rigid nature of their siblings with ASCs had manifested in significant disruption. This quotation from Michelle was generated whilst she observed a picture she had taken of her brother with ASCs; it illustrates the precarious nature of the difficulties involved in foreseeing the fine details with which people with ASCs can struggle to cope.

Michelle: "*We went camping once and [name of brother with ASCs] started ripping the tent, kicking, screaming, hitting my mum in the face because my dad had cut his gammon up too small; it went on for two hours.*"

Some of the adolescents found it difficult to experience their siblings "turning" on them for no apparent reason, making life seem more of a struggle because of the uncertainty associated with the challenging behaviours associated with the ASCs. A photograph taken by one of the adolescents of his brother with ASCs led to the adolescent reflecting on some of his brother's behaviours and his reaction to his brother's behaviour.

Peter: "*..like today [name of brother with ASCs] came in and asked me if I was going out and got right nasty with me when I said I wasn't. Then I have to think to myself it's not him; it's not like him. But it is.*"

Adolescents experiencing life as more challenging and living their life on tenterhooks because of their siblings with ASCs was closely linked to the category of how siblings seemed able, or otherwise, to adjust to living with their siblings.

Adjusting to siblings' ASCs

Six of the adolescents expressed an increasing acceptance or tolerance of their siblings' ASCs behaviours that presented the greatest challenges (e.g. meltdowns, physical aggression) as well as routine and repetitive tasks, such as helping to button shirts and tie shoelaces. This acceptance appeared to be associated with the length of time that adolescents had been aware of their siblings' diagnosis. To this end, adolescents that had known about their siblings being diagnosed with ASCs for longer seemed to have developed an ability to have come to terms with adjusting to meeting the demands of their siblings.

Davina: *"...because I'm used to it now, it's just like normal now for me to do things that she needs doing, for her."*

Increased acceptance of adolescents towards their siblings also appeared to coincide with improved knowledge and an enhanced understanding of ASCs and how these manifested in the behaviour of their siblings. This particular adolescent frequently referred to a photograph of his brother with ASCs during his interview.

David: *"I was less understanding then, and, [name], he, over time, um... we learned more about him because he explained to us what we needed to [pause] um... assist him with."*

Other adolescents used photographs of their siblings with ASCs to help them reflect on noticing changes in their emotional reactions to their siblings. That is, increasing their understanding of their siblings made living with them easier but this did not mean that there were not times when feelings were strained.

Davina: *"I think it's 'cos I understand her better. I still kind of like, like it's still hard sometimes 'cos you just feel like crying with her sometimes but not like it used to be before."*

As adolescents built knowledge and increased their understanding of ASCs and how these impacted on their siblings, adolescents described being able to develop skills in managing and interacting with their siblings more effectively. Adolescents expressed how they felt that sometimes they could be more helpful than their parents in managing negotiations with siblings or were at least capable of simulating more of a parental role in looking after their siblings if required.

Michelle: *"Like say if [name] asks my mum if he can watch a DVD and my mum just tells him no without giving him a reason then he'll kick off... and I feel like saying to my mum that if you give him a reason and not just say no then he probably won't kick off..."*

There were also adolescents who felt that their lack of understanding of ASCs made them feel uncomfortable about the idea of informing their friends about the difficulties they experienced in relation to their siblings' ASCs, which negated a potentially valuable source of support. Some adolescents found it helpful to refer to photographs of friends when discussing their understanding of ASCs.

Tony: *"It's [ASCs] not an easy thing cos people don't really know about it...it's just letting select friends know but I don't know it well enough to try and explain it to other people."*

Not being able to, or feeling uncomfortable with the idea of discussing with friends the consequences of living with a sibling with ASCs, also had an adverse effect on how some of the adolescents were able to adjust because they perceived this as a part of their lives which no one could empathise with or understand and so kept it private.

Sophie: *"It's like not many of my friends know that she's autistic or anything. So they don't really know what I have to do when I get home...what I have to deal with when I get home."*

The notion of having to pretend on occasion to be a friend to siblings was also a feature of adolescents' accounts. Adolescents talked about needing to adapt to a particular role or create a false reality with their siblings depending on the situation so that they could contain their siblings. One adolescent made the following reflection whilst she observed a photograph that had been taken of her and her sister with ASCs:

Carole: *"It's like you've got to pretend that like you're one of her mates and you've got to act like same age as her so that she don't get annoyed."*

All of the adolescents considered that adjusting to living with siblings and their ASCs took effort and energy. This effort and energy extended to various areas of the adolescents' lives and appeared to result in adolescents feeling as though they were often placed in positions where they had to make personal compromises.

Peter: *"I let him come out with me most of the time, but it does annoy me sometimes. He should be with his own age group."*

Other compromises were more internalised by the adolescents. Some adolescents felt that they had no option but to contain and hide their emotions in the knowledge that there was

already too much expressed emotion in the family. To illustrate this, one adolescent talked about how she had purposefully asked for her photograph to be taken whilst she posed with a blank expression on her face.

Davina: *"I've kind of had to learn to control my like emotions and my feelings...cos there's enough that goes on already."*

Several adolescents also described how they would often have to give in to their sibling demands if it meant that a potential fiery situation could be avoided. In this way, adolescents appeared to take on the responsibility of adopting a peace keeping role which often came at personal expense.

Mark: *"Say if it were mum and [name] that were arguing, I'd like, say if I had something [name] wants but I didn't want to give it to him then he started arguing then mum had to get involved, I'd just give it to [name] straight away just to save my mum the hassle of trying to calm him down and like see to him."*

In summary, this theme has provided an umbrella for the underpinning issues which adolescents have described as important in their everyday experiences of living with siblings with ASCs. The issues described by adolescents include (1) the demands created by the various roles of responsibility that can be attributed to having siblings with ASCs; (2) experiencing life as being challenging and pressured because of meltdowns and other repercussions that occur because of their siblings' ASCs, and the emotional distress that results as a consequence; (3) the concept of having to live life on the edge because of the unpredictable nature of their siblings with ASCs; (4) how adjustment to their siblings' ASCs occurs in adolescents, with regard to increases in knowledge and understanding of ASCs and how this impacts on adolescents' abilities to develop ways to manage their siblings in times of distress.

Theme 2: Adolescent psychological factors

This theme reports on the adolescents' experiences of how it is to live with siblings with ASCs whilst managing some of the typical developmental tasks associated with

adolescence, such as identity formation, developing relationships with peers, and studying for GCSE's. This theme also includes descriptions of some of the psychological factors that arose in adolescents as a result of their experiences. Several salient sub-categories emerged within this theme. These sub-categories incorporated adolescents' accounts of how they rely on finding ways of coping; how adolescents described dealing with the demands of adolescence; and descriptions of how adolescents felt about developing their sense of personality in respect of living with a sibling with ASCs.

Managing emotions through coping strategies

To some extent, the coping strategies used by the adolescents and the reasons for their particular approaches can be considered typical of those used by adolescents in general. However, all of the adolescents described various strategies that they found helpful for managing their emotions in relation to living with a sibling with ASCs. To this end, many adolescents took photographs of their bedrooms to help describe benefitting from being able to physically escape to a place of sanctuary where they could feel as though they had more control of how likely they were to be able to relax or just find peace.

David: *"If I'm upset, I can just go up to my room and leave the tension and [pause] almost, it's like m... my own personal space."*

In some cases, adolescents were able to reflect on how withdrawing to their room, for example, might impact on how they interacted with their family. In these instances adolescents saw the benefits of finding personal space as being a reasonable and pleasant thing to want to do and that it didn't mean they were turning their backs on their families.

Debbie: *"I like being in my room 'cos generally it's a bit hectic... So it's like, an escape to my room, it's not, I wouldn't want to give up my family but it's nice having a bit of quiet and time to yourself."*

To avoid experiencing personal negative feelings, a small proportion of adolescents found that they tried to block out their emotions and forced themselves to pretend to be as happy as possible for much of the time. However, there was awareness that this was perhaps not an adaptive or productive way of managing emotions.

Sophie: *"I don't show my emotions much. I try and stay as happy as I can for most of the time. Because I don't really express how I feel. But then it gets like a time bomb which goes off every once in a while."*

Several adolescents discussed how their imagination could be a useful method for distracting them from the real world of living with their siblings with ASCs.

Mark: *"...normally I'm just daydreaming, thinking about completely different things."*

Distraction was also seen by some adolescents as helpful for being providing a dual role of helping the adolescent to reduce stress levels and simultaneously assist with school work. This particular adolescent used reading as a way of becoming absorbed by their imagination which helped to alleviate stress levels. Several of the adolescents were able to refer to a variety of photographs that they had taken which helped to demonstrate some of their chosen distraction techniques.

David: *"... it's very good to read because it's just like really calming, and you escape all the tension and things when you read, and it builds your vocabulary, and it's just amazing."*

For one adolescent distraction formed the important role of providing an alternative to difficulties with self-harming, as it helped to contain and diffuse levels of anger which might otherwise have manifested in self-harming behaviours.

Michelle: *"Then there's my basketball hoop because that helps me with my anger instead of self-harming. So instead of taking it out on myself I'll go and take it out playing basketball."*

For other adolescents, individual interests were depicted by photographs that they had taken. These specific interests seemed to be important not just for distraction purposes

with negative connotations but also as a means of creating fun and enjoyment for themselves that they could look forward to as something special to do each week.

Debbie: *"That's the horse I ride at my riding school and he's called [name] and he's quite important because I really enjoy horse riding and I go once a week and it's just quite a fun activity to do for me.*

Sophie: *"This is a children's group I go to. I like it cos it gives me something to look forward to."*

Different adolescents were satisfied with doing an activity because it entertained them for a while and helped to occupy their minds.

Matthew: *"I like it [Lego] cause it keeps me occupied and each model's different; it keeps me entertained for a while."*

One adolescent reported a focused activity that he frequented with the specific aim of openly discussing his experiences with others about living with a sibling with ASCs. His adolescent appeared to gain something from knowing that there were other brothers and sisters who shared similar experiences with him.

Martin: *"I go to groups from time to time...it's nice to know that you can actually go somewhere and meet other kids who are going through the same thing."*

Without exception the adolescents discussed at length the role of friendships as a coping mechanism. One adolescent, whilst looking at a photograph he had taken of friends, talked about how important it was to have them for support, particularly when things were tough at home.

Mark: *"Yeah, yeah if I didn't have my friends I don't think I'd cope at all when home life is difficult."*

Several adolescents described how friends were a source of confidence for issues which they perhaps did not want to discuss with their parents.

David: *"There might be something that you can't like talk to your Mum about, and then your friends are always there for you."*

The option of visiting friends as a coping strategy was also observed by adolescents as having multiple and combined benefits. These included generating a feeling of being accepted, facilitating socialisation, and also finding an environment where they could have some fun. One adolescent had taken a photograph of her friend's living room to emphasise the importance she placed on being able to visit and spend time there.

Sophie: *"I just go round to my friend's to have fun and see everyone cos I like see the family and the family know me. So I go to see them as well. I'm like part of the furniture there!"*

These coping strategies are implicitly linked to dealing with the demands of adolescence and there is therefore some overlap with typical developmental adolescent behaviour. The next sub-category expands on some specific issues that adolescents discussed around what it meant for them to be living through their teenage years.

Working through the demands of adolescence

All of the adolescents made reference to finding life tougher as they entered adolescence. Mostly, these references were toward adolescence being a stage of life which required a greater degree of personal responsibility and effort. For some adolescents these issues were compounded by the perceived pressures associated with having a sibling with ASCs.

Martin: *"The fact that I have got all these other problems as well as [sibling with ASCs] because when you're younger, you know, everybody else looks after your problems but when you become a teenager you get more problems and then you've got [sibling with ASCs] as well."*

Other adolescents were reaching a stage where they needed to make educational choices and were beginning to recognise the importance of such decisions as well as their perceived self-efficacy to achieve success in statutory examinations. These considerations appeared as isolated anxieties away from other worries around living with siblings with ASCs.

David: *"Um... this is a thing I haven't given much deep thought to but I guess my GCSEs'll be a big thing and...I guess I have a bit of a worry of if I'll do well enough or if...but I'm gonna have to give it all I can do and then just...at least I tried to do my best."*

For some adolescents reaching the stage of puberty was expressed as an additional factor to accommodate in life other than the experiences of living with a sibling with ASCs.

Davina: *"Obviously I was growing up as well so I was going through things myself."*

Adolescents' discussion around tackling some of the typical demands of teenage life had a specific focus on thinking a lot about how they perceived their sense of identity developing. The next sub-category depicts the factors that adolescents highlighted as being important to them for developing their sense of personality.

Developing a sense of personality

Eight adolescents discussed several factors that they saw as important in helping to form their personal characteristics and sense of identity. The emphasis for adolescents was focused on these factors having what they saw as a positive influence on how they developed in themselves and in relation to their perceptions of other people, including their siblings with ASCs. This gave the impression that some adolescents had developed a tolerance and acceptance of difference due to their experiences of living with siblings with ASCs. Several adolescents reflected on photographs they had taken of their siblings with ASCs to discuss the impact on their personal development of their siblings with ASCs. This impact extended beyond how they questioned their potential attitude towards people with disabilities in to other areas of life that included how they envisaged their general behaviour might look if they hadn't experienced living with a sibling with ASCs.

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David: *"A big impact because if [name] wasn't here, I don't th... I don't know whether I'd have respect for other disabled people, whether I would be... if I would be someone who goes out every night on the streets with their mates and just hangs around."*

Some adolescents had taken photographs of and were able to identify other people close to them— parents, for example— as having an impact on developing a personality style that included traits such as being non-judgmental.

Debbie: *"I think my mum and dad have probably had the most influence on me because they've taught me not to judge people as much as I probably would have done if they hadn't have taught me that."*

A few adolescents found it difficult to be specific about particular people that they thought might have helped mould their personal development. However, these adolescents were clear that other people in general had been influential in terms of how they interacted with people and their attitude to life.

Matthew: *"I think the people in my school and the people, well the world around me has had a big influence on how I behave towards people and it has taught me a lot about learning to accept things."*

Whilst looking over photographs that they had taken of their friends, several adolescents expressed friends as being pivotal in how they saw their development of personality, acknowledging the benefits to be gained from being amongst a circle of friends that were able to be of positive influence.

Peter: *"If you're around good friends, then you... you know you turn to like that sort of characteristics, and it's really good so..."*

The majority of adolescents described how they perceived themselves as being different personalities depending on the situation. The adolescents were aware that in particular

they would act differently when with their friends than when they were at home. This feature of these adolescents' accounts was linked to them wanting to be noticed by their friends in ways that they could perhaps not experience in their home life because they felt that they needed to be constrained and contained in how they acted to keep a quiet and stable environment.

Davina: *"Well like they [friends] know me different than what I'm like at home. I dunno, I joke about with them and stuff cos I can when I'm not at home so they think obviously I'm funny and loud and weird."*

This desire to be acknowledged by friends was further developed in some adolescents' stories, in that the adolescents embraced the opportunity to assert leadership in certain circumstances; something that was unlikely to occur at home.

Michelle: *"Like when we go to a theme park I'm the one that wants to go on all the rides and tries to get everyone to go on all the rides. And then once they've been on they'll be like "I wanna go on that one again and they'll say to me you're immense".*

Some of the adolescents even described how they felt they hid their personality or had been unable to show their 'real' personality to family members, except in isolated situations where time and space allowed them to feel able to do so. This was seemingly different to the traditional differences in how adolescents might behave at home as compared when with their peers. That is, adolescents here appeared to have a real desire to behave in a more liberated and care-free fashion in the family home much as they might do with their friends.

Sophie: *"I don't think my mum knows as much of my personality because I've never really shown it, like my fun side apart from when we go like shopping or something then I'm like more fun and bouncy and stuff."*

Five of the adolescents discussed how, in contrast with their friends, they felt it important to focus on their long-term future. These adolescents showed signs of increased maturity and signified that they valued making plans and having a sense of order about their lives in

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the present so that they accrued the benefits in the longer term. One of these adolescents had taken a photograph of some school books to show how she valued her education as a means for promoting her future prospects.

Debbie: *"...some [school peers] are quite bright but most of them are more phased by having a good social life and being cool. And I'd rather get good school grades and have a better life after school cos that's like the long term."*

Some adolescents living with younger siblings with ASCs also saw the responsibility as helping their personal development in practical ways, such as preparing for motherhood.

Davina: *"...it's kind of getting me ready for my own life with my own children."*

To summarise, this theme and its associated sub-categories has identified the impact of the psychological and internal factors that emerged from adolescents' experiences of living with siblings with ASCs. The principal issues discussed by adolescents include (1) regulating emotions by using a variety coping strategies, such as escapism, distraction, and friends; (2) the additional pressures of working through the typical demands faced during adolescence that can include increased responsibility, puberty, and school work; (3) establishing a sense of identity and understanding the factors that influence their personal development, not least their experiences of living with a sibling with ASCs.

Theme 3: Social impact of ASCs on interpersonal relationships

This theme outlines adolescents' descriptions of how their siblings' ASCs had impacted on social and interpersonal areas of life. Five sub-categories were identified within this theme. The sub-categories that emerged from the analysis included how adolescents described their relationships with their siblings with ASCs; adolescents' experiences of other relationships within the nuclear family; how adolescents perceived the value of relationships with extended family members; the importance adolescents placed on family pets; and how adolescents described the meaning of friendships with peers.

Relationships with sibling

All of the adolescents discussed the impact of ASCs on their relationships with their siblings. Many of the adolescents described relationships with their siblings with ASCs as changing over time and in quality but they saw this as ordinary in the sense that relationships tend to fluctuate. The illustrative quotations selected highlight that these discussions also ranged from some accounts being positive and fulfilling in terms of the quality of sibling relations, to others that were predominately negative. Some adolescents had taken photographs of their siblings and were able to use these to demonstrate that when it came to understanding their relationships with their siblings, sometimes it was a case of taking the rough with the smooth and making the most of the good times.

> Mark: *"It's like yin and yang, there's a good side and a bad side and it's like we have, we have amazing days and we have average days and we have terrible days but when it is a good day you see a massive change in him and it does help him."*

One adolescent (Mark) also described how he had noticed a significant change in his sibling's attitude towards him since receiving the diagnosis of ASCs. However, the adolescent had also become aware that the sibling with ASCs did not seem to have generalised this change in attitude towards a younger sibling in the family. In fact, the sibling with ASCs had become much closer to one of his younger siblings and adopted a paternal figure for the youngster. (Although not quoted, this had coincided with the father leaving the family home).

> Mark: *"I mean it's, he's still stayed really close with [name] and stuff but he like seems to resent me a lot more."*

Six adolescents expressed that, despite finding their sibling with ASCs a challenge at times, this did not impact on their sibling relationship and that they deeply valued the relationship with their siblings. Several of these adolescents used photographs that they had taken of their siblings with ASCs to facilitate discussions around sibling relationships.

David: *"Um... Like I said before, you couldn't wish for a better brother, and, at times, he's annoying and I just deeply appreciate it because we both have a deep connection of each other."*

Peter: *"Sometimes when my brother kicks off, I have just got to forget it and help him...we love each other and I wanna help my brother."*

There were also a few adolescents who described their relationships with their siblings with ASCs as very difficult and strained, largely because of the challenging behaviours that they were happened to experience daily.

Martin: *"It's really difficult being with [brother with ASCs] because it is really hard when he is kicking off and that."*

Some adolescents had developed high thresholds with regard to tolerating high levels of aggression from their siblings with ASCs, and seemed to have established their personal frameworks for what might be considered to transcend the boundaries of acceptable behaviour.

Michelle: *"Ye, it's got, I think that's the worst I've had for ages because normally he just uses his fists and feet and nails and teeth and head but I think he's took it way too far this time by actually using a weapon."*

Another aspect of adolescents' accounts of their relationships with their siblings with ASCs was connected to what might be described as typical sibling rivalry. This discussion evolved around adolescents reflecting on how they were also aware that their relationships with their siblings were not always dominated by ASCs but often by traditional sibling disagreements. To this extent, the adolescents recognised their parts in situations of conflict.

Peter: *"I know all his little sneaky moves and what winds him up and what... what he tries to do to wind me up...sometimes we have an argument over my cousin and stuff*

like that... and bikes and toys... who's got biggest bedroom, who should have it decorated first...we'll both argue."

From the adolescents' accounts here there also appeared to be a consistency across gender in respect of competition between siblings. For example, adolescent girls living with sisters with ASCs described how there would be some rule bending in a bid to win when playing games. This adolescent referred to a photograph she had taken of her sister with ASCs when describing some of her patterns of behaviour when playing games.

Carole:*"She doesn't [sister] always like to play fair...if I win the game she doesn't like it. Sh... she claims [yawn]... Sorry. Uh... She claims that I've cheated, and she thinks I've been cheating just cos I've won."*

Where adolescent boys had male siblings with ASCs and male siblings without ASCs this competitive edge would become apparent in each brother to varying degrees when a particular social situation or setting provided the necessary ingredients. This adolescent had arranged for a photograph to be taken of him and his three brothers and used it to talk about their competitive tendencies.

Mark: *"Yeah we are competitive with each other but like [name] and [name] are competitive with each other, like on Fifa they'll not stop until someone wins and [name] brings out a competitive side in [name]."*

The inter-sibling rivalry described by adolescents is linked also with the next sub-category with regard to how living with a sibling with ASCs was perceived to impact on other relationships within the nuclear family.

Experiences of other internal family relationships

All of the adolescents spoke about family relationships. Some adolescents described their general perceptions of how their family viewed them. Although some of these perceptions did not appear to have explicit links with their siblings' ASCs, it seemed important to include them in the analysis as it provides a context in which to discuss specifically the

impact of ASCs on family dynamics. In this regard, some adolescents emphasised the importance that they placed on having family support available to them. Eight adolescents appreciated feeling a sense of unity within the family. This unity provided adolescents with social support which made them feel as though there was always help available for when they felt stressed and needed assistance in dealing with a problem. Adolescents frequently used photographs taken of family members to illustrate their perceptions and experiences.

David: *"Um... I'll start with my Mum. Mum, she's just amazing cos she always helps me and if I'm stressed or something, she'll always come and find a way to sort the problem, and we all stick together, like a little group."*

Some problems for adolescents arose from difficulties with their siblings as a result of their ASCs. The adolescents appreciated and took comfort from having a mutually supportive understanding with other family members of the specific issues created by siblings' ASCs.

Martin*: "I took this photo because my mum will give me support 24/7. She's seen it and actually lives it just like me about how [name] acts and behaves and, you know, we're in the same boat so it's good to know there's someone there that you can talk to."*

Other adolescents indicated that on the whole they felt undervalued and dismissed by family members, unless a situation arose in which family members felt obliged to make an effort to be inclusive.

Matthew: *"...they're [family members generally but other siblings in particular] normally only happy with me when they're wanting to play a game with me or when I have something like chocolate or biscuits or sweets. Otherwise they're not really that friendly. Well, they're friendly when strangers are around."*

Other adolescents showed their emotional pleasure in terms of being pleasantly surprised when they felt noticed and acknowledged by family members, in a way that suggested these adolescents often felt as though they weren't taken seriously.

Michelle: *"..with my family I was feeling really happy because all my family actually bothered to come downstairs or from the kitchen to actually let me take the photograph."*

The effects of siblings' ASCs on the family varied in degree and in nature. Adolescents described a number of issues that ranged from impacting on the entire family to one individual family member. Different accounts from the adolescents indicated also that the effects on the family of siblings with ASCs could be very positive or induce a culture of blame and antipathy towards the sibling with ASCs. For some adolescents there were powerful and positive effects on all the family when siblings with ASCs were seen to be having a stable day and were apparently content within themselves. Interestingly, one of the adolescents also introduced the notion that during these days their sibling was almost back to being how he always was, his 'old self'.

Mark: *"Yeah it helps everyone, to see [name] have a good day, everyone's happy then. If [name] had a good day, he's full of jokes, that means that he's brightening everyone else's day up by just being himself."*

There were several adolescents who not only felt personal emotional upset because of their siblings' ASCs but also empathised and were sensitive to the impact on other family members. This added to the emotional distress experienced by the adolescents.

Peter: *"he's [sibling with ASCs] had me in tears before, my Mum and then my Dad. And it upsets me cos we try and look after him as hard as we can, but he just... he don't listen most o't time and it's hard for my Mum. I know it is."*

The experiences which adolescents expressed in relation to internal family dynamics extended to the importance which they placed on relationships with extended family members, as described in the following sub-category.

Relationships with extended family

This sub-category had a focus on adolescents searching for ways to make good use of support networks readily available in the form of extended family members. For some

adolescents the search for respite was the main advantage of being able to make use of relationships with external family members. Adolescents described being able to find a place in which they could feel comfortable and relaxed in the knowledge that their siblings with ASCs would not be challenging in ways that they would be in the home environment of the nuclear family. In a similar vein to the previous sub-category, this was another area in which a large proportion of the discussion was generated by photographs taken by the adolescents.

Martin: *"I took this picture because I know I can always go to my aunty and I go there quite often and it's a nice place to be because [sibling with ASCs] won't kick off there so it's a nice relaxing place to be."*

Other adolescents also enjoyed reaping the rewards of having satisfying and fulfilling relationships with external family members. This was of special additional value to the functional objective of being able to get away from the family home and thus be able to avoid difficult and challenging situations that might occur because of their siblings' ASCs.

Peter: *"I... I chose my Granddad because I love him, and me and him will go all over together, and I spend time with him more than I do in my house."*

Adolescents also valued external family relationships for providing an outlet that allowed them to offload about their difficult experiences. Of particular importance was not necessarily the total understanding that the external family member had of ASCs but more so the proximity in ages which enabled the adolescents to feel as though the relationship created a pool of empathy for them.

Martin: *"And this is my cousin and she gives me a lot of support because I can call her and that and she doesn't know about [sibling with ASCs] 100% but she's seen it and she knows how I'm feeling so it's good to know that there's someone there who's close to my age who I can talk to."*

The ability to remove themselves intermittently from the vicinity of their siblings was prevalent in all the adolescents' accounts and drew both stark similarities and contrasts in

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adolescents' experiences depending on the context of their individual circumstances. For example, two siblings from the same family had very different accounts of their experiences of their sibling with ASCs as illustrated by the following quotations. The first quotation is from an adolescent that lives with and shares a bedroom with her sibling with ASCs.

Sophie: *"...when she's [sibling with ASCs] had a problem at school and shouts that I'm stupid and she gets all bouncy and everything, that just does my head in like cos I've been at school and I'm tired and everything and I just wanna relax. She's really annoying."*

Another sibling from the same family but often living away from the family home expressed some perspectives that hinted at greater tolerance levels, perhaps because there was frequent departure from the home which created an opportunity for respite. This potential for increased tolerance overlapped with the importance of needing somewhere to escape to as a place of sanctuary.

Tony: *"It don't really affect me much cos I'm away a lot. You can have a laugh with her [sibling with ASCs] but she will go too far sometimes cos she's in your face; it does get annoying."*

Regardless of how tolerant or accepting adolescents were of their siblings' ASCs, there was an undercurrent that they also looked for opportunities to find other meaningful relationships.

Animal lovers: searching for meaningful attachments

Seven adolescents talked about their affection for animals and how much they enjoyed having animals as part of their lives. These adolescents had taken numerous photographs of a range of animals and enjoyed talking about them in a variety of ways. The adolescents expressed the reciprocal nature of friendship as being an integral aspect of their relationships with pets in ways that were parallel to the processes of building relationships with humans. These relationships with animals were private and personal and sometimes connected to activities that were away from the family home, in places where the adolescents felt they had time and space to nurture such relationships.

Debbie: *"...'Cos like at first it takes a while for the bond or whatever you want to call it, to connect to the, between the rider and the horse. But now well I imagine we're very good friends."*

One adolescent valued the closeness of the relationship with the animal with an emphasis on the friendliness of the animal and the trust that it had placed in him.

Matthew: *"It [chicken] were really friendly and it were coming to eat out me hand and some out the back garden and it is... friendly."*

Animals evoked a mixture of emotions in the adolescents because of the attachments and connections between them. These emotions fluctuated and varied depending on changes in the adolescents' situational context and circumstances that were out of the adolescents' control. For example, the following two quotations respectively illustrate a decision for a pet rabbit to be removed from the house because it had become aggressive and the impact of moving accommodation.

Michelle: *"With [name of pet rabbit] I was feeling happy but sad at the same time knowing that like it would only be a couple of days until she'd be going."*

Matthew: *"I don't really get to see the chicken anymore which is upsetting."*

One adolescent also expressed the impact on his mood and the general mood of the family as being one of relief and happiness at the return of a pet cat that had been missing for ten days.

Peter: *"We'd all just had... had a laugh cos cat had just come in, and I were feeling right happy cos he'd come back and he hadn't been back in about a week and a half".*

These relationships with animals were important to adolescents. The accounts of their experiences with animals suggested that they added emotional richness to the

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adolescents' lives. In a similar vein, the concept of peer friendships was also an obvious sub-category that emerged from the data analysis.

Friendships with peers

All of the adolescents discussed relationships with their peers. This discussion took on various guises which included how adolescents described the values that they placed on friendships; what adolescents perceived to be the function of useful peer relationships; and how they considered their siblings with ASCs impacted on their peer friendships. Some of the adolescents emphasised that their friends needed to have certain qualities, such as ability to understanding as well as a flexible and non-judgmental attitude. One adolescent had taken a photograph of his best friend and discussed what special values he liked about him.

Mark: *"I dunno, he's just like an understanding person, like he won't judge me no matter what I say."*

Several adolescents also highlighted the positive impact that their network of friends could have in terms of providing a social network for their siblings with ASCs. This was significant for some adolescents as it combined a number of advantages consisting of enabling the adolescents to feel supported, to enhance their social life, and to be a part of their siblings' lives. This helpful mixture of benefits also helped the adolescents to feel that their siblings were accepted notwithstanding their ASCs. One adolescent used a photograph of three friends to initiate a conversation which helped him to describe the importance of his friends to him and to his brother with ASCs:

David: *"And they're always there, and they understand my brother which is... it's amazing cos, and not only are my friends to me, they're friends to my brother."*

Adolescents also perceived the function of friendships with peers from the perspective of just having company and people with whom they could fill in spare time. In some

circumstances, adolescents described their peers using photographs that they had taken as being the reason that they continued to follow a pathway in life, such as college for example.

Mark: *"I wouldn't be able to go to college without friends, it's like college would just be dull completely. And it's like, in college I have a lot of free periods so it's like, what would I do in them without having someone to sit with and have a laugh."*

In contrast, another adolescent had taken a photograph which illustrated their ability to find different ways to keep in touch and socialise with their peers through a world of virtual reality. This provided this particular adolescent with alternative opportunities for socialising, given the limitations and restrictions to go out and socialise because of having the responsibility of looking after her sibling with ASCs.

Davina: *"I'm on Facebook a lot..cos I don't out that often so it's how I socialise.. just like stuff what teenagers do really."*

There were also adolescents that described being unable to develop friendships with peers because of the pressures of having a sibling with ASCs. That is, these adolescents described feeling that having a sibling with ASCs created a barrier to having a social life and that this had a negative impact on their sense of self-esteem because they felt alienated from their peers.

Martin: *"Well it's like hard to socialise when you know you've got [name] and the pressure of [name] and that so it gets your self esteem down and then you don't feel as comfortable like talking to friends and that whatsoever. So it's harder."*

In contrast to the positive impact for adolescents who perceived their friends to be non-judgmental, the fear of being judged in association with having a sibling with ASCs was a significant factor for some adolescents. For one adolescent the idea of being judged as similar to their sibling with ASCs by association made it difficult to aspire to making the effort to socialise and develop relationships with peers.

Martin: *"...because some people interpret you as being the same as your brother and who he is so it's not as easy to socialise and that."*

In summary, the description of this theme has outlined several sub-categories identified as being important features of how adolescents feel having a sibling with ASCs impacts on their social life and interpersonal relationships. Adolescents described their relationships with siblings with ASCs as fluctuating, challenging, and competitive. Adolescents also had a focus on describing their experiences of relationships with other members of the nuclear family, such as parents and other siblings. Relationships with extended family members provided adolescents with opportunities to find respite from environments that could be challenging because of their siblings' ASCs. The chance to develop loving and fulfilling relationships was also an important feature of adolescents' accounts, as was their appreciation of having someone to empathise with their situation. Attachment to animals, particularly pets, was also a strong trend within this theme. In discussing their friendships with peers, adolescents also expressed the values and the meanings they attached to these friendships as well as the impact they perceived siblings with ASCs had on their social life. In keeping with the perceptions of adolescents, the final theme identified by the data analysis illustrates the particular perceptions that adolescents discussed in relation to their siblings with ASCs.

Theme 4: Adolescents' perceptions of siblings with ASCs

This theme illustrates how adolescents regard their siblings with ASCs as individuals in a variety of contexts. Within this theme, three sub-categories were identified as being integral to adolescents' perceptions of their siblings' lives. These sub-categories included (1) the meaning that adolescents attached to their siblings' ASCs diagnosis; (2) the aspirations and expectations that adolescents held for the successful development of their siblings; (3) the extent to which adolescents appeared to ruminate about their siblings with ASCs. A significant omission within this theme is that the adolescents were focused on their siblings to the extent that there was almost a complete absence of any discussion around what the adolescents held as personal aspirations for their own futures.

The meaning attached to diagnosis

Over a third of the adolescents expressed that personal experiences of coming in to contact with other people with disabilities had helped to orient them to being able to accept and understand their siblings ASCs more readily. Moreover, there was an additional impact on the personal development of some of these adolescents who were able to extend this knowledge and understanding of disability to wider issues such as race.

Debbie: *"But I wasn't fazed with it 'cos I know people that are perceived as being different and I just treat them as a normal, well someone whose depicted as being normal. I'm not bothered about how they look, how they behave, if they're a different race or whatever, I'd just treat them how I'd like to be treated."*

A sense of familiarity with individuals who had similar diagnoses to those of their siblings with ASCs was also important for some adolescents, allowing them to form a picture over time of the kind of presentation that could be linked to a person who is considered to be on the autistic spectrum. This helped the adolescents to normalise the ASCs and to dispel the myths around the diagnosis.

Debbie: *"..'cos I think one of my mum and dad's friend's sons has Asperger's syndrome and he's got ADHD [Attention Deficit Hyperactivity Disorder] as well and I've known him ever since I was born. So I have kind of grown up with that autistic presence in a way."*

Where applicable there were also adolescents who identified with disability because they also struggled with the consequences of experiences of personal illness and disability. In such cases adolescents were keen to be dismissive of their illness or disability regardless of the impact on their lives, ultimately wanting to reinforce the message that being siblings was more pervasively significant than the illness or disability. One adolescent looked over a photograph of him together with his brother whilst reporting on his perceptions around diagnosis.

Peter: *"...cos he's got autism and I've got [personal illness]. We're both two different things. We just leave medical illnesses out of the way. We're brothers."*

More than two thirds of the adolescents were compelled to look beyond the clinical diagnosis of their siblings' ASCs. These adolescents placed significant value on emphasising that they were in favour of focusing on their siblings as a brother or a sister rather than allowing themselves to be distracted by and overwhelmed with the part of their siblings' lives ruled by ASCs.

David: *"Um... It's... it's one of those things that once... once you understand about him y... uh... it's, you know, it's family and eh... sometimes you don't have to... you don't look at them as I... you know, disabled, one of your family. To me, he's a brother. That's what counts."*

Adolescents generally wanted to normalise and account for the difference between themselves and their siblings created by the ASCs. This helped adolescents to translate normalisation so that they could be more accepting and more tolerant of their siblings ASCs, particularly in times of distress.

Carole*: "I can't tell the difference. She's just like a normal little girl to me."*

In their quest to normalise their siblings, some adolescents expressed the reality that this was at times a difficult thing to be able to do. These adolescents were open about wishing that their siblings could be less difficult to deal with but they demonstrated a determination to tolerate the problematic situations in recognition that being siblings meant that the end justified the efforts. One adolescent had asked for a photograph to be taken of him and his brother with ASCs. The photograph showed them with an arm around each other.

Mark: *"It is hard but then again I wouldn't change him for anything so, I know he wouldn't change how I am so I wouldn't change him. I mean, it'd be a lot easier if he were a lot toned down and stuff but you can get around it. It is hard at times but still he's my brother isn't he so got to make the best of it."*

The concept of 'making the best of' things was something that adolescents drew on further and more specifically in their thoughts and feelings around their hopes and expectations for their siblings' development.

Aspiring for successful sibling development

More than half of the adolescents described wanting and hoping for their siblings with ASCs to succeed in life and to develop across the lifespan as might people of 'typical' development. These adolescents went as far as to aspiring that their siblings with ASCs could excel in life to a greater degree than typically developed individuals, focusing on their siblings' unique abilities as a source for real positivity. Many of the adolescents used photographs that they had taken of their siblings with ASCs to facilitate discussions about their hopes and expectations for their siblings in the future.

Mark: *"...cos he's got autism, it doesn't mean that um... he will achieve anything less than anyone else could achieve. If anything, he'll achieve more because... he can see the things that we can't."*

This group of adolescents was eager to promote the individual skills and talents of their siblings with ASCs. There was a genuine and loving attitude depicted in some of the adolescents' reporting, particularly when describing areas in which their siblings with ASCs clearly had outstanding ability and thus there was a realistic expectation that success could be achieved in this area.

Debbie: *"And I'd absolutely love it if (name) could be a comic designer and that's what he's said he wants to be. I'd love to see (name) succeed in that certain area of art. Because he is really, really good at it and as I said, some of the stuff he produces is of such a high standard."*

Other adolescents were more exaggerated in their hopes that their siblings with ASCs would be able to develop in ways that would enable them to have a fuller understanding of life's complexities. One notable example was derived from an interview with an adolescent

whose sibling also had a significant learning disability and was realistically very unlikely to ever have any sense of independence as levels of understanding and functioning were unlikely to markedly improve.

David: *"... Over time, he's learnt these different things and you never know, in another ten years, he might be able to understand everything."*

Adolescents were also hopeful that their siblings' progress through education would be a fulfilling experience for them. Responses incorporated an awareness of the growing skills of teachers in schools and how the levels of time and effort that these teachers were able to offer atypically developing pupils could be beneficial for siblings with ASCs.

Michelle: *"One boy in year 12, he's in the sixth form and he's got Down's syndrome and there's certain teachers that do deal with people with severe mental illnesses and this boy, he's got like 12 GCSE's or something because of the input that these certain members of staff have had. So I think (name) going up to High School, it will be a very good experience for him."*

Almost a third of the adolescents were content to concentrate on current progress with their siblings with ASCS, often with a focus on how they noticed that their siblings were apparently becoming happier individuals as they grew and developed with age. One adolescent discussed this whilst looking at a photograph that she had taken of her sister with ASCs, which showed her dancing and smiling. This seemed to be of real comfort to the adolescent during this particular part of the interview.

Carole: *"And as she gets older, she gets happier and more cheerful."*

There were also a high proportion of adolescents that were struck by the stark reality that their siblings with ASCs had not shown any improvement in realising potential for development. For some adolescents this reality was faced following their perceptions that professionals had planted seeds of hope for thinking that their siblings might develop to a higher level of functioning.

Davina: *"I'm not sure, I think when I, when she was first diagnosed, like a few years after that they said she would get better while she got older but she hasn't done."*

Adolescents that had previously described hopes and ambitions for their siblings with ASCs occasionally reflected during discussion of photographs that they had taken of their siblings with ASCs about the reality of their siblings' existence and the ongoing struggles that their siblings experienced as a result of their ASCs and learning difficulties.

David: *"Over this last year, he learnt to do the toilet. Start of the year he'd go do it and it'd be fine and he then... he started to go backwards with his learning, so he knew how to go on the toilet and then the next week he'd just sit there, and he'd be like "What shall I do?""*

Adolescents' perceptions of how their siblings were able to function emerged as a strong theme within the data. This sub-category conjured several concepts that revolved around the adolescents' perceptions and understanding of their siblings as well as the adolescents' perceptions of how others viewed their siblings and their ASCs. This sub-category links with the one described next in that it demonstrates the pervasive nature to which the adolescents reflected on their experiences of living with a sibling with ASCs.

How adolescents ruminate about their siblings with ASCs

More than two thirds of the adolescents were conscious about the impact that ASCs might have on their siblings. Adolescents appeared to spend a lot of time reflecting on a variety of issues that interacted with and exacerbated their siblings' ability to manage life, particularly in light of them having the burden of ASCs. Some of the factors discussed by adolescents were of an individual and idiosyncratic nature; specifically related to a change in family circumstances, for example, as illustrated by the following quotation.

David: *"My Dad left about two years ago and th... this had a bit of impact on him [sibling with ASCs]."*

Some responses from adolescents were more typical of difficulties considered to be closely associated with specific and pervasive issues around ASCs. Adolescents often focused on photographs that they had taken of their siblings with ASCs when discussing their awareness of the effects and impact on siblings with ASCs of inevitable and relatively simple processes in life, such as breaking up for school holidays.

David: *"If routine is broken, sometimes... he can be really upset, and um... like when we have the school... school holidays, they start... he'll be a bit confused. He'll be like "Why am I not going to school?"*

For other adolescents there was a realisation that the difficulties arising from their siblings' ASCs had resulted in their siblings struggling to meet the specific demands of adolescence of developing communication and social interaction with peers. In these cases, there was a genuine acknowledgement of how adolescents perceived that ASCs had the potential to make life that much tougher for them but also for their siblings.

Martin: *"He doesn't get [understand] normal day to day stuff which makes him frustrated which causes him meltdowns and stuff, which are not nice to deal with."*

Some adolescents had also noticed the negative impact of ASCs on their siblings in the context of peer relationships with regard to the gradual but palpable changes in behaviour of their siblings with ASCs.

Mark: *"But he's a lot less confident now, like he's gone from being like one of the most popular boys in his year to becoming like socially recluse."*

In the same vein, adolescents were acutely aware of the realisation that others began to notice differences in their siblings with ASCs. Adolescents expressed that, although friends of their siblings with ASCs would try to interact with their siblings, the responses and reactions of their siblings with ASCs were difficult for other adolescents to comprehend and accommodate.

Peter: *"He's [sibling with ASCs] made loads of mates, but as he's got older they've all started to realise he's not like who they thought he were. Some of his mates won't... some of his mates will try and speak to him, but he'll just sit there with his head up saying "Shut up. Shut up" and they don't realise what's the matter with him."*

Most of the adolescents were also sensitive to others' perceptions and observations of their siblings with ASCs and how their siblings' behaviours might or might not be tolerated and understood. For some adolescents the emphasis lay with the general public not being knowledgeable about ASCs and therefore being judgmental. Some adolescents were wary of the relatively covert presentation of ASCs in terms of their siblings' physical appearance, in contrast to a person with Down's syndrome for example.

Martin: *"Not many people like know about or are educated in the disability so it's like people when they see [name] they don't think about the fact that he might have a disability cos he doesn't look as though he does so a lot of people will just view it as bad behaviour."*

Some adolescents had recognised that the significance of how a diagnosis of ASCs could also impact on how important figures such as school teachers acted towards their siblings with ASCs. These adolescents had seen that a diagnosis had altered the attitudes of influential figures like school teachers in positive ways that enabled siblings to focus more on consolidating their strengths as much as struggling with making improvements in areas which they were less skilled.

Debbie: *"Before we got the diagnosis that he was autistic, school didn't persuade him as much to do artistic stuff...and because (name) was lagging in some subjects, he got, well not upset but he got quite annoyed that they were trying to persuade him into doing well in science or something."*

Many of the adolescents demonstrated an awareness of changes that they saw in their attitudes towards their siblings with ASCs. These adolescents expressed how they had struggled initially with the extra demands placed on them by their siblings' ASCs through having to care for and be responsible for them. But these adolescents were also able to be

empathic of their siblings' circumstances, understanding that their siblings could not help having ASCs and realising ASCs had big implications for how their siblings were able to function. Building on these reflections helped these adolescents to become more accepting of their siblings' ASCs as well as their adoption of caring and responsible roles with regard to looking after their siblings.

Davina: *"I used to kind of get a bit, you know, pi[**]ed off about it but now, 'cos I understand that it's not her fault that she's like that then it's like, me not being able to go out is like not that important, like, compared against what she's going through."*

Over half of the adolescents perceived that their siblings were able to actively manage and work with their ASCs to suit themselves in some situations. There was a consensus among these adolescents that their siblings could make the most of their uniqueness and different ways of being in ways that would be perceived as endearing by others.

Mark: *"He [sibling with ASCs] was just a funny person, they loved his humour. I think it's he were a bit like, he were a bit like docile and a bit slow and people found that funny and like he worked on that and people laughed at him."*

In contrast to some adolescents' perceptions that their siblings were unpredictable, this group of adolescents described how they perceived their siblings with ASCs were capable of behaving differently in different contexts. This suggested that these adolescents viewed their siblings as being able to have a sense of control of the various ways in how, when, and where they exhibited certain behaviours.

Davina: *"I think when she [sibling with ASCs] goes out with, you know the people that look after her sometimes, when she goes out with them she's more behaved but when she's with the family she's like, acts like she would act up."*

These adolescents even had explanations for how they perceived their siblings to be able to behave differently depending on the context of a situation or circumstances, expressing the opinion that their siblings with ASCs could keep maintain tight boundaries on when they 'chose' to have meltdowns, for example. One adolescent when speaking about a

photograph of his bedroom illustrated a good example of how a photograph could generate a wider and deeper discussion relating to their siblings' behaviour.

Martin: *"And then as soon as he gets home, he won't do it in school because that's not one of his safe zones, as soon as he steps through the door he can actually just go into meltdown."*

In summary, the description of the fourth and final overarching theme here has accounted for some integral sub-categories identified as being important features of how adolescents seem to ruminate about a variety of issues associated with their siblings' ASCs. Adolescents described several factors of importance in the meaning that they attach to their siblings' diagnosis of ASCs: personal experiences and understanding of disability and how this mediates their tolerance and acceptance of their siblings' ASCs; and valuing their siblings as brothers or sisters, thereby seemingly trying to normalise their siblings as distinct entities from apart from their ASCs. Adolescents also expressed how they harboured aspirations and expectations for the successful development of their siblings with ASCs, some of which *prima facie* appeared more realistic than others. A notable feature of the interviews with the adolescents is the extent to which they appeared also to ruminate about their siblings in a meaningful and selfless manner. Adolescents unanimously demonstrated that they tend to ruminate in a variety of ways about their siblings, particularly the impact that their ASCs have on them. The adolescents described a variety of observations and perceptions of how they think their siblings act and are acted towards. These deep levels of thought, reflection, and expressions of empathic and sensitive understanding lean towards the assumption that these adolescents are somewhat preoccupied by their siblings and, perhaps more specifically, their ASCs.

CHAPTER FOUR: DISCUSSION

This discussion aims to synthesise the findings from this study so that a greater understanding can be gained around what adolescents have to say about the perceived psychosocial impact on them of living with a sibling with ASCs. In doing so, this chapter reviews the original research aims and incorporates a discussion of the findings from this study in relation to the research from the initial literature review. This discussion is carried out in conjunction with further literature reviews that were conducted to help explain the findings in this study. This chapter includes consideration of how psychological thinking can tease out the clinical implications of this research. There is also discussion of the strengths and limitations of this study, together with some implications for future research and service delivery.

This research identified four aims:

(1) To explore the subjective experiences of typically developing siblings of children with ASCs

(2) To explore how these experiences might impact on these adolescents' psychosocial adjustment

(3) To assess possible implications for service delivery

(4) To generate a theoretical account of the pertinent factors influencing adolescent psychosocial adjustment, with a view to identifying possible areas for future research

Review of the main findings

Exploration of subjective experiences of typically developing siblings of children with ASCs revealed four overarching themes:

- (i)   Experiencing ASCs in daily life
- (ii)   Adolescent psychological factors
- (iii)   Social impact of ASCs on interpersonal life
- (iv)   Adolescents' perceptions of siblings with ASCs

Experiencing ASCs in daily life discussed how adolescents felt about their experiences of living with a sibling with ASCs as part of everyday life. The theme focused on the complex issue of how adolescents perceive their roles of responsibility in relation to the care of their siblings, the challenges that adolescents struggled with as a result of having a sibling with ASCs, how adolescents reported living life on edge as a result of having a sibling with ASCs, and how adolescents reported that they learned to adjust to and interact with their siblings. *Adolescent psychological factors* reported on the adolescents' experiences of how it is to live with siblings with ASCs whilst managing some of the typical developmental tasks associated with adolescence, such as identity formation and school life. This theme also included discussion about some of the psychological factors that arose in adolescents as a result of their experiences, such as how they rely on coping strategies and how they felt about developing their sense of personality in respect of living with a sibling with ASCs. *Social impact of ASCs on interpersonal relationships* revolved around discussion of adolescents' descriptions of how their siblings' ASCs had impacted on social and interpersonal areas of life. This discussion included how adolescents described their relationships with their siblings with ASCs; adolescents' experiences of other relationships within the nuclear family; how adolescents perceived the value of relationships with extended family members; the importance adolescents placed on family pets; and how adolescents described the meaning of friendships with peers. *Adolescents' perceptions of siblings with ASCs* illustrated how adolescents regarded their siblings with ASCs as individuals in a variety of contexts. This discussion focused on specific considerations that included the meaning that adolescents attached to their siblings' ASCs diagnosis; the aspirations and expectations that adolescents held for the successful development of their siblings; and the extent to which adolescents appeared to ruminate about their siblings with ASCs.

An overview of how having a sibling with ASCs impacts on adolescents' psychosocial adjustment

Caring for a child with a constellation of conditions that manifest in a pervasive developmental disability such as ASCs places a variety of demands on the entire family (Opperman & Alant, 2003). Parents and siblings alike will be affected. These demands will require adjustments on behalf of each family member to accommodate the needs of the

child with ASCs. This discussion will bring to the forefront the considerations reported by the adolescents in this study as being significant for their psychosocial adjustment to the experiences of living with a sibling with ASCs.

The adolescents' accounts revealed a variety of salient dimensions with regard to living with a sibling with ASCs and siblings were individually and collectively both different and similar in their attitudes to their siblings with ASCs. For example, whilst some adolescents described living on tenterhooks or feeling aggrieved at being a target for aggressive behaviour others reported that they learned to be more accepting of people with disabilities and to be more prepared for life as an adult through their experiences of living with their siblings with ASCs. These divergent experiences were also in co-existence for many of the adolescents. These accounts are in line with the inconsistent findings of previous research, with some studies highlighting the negative aspects of living with a sibling with ASCs such as feeling isolated and anxious (e.g. Bagenholm & Gillberg, 1991; Cox et al., 2003; Gold, 1993; Gupta & Singhal, 2005) and others indicating that that there are also positive aspects of having a sibling with ASCs such as having a robust self concept and positive perceptions of relationships and outlook for the future (e.g. Petalas et al., 2009; Kaminsky & Dewey, 2002; Mates, 1990). The pertinent point here is that whilst the experience of living with a sibling with ASCs can be challenging (e.g. when dealing with aggression), the outcome can also be positive (i.e. increased tolerance).

On the balance of the findings yielded by this study, the researcher would argue that 8 out of 11 adolescents gave an overall favourable interpretation of their experiences of living with a sibling with ASCs. Three adolescents, however, found it difficult to identify any positive aspects of living with a sibling with ASCs. The researcher does not attach any meaning or make any assumptions about these findings, given the small numbers up for discussion, but merely illustrates them as an interesting point of observation for the reader to bear in mind.

All of the adolescents acknowledged that living with a sibling with ASCs required effort and adaptation. As this discussion gradually moves towards theory development, it is useful for the reader to consider here that this required effort and adaptation essentially encapsulated the process of 'coping'. That is, the extent to which adolescents were able to regulate positive psychosocial adjustment appeared to be a function of their ability to cope with accommodating their siblings with ASCs alongside life's other demands. As will

become clear, the coping processes of individual adolescents were mediated by a variety of psychological and social factors.

Influential factors in adolescents' psychosocial adjustment

Processing daily experiences of siblings' ASCs

The adolescents reported that living with a sibling with ASCs made life challenging. The issue of increased responsibility was recurrent in the adolescents' accounts. Research suggests that this is a common feature of being a sibling of a child with a disability (e.g. Fisman, Wolf, Ellison, Gillis, & Freeman, 2000; Knott, Lewis, & Williams, 1995; Lobato, 1990). Some adolescents had learned over time to accommodate their increased responsibilities and had started to perceive them as a positive aspect of their life experience. Some adolescents reported that they were able to tolerate some of the responsibilities but that these became tiresome at times. Other siblings felt that they could have been afforded further responsibility but their parents were reluctant to do so. This seemed reasonably appropriate, however, given that increased responsibility typically appeared to correlate with older aged adolescents.

Younger adolescents who wanted increased levels of responsibility reported that they did not have a good understanding of why their parents did not allow them to have a more influential role in their siblings' care, suggesting that lines of communication were not open and transparent. This is an important issue in the context that freedom to express feelings, open communication with parents, and prevention of breakdowns in communication are associated with positive sibling adjustment in family systems (McHale & Gamble, 1987; Powell & Gallagher, 1993; Siegel & Silverstein, 1994). Adolescents in this study that had improved knowledge and an enhanced understanding of ASCs through discussion with their parents appeared to be more accepting of their siblings and therefore were able to adjust to and manage some of their siblings' challenging behaviours when they occurred.

In some cases, there were adolescents who indicated feelings of rejection or being overlooked by their parents. This is another worthy consideration, given that research has indicated siblings of children with disabilities adjust better if they do not feel rejected and that feeling rejected is an increased risk for siblings of children with disabilities who require

extra attention (McHale, Sloan, & Simeonsson, 1986). In addition, however, siblings are also likely to be more negative in their perceptions of their brother or sister with a disability if they perceive that their parents and peers are rejecting of the disabled child. Conversely, when siblings perceive their parents and peers being positive towards the child with a disability it can enhance the quality of the sibling relationship (McHale et al., 1986).

All of the adolescents' accounts featured reports of the coping strategies that they adopted to help with emotional regulation with regard to their siblings with ASCs. For further discussion, it is also helpful to refer to the appraisal processes of coping suggested by Lazarus and Folkman (1984b). This seems particularly relevant given that there appears to be variation in how successfully adolescents cope with living with a sibling with ASCs. The findings from this study indicated that adolescents used emotion-focused approaches as a primary coping strategy, adopting techniques that included escapism and distraction.

Although adolescents are thought typically to adopt more emotion-focused coping strategies than problem-focused approaches (Skinner & Zimmer-Gembeck, 2007) this is interesting if considered in the context that people tend to use emotion-focused approaches when they believe that they can do nothing to change the stressful conditions (Lazarus & Folkman, 1984b). This may be what the adolescents perceived to be reality during times when their siblings with ASCs were distressed and displaying challenging behaviours. Thus, perhaps withdrawing or distancing themselves from a given stressful situation may act as an effective buffer for adolescents in adapting to the potential negative impact of behaviour problems in their siblings with ASCs. Yet active forms of coping that combine closeness and autonomy tend to be associated with optimal family atmosphere (Opperman & Alant, 2003). That is, research suggests that adolescents who use more active problem-solving approaches may reflect more cohesive, open, and communicative family relationships (Harvey & Byrd, 2000).

The tendency for adolescents to withdraw from volatile situations involving their siblings with ASCs may therefore be an attempt to minimise familial friction; it may also be related to a lack of opportunity to learn active strategies if the adolescents feel isolated from the family. Several adolescents made reference to making personal sacrifices to avoid or reduce the potential for conflict with their siblings with ASCs. In this way, adolescents can account for the contradictory nature of their passive appraisal coping strategy if we consider it as an adaptive two-step coping process. First, it may serve the purpose of

increasing the adolescents' perceived ability to act autonomously. Second, personal compromise on behalf of the adolescents which reduces the potential for friction with their sibling with ASCs is likely to be appreciated by parents and enhance closeness and acceptance within the family. The adolescents in this study appeared to respond well to being part of a supportive family atmosphere. But previous research has suggested that a supportive family atmosphere alone is insufficient for the adolescent to adopt effective coping responses to living with a sibling with severe disabilities (Seiffge-Krenke and Shulman, 1993). To this end, while reflecting on the coping responses with regard to the findings from this study, an essential additional consideration is the developmental stage of adolescence and the issues surrounding identity formation, peer conformation, and typical school demands. Such issues can all impact on how a person responds to the additional stress of having a sibling with ASCs (Newman & Newman, 1997).

Features of adolescence

Adolescents in this study generally did not seem to focus on adolescent tasks typically associated with school. Some did, however, acknowledge that greater effort was required to keep pace with homework demands and some of the younger adolescents were in a position of beginning to think more about GCSEs. The concept of identity formation and developing a sense of personality was a comparatively significant part of the adolescents' lives. Most of the adolescents were aware of developing their sense of identity. The majority of the adolescents emphasised factors that they perceived as having a positive influence on their personal development. Apart from acknowledging the role of their parents in helping them to develop healthy social values (e.g. a non-judgmental attitude) some of the adolescents discussed the important influence of their sibling with ASCs in helping them to develop a tolerance and acceptance of 'difference' in society. One adolescent (David) even questioned whether he might have taken a different, more rebellious path in life had he not experienced living with his sibling with ASCs and that he might not have developed as much respect for other disabled people.

The influence on identity formation of interaction with friends and peers also emerged as a recurrent theme within the adolescents' accounts. This is consistent with previous research that suggests peers provide adolescents with support as well as an environment in which to develop feelings of self-worth (Seiffge-Krenke et al., 1993). Peers

and friends impacted on how the adolescents perceived their pervasive sense of identity formation in terms of the kind of person that they wanted to be as adults and across settings. Some adolescents considered it appropriate to be around like-minded individuals with 'good characteristics' who would be a 'positive' influence on them. There were also adolescents who typically considered themselves to be different at home compared to when with their peers. There seems nothing immediately remarkable about this concept. However, in contrast to traditional adolescent style, there were several adolescents who felt that they would have liked the opportunity to be able to behave in similar ways at home with their families as when with their friends (e.g. to be more bouncy and show their 'fun' side). That is, there appeared to be a tendency for some of the adolescents to need to be reserved and contained at home for fear of impacting on an already tense family atmosphere because of the potential for their sibling with ASCs to have a meltdown. These adolescents found it difficult to *be* who they wanted to be, which might suggest that they felt restricted in their freedom to explore their identity, thus encouraging foreclosure rather than an achieved identity (Marcia, 1980). One adolescent (Sophie) felt she had to contain herself so much that her mother didn't actually know much of her personality. Sophie's account brings up an interesting point of discussion as she had a difficult relationship with her sibling with ASCs. At this juncture, it is helpful to elaborate on the importance of relationships within the context of having a sibling with ASCs.

Social support networks

Relationships appeared to be one of the cornerstones that helped adolescents to cope with and adjust to having a sibling with ASCs. The relationships that adolescents experienced with their siblings with ASCs varied along a continuum which ranged from being very positive to very difficult. Some of the adolescents, such as David and Debbie, reported that they had fulfilling and satisfying relationships with their siblings which acted as a buffer against the challenging behaviours that that their siblings with ASCs sometimes exhibited. Towards the other end of the scale, some adolescents (Sophie and Martin) described having very difficult relationships with their siblings with ASCs mostly because they found the challenging behaviours too much to cope with on a daily basis. Two interesting differences in these polarised views of sibling relationships stand out. First, adolescents with positive views about their relationships with their siblings with ASCs reported that

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that they could find their own space when they wanted so that they could withdraw from challenging periods of conflict. Because of the spontaneous nature of siblings demonstrating challenging behaviour, it was simply a matter of these adolescents retreating to their rooms. In Martin's case he had no desire to be in his bedroom because it was undecorated and messy. Martin had attributed this to spare time that could have been allocated to decorating his room being spent dealing with his sibling's meltdowns and appointments with professionals. This had left Martin feeling disappointed and resentful because he was more vulnerable to his sibling's meltdowns without a place of sanctuary to which he could withdraw. In Sophie's case she did not have a place of sanctuary that she could use for personal space as she shared her room with her sibling with ASCs. Both Martin and Sophie compensated by having places outside of the family home that they could withdraw to but this was not always immediately possible. To this end, it appeared that adolescents were able to adapt to their siblings' challenging behaviour more effectively when they had personal space and successful coping was about finding opportunities for places of sanctuary. Second, adolescents who described positive relationships with their siblings with ASCs appeared to have a good understanding of ASCs which increased their tolerance and acceptance of some of their unpredictable behaviours and rigid thinking. By comparison, adolescents with strained relationships often referred inaccurately to their siblings' diagnosis (interchanging autism with Asperger's and vice versa) and they seemed less able or less willing to acknowledge that their siblings were fundamentally different in their ways in terms of social interaction and communication. This seems to be an important issue in adolescent psychosocial adjustment to living with a sibling with ASCs. Siblings appear in need of good information with regard to ASCs to facilitate their own coping responses. For example, although some adolescents reported experiences which could be described as typical sibling rivalry, there was a suggestion from others that they thought their siblings were 'trying it on' and more able to control their behaviour. This created ill feeling toward their siblings which may shed some light on why some of the adolescents who did appear to be well informed about ASCs were unable to make sense of it or trust the reliability of the information, instead believing that their siblings were acting out at times to get their own way.

There was also the potential for these adolescents to feel overlooked by their parents. The combined experiences of parental inattention and having ill feeling towards

the sibling with a disability have been shown to contribute to the development of problems in gaining positive self-esteem and self-confidence (Abell & Gecas, 1997). There is perhaps an interplay here that might suggest adolescents who feel valued by their parents are more able or willing to be more accepting of their siblings' challenging behaviour.

Descriptions of other relationships within the nuclear family also featured in the adolescents' accounts. Adolescents emphasised the importance of needing parental support to cope with the added pressures that sometimes were presented by their siblings with ASCs. For those adolescents that felt underappreciated and undervalued by family members, this compounded the difficulty in adjusting to their siblings' ASCs. These adolescents appeared to compensate for their perceived inattention from family members by looking for alternative sources of support. For some, this was found through members of the extended family (e.g. grandparents, cousins, or aunts). Martin, for example, found this external support particularly valuable as he was also aware that being in his relatives' houses provided him with respite because his sibling with ASCs did not display challenging behaviour whilst there. For others, animals provided a channel for finding meaningful attachment that appeared to help with psychosocial adjustment. The adolescents appeared to enjoy the reciprocal feeling of being wanted or needed.

Relationships and friendships with peers also featured throughout the adolescents' descriptions of how they felt able to adjust to adolescence and to living with a sibling with ASCs. On a general level, adolescents reported typical reasons for liking friends in that they enjoyed having friends and sharing life experiences with them because this made life more interesting. But there were also several adolescents who valued friendships specifically because their friends were kind and a source of socialisation to their siblings with ASCs. Adolescents viewed their relationships with friends as important for their sense of self worth and were prepared to be creative to build such relationships. One adolescent (Davina) described that due to her caring responsibilities for her sibling with ASCs she was unable to go out and socialise often. However, she had found innovative ways to compensate by keeping in touch with friends and peers through the Internet using social networking sites.

There were, however, notable examples within the group of adolescents that participated in this study for whom socialising with peers and making friends had become a

difficult exercise. These adolescents had established alternative forms of social support either through family, relatives, or pets to enlighten their lives. This follows research that has suggested some siblings of children with ASCs can experience a sense of loneliness and isolation (Opperman et al., 2003); feelings of loneliness in these adolescents and a sense of being isolated and becoming withdrawn could interfere with their relationships and result in them having increased distance in their relationships with siblings with ASCs. Also, the lack of a typical relationship with a sibling with ASCs emphasises the significance of maintaining positive relationships with peers and extended family. This is important as previous research by Seiffge-Krenke et al. (1993) indicated that the perceptions of adolescents about their siblings with ASCs and about others' perceptions of their siblings seemed an integral part of how the adolescents coped and adjusted.

The influence of perceptions in adjustment to ASCs

The ways that the adolescents processed the daily experiences of living with a sibling with ASCs, together with the calibre of relationships and the perceived levels of support experienced by adolescents filtered in to the fundamental perceptions that adolescents held about their siblings with ASCs. For the adolescents that struggled with building friendships with peers there was a perception that they would be seen in a similar light to their siblings with ASCs. That is, these adolescents perceived others to have a lack of knowledge of the consequences of ASCs and therefore to see their siblings with ASCs as 'badly behaved'. This proved to be an interesting consideration for Martin who showed a sensitive and empathic understanding of his sibling's difficulties that had previously not been transparent in the interview, particularly as he had described a strained relationship with his sibling with ASCs. This perception has parallels to those experiences of individuals of siblings with visible disabilities who report that people do not know how to act in the presence of someone with overt physical disabilities (Opperman et al., 2003). Given that ASCs are relatively invisible to the untrained eye, people might be inclined to make more negative assumptions about the 'bad' behaviour in the supermarket, for example, rather than with a physical disability which may evoke uncomfortable feelings in a person but not necessarily negative.

      The meaning that adolescents attached to their siblings' diagnosis of ASCs was an important factor in how they were able to adjust. Some adolescents were helped by

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personal experiences of other people with disabilities so that they were able to adapt more easily to their siblings' ASCs. The main benefit of this alternative experience was that it helped the adolescents to understand the reality of the consequences of ASCs which allowed them more of an opportunity to make informed choices around adaptive coping strategies. Two adolescents also had personal experience of illness which had impacted on their lives. These adolescents were similar to other adolescents in wanting to normalise their siblings with ASCs as much as possible so that they were able almost to overlook the fact that their siblings had a diagnosis of ASCs. The function of this appeared to be that the adolescents were keen to avoid thinking about the fact that their siblings had ASCs. However, the adolescents were aware that this avoidance was almost an impossible venture. Some adolescents had a 'wish' for their siblings to be different, not to have ASCs, because this would make life easier for all the family, including the sibling with ASCs. There was a consensus among the adolescents that maintaining a positive outlook and making the best of things with their siblings with ASCs facilitated the most effective and adaptive adjustment, perhaps because diminishing the extent of the problem made life easier.

The philosophy adopted by the adolescents to try to be positive in the meaning that they attached to their siblings' diagnosis of ASCs also transferred to how the adolescents viewed their siblings' future prospects. More than half of the adolescents described aspirations for their siblings that would be likely to concur with the hopes and expectations that might be associated more commonly with typically developing individuals. This positivity is in line with previous research (Taunt & Hastings, 2002) and may serve as further evidence that it is a meaningful way which adolescents choose as an effective method of adjusting to the emotional demands of living with a sibling with ASCs. But it could also be a reflection of the adolescents having inadequate information about the pervasive and enduring nature of ASCs. Certain adolescents, such as Debbie, had identified specific aspects of their siblings' lives which they hoped would develop into a career opportunity. But more than being a way of making a living Debbie aspired that her sibling would have the additional benefit of being able to pursue something that he really enjoyed which would make him happy. There were also adolescents that perhaps held hopes that were too optimistic for their siblings. This raised the question of when maintaining positive aspirations for siblings might become counterproductive, given the likelihood that these hopes were unrealistic and therefore a source of inevitable

disappointment for these adolescents. Some of the adolescents who appeared more informed about the developmental trajectory of ASCs were already beginning to realise this inevitability, and had come to accept the reality of the consequences of the pervasiveness of their siblings' ASCs. This sense of realisation in some of the adolescents appeared to be functional in a similar way to experiencing the process of grief and reaching the stage of acceptance. In line with grieving, for some adolescents the process seemed to follow a trajectory of having high hopes (denial) for their siblings which resulted in disappointment (as opposed to anger) in realising that their hopes were unrealistic, and ultimately led to acceptance in coming to terms with the reality of the pervasive limitations of their siblings' ASCs.

One of the most striking interpretations from the adolescents' accounts is just how much they appeared to think about and ruminate about their siblings. All of the adolescents reported that they often thought about their siblings. With few exceptions, the adolescents seemed to ruminate about the impact that living with ASCs had on their siblings. In short, they were concerned and anxious on behalf of their siblings. This is noteworthy as the adolescents' thoughts and worries about their siblings appeared to preoccupy them more than would be observed in other families. Perhaps this sheds light on why the adolescents generally tried so hard to maintain a positive outlook for their siblings.

The adolescents' accounts revealed observations on their siblings that related to specific deficits associated with ASCs, such as their rigidity and difficulties in understanding the world as others with typical development might see it. However, these observations extended to the adolescents describing their emotional struggles that manifested as a result of their empathy for their siblings with ASCs. For example, some adolescents expressed real sadness because peers and friends of their siblings had gradually noticed that their siblings were different and had subsequently become less involved with them. This awareness of change was compounded for some adolescents by their relative lack of understanding about the impact of ASCs, which left the adolescents feeling incompetent to explain to peers why their siblings were becoming noticeably different. Other adolescents felt saddened because they had noticed that their siblings with ASCs had changed since receiving the diagnosis, becoming reclusive. Some adolescents continued to maintain a positive perspective, however, observing that a diagnosis of ASCs had brought about a

healthy change of attitude in their siblings' teachers as they had started to focus on maximising the strengths of their siblings. This seemed to be an important factor in promoting these adolescents' adaptive psychosocial adjustment.

This discussion has illustrated the complex nature of adolescent experiences of living with a sibling with ASCs. Some of the findings are consistent with previous research but it has also opened some new avenues for exploration. The next section attempts to synthesise the current findings along with those of previous research with a view to moving towards a theoretical model of how adolescents might most effectively adjust psychosocially to living with a sibling with ASCs.

Adolescents' experiences of living with a sibling with ASCs: A theoretical model of the psychological and social processes influencing adjustment to living with a sibling with ASCs

The limited previous research with regard to the psychosocial impact on children living with a sibling with ASCs has continually yielded inconsistent findings with regard to its positive and negative effects. This has made it difficult to be coherent in conceptualising the interplay between variables that might account for effective adaptation. This absence of cohesion has made it difficult to develop a meaningful theoretical understanding of the significant factors involved in the process of psychosocial adjustment to living with a sibling with ASCs. The intention here was to develop a preliminary theoretical account that helps synthesise what appear to be the necessary factors for adolescents' adaptive psychosocial adjustment to the experiences of having a sibling with ASCs.

A difficulty in research with siblings of children with ASCs is that it has yet to fully explore the personal and subjective experiences of what it really means to be the sibling of a child with ASCs. This study aimed to build on the existing research in this area, with a specific focus on adolescents' accounts. In doing so, this research has yielded some interesting findings which suggest that there are important aspects of the adolescents' individual circumstances that interact with and shape their responses to living with a sibling with ASCs. An integral feature recurrent in the interpretations of adolescents' accounts was their awareness that living with a sibling with ASCs is a learning process that requires effort and is a major consideration of adolescents' daily existence. Similar to previous research (Cohen & Lazarus, 1983; Diamond, 1983), the adolescents reported that

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they had to make changes in order to adjust constructively to life's circumstances if they were to enhance their quality of life by promoting their psychological and social functioning. According to the adolescents, this process of adaptive psychosocial adjustment demanded an innovative ability to devise a range of coping strategies which act as buffers against stress, particularly during times when siblings with ASCs display behaviours which would generally be conceived as challenging.

There has been scant research exploring the coping strategies of children living with a sibling with ASCs. Royers and Myche (1995) found that children living with siblings with ASCs tended to try to blame others than their siblings for their stressful lives, thus adopting 'other-directed' cognitions as a coping strategy. Ross and Cuskelly (2006) identified that siblings of children with ASCs also used emotional regulation and wishful thinking to help them cope. Other research investigating the coping responses of adolescent siblings of children with severe disabilities found that the availability of social support networks and knowledge of disabilities impacted on effective coping (Opperman et al., 2003). The research by Opperman et al. (2003) also identified as a function of adaptive coping the significance of adolescents' perceptions of how others view them and their siblings. That is, adolescents who perceived being negatively judged by peers by association of having a sibling with a disability were at added risk for feeling lonely, isolated, and insecure. To this end, it is feasible that siblings who maintain positive perceptions about how others view them and their siblings may be a factor in adapting more functionally to growing up with a sibling with ASCs (Taunt & Hastings, 2002). In this study the findings indicated that positive perceptions were likely to be maintained when adolescents felt supported by family, relatives, and friends, when they were able to find time and space for themselves, and when they felt that they had a close relationship with their siblings with ASCs.

The theoretical model illustrated by figure 1 provides a cohesive picture of the findings from this study in terms of what adolescents indicate from their subjective experiences as being crucial factors for adaptive psychosocial adjustment to living with a sibling with ASCs. The model incorporates a combination of multi-level coping processes as purported by Skinner et al. (2007) and builds on a variety of individual, psychological, social, and environmental factors adapted from Wallander and Varni's (1998) conceptual model of child adjustment to paediatric chronic physical disorders. In essence, the model

demonstrates that adolescents feel most able to cope with and adjust psychosocially to living with a child with ASCs when they experience open and collaborative channels of communication with parents; supportive social networks that include friends, peers, family, extended family; positive perceptions of their siblings, including realistic hopes for their siblings' development; knowledge and understanding of ASCs and a perceived sense of self-efficacy in being able to manage their siblings in times of distress. The extent to which an adolescent accepts their sibling with ASCs is an interesting feature of the model and one that perhaps needs further exploration. This theme also emerged from the study by Petalas et al. (2009) and is introduced in the model presented here as a plausible mechanism by which siblings may facilitate increased tolerance and acceptance of their siblings' ASCs.

The model can be explained further by highlighting some of the salient components of accounts of those adolescents who appeared less adjusted to living with a sibling with ASCs. Those adolescents who had the most contact with their siblings with ASCs and the least available 'escape' routes during times when their siblings were having meltdowns appeared to have the most strained relationships with their siblings. These adolescents also felt less able to manage their siblings' behaviour which added to feelings of helplessness and hopelessness. Ultimately, these adolescents were able to resort at times to coping by leaving the house to visit friends of extended family members. However, this was not always possible (at night, for example). Feelings of helplessness and hopelessness led these adolescents to develop internalised difficulties of anxiety (e.g. waiting for a meltdown) and low mood because of the negative perception that their situation would never improve. The lack of quality of sibling relationships in these given contexts was therefore inevitable.

Psychosocial Issues
- siblings' challenging behaviours
- tasks of adolescence (e.g. identity formation; peer conformation; educational commitments)
-levels of responsibility

PREVIOUS EXPERIENCES/ CURRENT DEMANDS

Cognitive Appraisal

ADAPTIVE COPING PROCESSES
- functional emotion/problem focused strategies

Individual Factors
- resilient temperament
- good perceived self-efficacy to manage siblings alongside life's other demands
- increased knowledge/understanding of ASCs

Socio-environmental Factors
- supportive social networks (e.g. friends, family, extended family, peers)
- opportunities to find personal space (e.g. bedroom)

Sibling relationship
Adolescents with above individual/social/environmental factors as resources likely to be more accepting and tolerant of ASCs and have better sibling relationships

Increased potential for
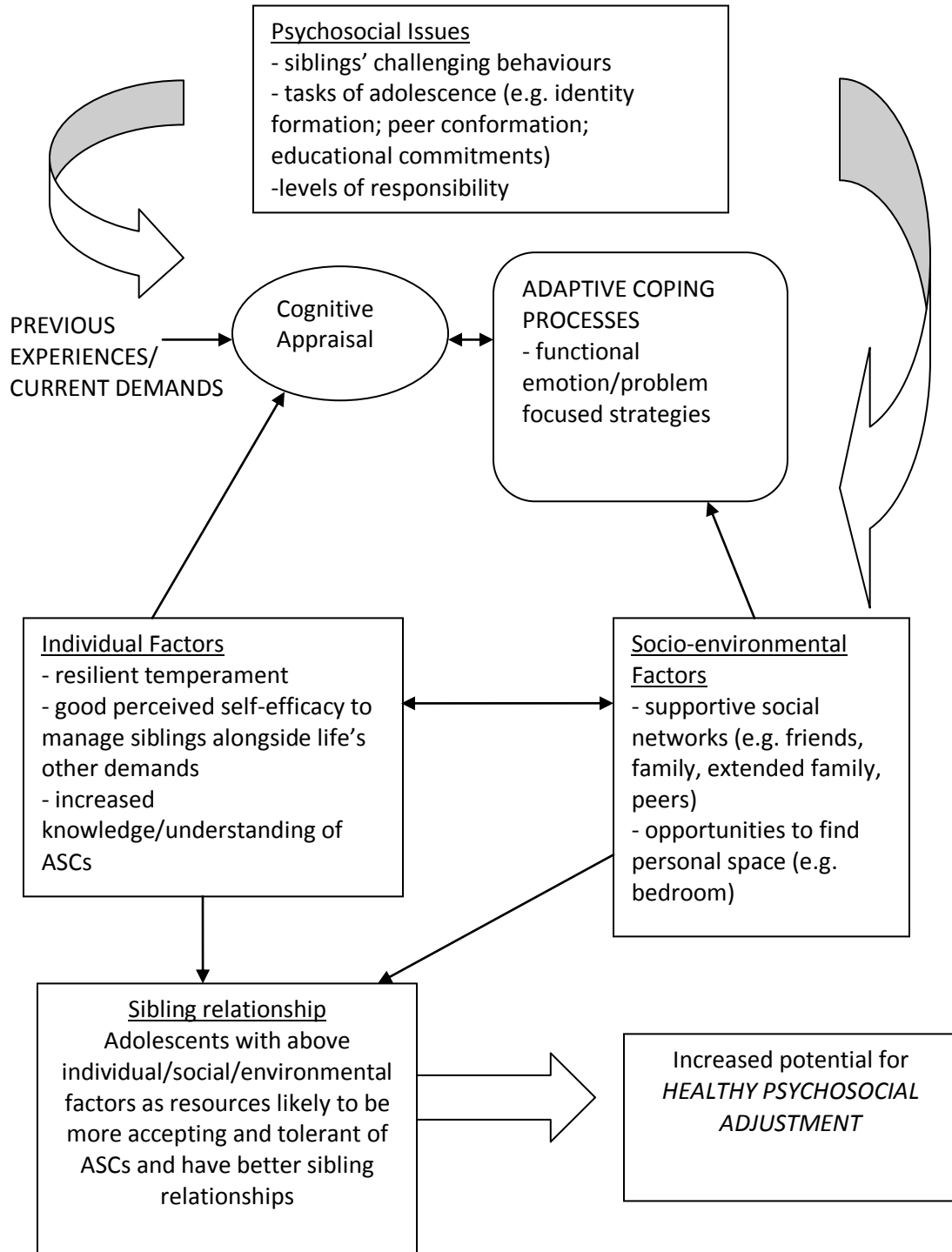*HEALTHY PSYCHOSOCIAL ADJUSTMENT*

Figure 1. A conceptual model representing the significant factors necessary for optimising potential for adolescents' healthy psychosocial adjustment to living with a sibling with ASCs.

Testing the validity of the conceptual model

An important function of making theoretical claims from qualitative data is to test that these claims are grounded in the data of the participants' individual accounts. That is, it should be possible to follow how a theoretical perspective has been developed and modified through the study of the participants' accounts as individual case studies (Smith, 1997). To this end, this examination of individual cases tests the validity of the theoretical model on the basis of how well each of the participant's accounts fits with the model.

The approach outlined here is a version of negative case analysis used by Smith (1997). Negative case analysis begins with a preliminary theory which is then examined through the study of each participant's data. As each of the participant's accounts is studied, the hypothesis is then modified depending on the material that fits or doesn't seem to fit with the proposed preliminary theory. The aim is to develop a theory which becomes much more specific throughout this process. The developed hypothesis can proffer strong claims for the group of participants that are examined, making negative hypothesis testing extremely stringent (Robson, 1993).

Using individual accounts to refine the proposed conceptual model

The preliminary hypothesis based on a combination of existing literature and analysis of the data accumulated in this study was proposed as follows:

The conceptual model illustrated in figure 1 predicts that adolescents will have optimal psychosocial adjustment to living with a sibling with ASCs if they have knowledge and a good understanding of ASCs. Such perceived knowledge and understanding can enable adolescents to be more understanding and accepting of their siblings' challenging behaviours which can facilitate better sibling relationships. These adolescents also feel better equipped to discuss issues around ASCs with their friends, thus making use of a valuable social support system. Moreover, such adolescents are likely to have an increased sense of self-efficacy in their ability to manage their siblings when they display behaviours which would be typically described as challenging. These adolescents are likely to be able to manage levels of responsibility that they might have regarding their siblings with ASCs and to adopt adaptive coping strategies, allowing them more resources to meet developmental tasks of adolescent development such as peer conformation and developing a sense of

identity. This helps to act as a buffer against stress, whilst also promoting a sense of
resilience.

Each individual account of the participants was examined in the order illustrated in table 2 in the findings section. The individual examinations of how each individual account relates, or not, to the model illustrated in figure 1 are described in detail below.

Michelle's account revealed that she perceived her brother's behaviours as challenging and unpredictable but that she felt she was well placed to manage such behaviours. However, Michelle was frustrated as she felt that her parents overlooked her ability to calm her brother down when he displayed challenging behaviours. Michelle also felt that she could not discuss with her parents the idea that she thought she would be able to handle more responsibility for helping out with managing her brother. Michelle demonstrated a good understanding of how ASCs affected her brother and her perceived self-efficacy in being able to manage her brother appeared valid. Michelle coped with her frustrations by withdrawing to her bedroom where she would draw or by playing basketball in the garden. Overall, Michelle reported a good relationship with her brother alongside some typical sibling rivalries. Michelle described having a forgiving nature with regard to her brother, showing empathy, sensitivity, and a willingness to understand how ASCs impacted on her brother but expressed a wish that he would not target her so much during his 'meltdowns'. Scrutiny of Michelle's account led to the following modification of the preliminary hypothesis:

Adolescents are likely to have better psychosocial adjustment to living with a sibling with ASCs when they have a good understanding of how ASCs impact on their sibling. A level of empathy and sensitivity allows adolescents to develop more tolerance and understanding of their siblings with ASCs whilst there is recognition that they would prefer their siblings not to be so challenging. Wanting to be acknowledged as being capable of managing their siblings' ASCs and thus delegated proportionate levels of responsibility in this area also appears to be an important feature of adolescent reports. Building the confidence to communicate this to parents is important for adolescents.

Martin's account highlighted the additional pressure in life that he felt because of his brother's ASCs. Martin felt helpless and hopeless and reported being highly stressed because of his brother's ASCs. Martin reported that the burden of typical adolescent demands, such as developing increased autonomy and responsibility for self as well as increasing educational demands, was heavily weighed upon by the additional demands of living with a brother with ASCs. Martin found comfort in discussing these issues with his parents but his primary coping strategy was to vacate the house when possible and visit members of his extended family. He did not want to spend time in his room because it was undecorated, something which he attributed to spare time being used up dealing with his brother's meltdowns. Martin's sense of self-efficacy in helping to manage his brother's meltdowns was minimal as was his mother's, to the extent that this responsibility had been assigned solely to his father. Furthermore, Martin had struggled to develop a network of friends fearing that they would associate them with his brother and that this would be embarrassing for him. Thus the hypothesis continues to develop in the following way:

Adolescents with perceived low self-efficacy in managing their siblings' challenging behaviours are likely to feel helpless which may compound stress levels pertaining to existing demands of adolescence, particularly when educational commitments begin to increase. Perceptions of how they might be viewed by peers because of being associated with their siblings also concern adolescents and may interfere with their ability to develop relationships with peers. The importance of finding time and space for respite away from the siblings' challenging behaviours seems palpable and that this is readily available (e.g. own bedroom) would seem to be the most appealing option.

David reported that he had a wonderful relationship with his brother and that the family was close knit, enjoying open lines of communication. David was competent in using his extensive knowledge of ASCs to help out with his brother when necessary but he also appreciated having his bedroom as a place that he could go and relax or spend time doing his schoolwork. David also enjoyed reading and writing poetry. He reported that his friends were also friendly and respectful of his brother and that he valued this immensely. David's account was one of the most positive of all the participants and appeared to fit most

closely with the conceptual model and therefore the preliminary hypothesis initially outlined above.

Peter's account emphasised the importance of feeling close to his brother and the need to overlook the diagnosis of ASCs in favour of retaining a focus on 'being brothers'. In line with this sentiment, Peter described some examples of typical sibling rivalry but also commented on some of the strains that he felt as a result of having to sometimes 'look out' for his brother when in the company of peers. This related to peers not understanding the nature of ASCs and Peter feeling protective of his brother given his reasonable understanding of why his brother behaved in certain ways in given situations. Peter also described having a very close relationship with his granddad. Peter valued this relationship because he could tell his granddad about the worries he had about his brother, something which he kept quiet from his parents because he did not want to worry them. Peter also spoke about needing to find time to think and to reflect and that he had a special place for doing this away from the house. This account induces the following modifications to the hypothetical model:

Adolescents find it important to maintain a sense of being in a 'typical' sibling relationship, despite clearly observing situations when they recognise that their sibling with ASCs is not typical. The presence of a significant relationship in which an adolescent can openly discuss such issues that are specific to living with siblings' with ASCs appears to be beneficial. The ability to find available time and space for personal reflection seems consistently important to adolescents.

Carole reported that she noticed very few differences between her sister with ASCs and other girls of a similar age and frequently described her sister as 'just a normal little girl, no different. She's just my sister'. Carole did not describe feeling stressed by her sister with ASCs and only commented that at times she might talk about the same thing for a long time. Carole also spoke of how her sister could play the same game for hours and hours, when most others would have long stopped. This interview was probably unique in that Carole reported no evidence that suggested she genuinely perceived her relationship with her sibling to be anything other than 'typical'. This developed the idea that the preliminary hypothesis could be reduced in its simplest form as follows:

Acceptance by adolescents of their siblings for who they are rather than having a focus on their siblings' ASCs may be a significant factor in adolescents' psychosocial adjustment to living with a sibling with ASCs.

Debbie's account was remarkably similar in context to David's. The notable additional factor was that Debbie expressed high hopes for her brother to excel in drawing and that he might pursue this for a potential career. She reported that she saw this as a realistic prospect for her brother and that this was a source of comfort to her. This can also therefore be factored into the developing hypothesis.

Matthew's account focused on his feelings about his perceptions of his family members generally rather than on his brother with ASCs. Matthew reported that his brother would just 'do his own thing' and that this didn't bother him or take up much of his time. Matthew was more concerned about perception that his family didn't really care about him and that he often felt disrespected by family members. Matthew was also interested in talking about how he had been bullied in school and how this had affected him. This was similar to Carole's account of not seeing anything particularly troublesome or notable with her sister, with Matthew reporting that there were other factors that were more significantly related to his well-being, thus leading to further modification of the hypothesis:

For adolescents, having a sibling with ASCs is just one part of their experience. Adolescents may perceive other factors to in fact be more significant with regard to their well-being.

Davina incorporated some interesting observations when reporting on how she felt she had adjusted to living with a sister with ASCs. In the first instance Davina had been aware of her sister's diagnosis for the longest period of all the participants. Furthermore, Davina was one of the older participants interviewed and she had developed a reflective and mature attitude to her sister's diagnosis of autism. In particular, Davina had noticed that things had become easier as her knowledge of ASCs had increased in terms of managing the responsibility of looking after her sister. However, Davina described things as still being difficult sometimes and that she had to be creative, using Facebook, so that she could maintain contact with friends if she had to look after her sister and could not go out.

Ultimately, Davina had come to view her roles of responsibility in terms of looking after her sister as being useful experiences for preparing her for motherhood. This account helps modify the hypothesis as follows:

How adolescents adjust psychosocially to living with a sibling with ASCs will depend on a variety of factors. These factors can incorporate the length of time the adolescent has been aware of the diagnosis, the knowledge gained during that time, and the age and gender of the adolescent as this may influence the adolescent's perceptions of their experiences where they have had some responsibility for looking after their sibling with ASCs. Being creative by using computer based social networking sites can help adolescents to function socially if there are limitations on their time for going out to socialise. However, it would appear that given the choice adolescents would prefer to meet up with friends in real life to engage socially.

Mark described in his account that he wanted to make the best of things with regard to his brother's diagnosis of ASCs. His brother had not wanted to accept the diagnosis and this had created further difficulties for Mark as he had observed his brother becoming a recluse. At the time of interview Mark's brother had only recently been given a diagnosis and Mark knew very little about ASCs. This compounded Mark's struggle to understand how ASCs impacted on his brother, although he was aware that he had been aware for a long time that his brother was 'different'. Mark reported that he spent a lot of time with his friends and that this was how he had managed to cope with seeing his brother so upset. However, Mark's lack of knowledge about ASCs and his brother's rejection of the diagnosis meant that Mark did not discuss this issue with friends and he wished that he could. This account also modifies the hypothetical model:

Knowledge and understanding of ASCs would seem to be important if adolescents are to feel confident enough to discuss such a potentially sensitive issue with friends. The impact on adolescents' psychosocial adjustment can be further mediated by how they observe their siblings' reactions to receiving a diagnosis.

Participants 10 and 11 (Sophie and Tony, respectively) were especially interesting as they were siblings. Whilst Sophie emphasised that her experiences of living with a sibling with ASCs were very stressful, Tony reported that he was indifferent to living with a sibling with ASCs and that it bothered him very little if at all. The fundamental consideration in these diverging sibling accounts is that Tony had moved away from the family home in recent months and had plans to move away from the area to begin a University course. In contrast, Sophie shared her bedroom with her sister with ASCs and her sister frequently displayed extremely challenging behaviours. Sophie's only respite was to visit friends, which of course was not possible at night time when some of her sister's behaviour could be at their most challenging. These accounts inform the theory in relation to how adolescents adjust psychosocially to living with a sibling with ASCs in the following way:

Social living circumstances and the availability of respite for adolescent, particularly when their sibling with ASCs displays extremely challenging behaviours, will have a significant impact on how those adolescents are able to adjust psychosocially to living with a sibling with ASCs.

Outcomes of negative hypothesis testing

Further examination through negative hypothesis testing of the validity of the proposed preliminary conceptual model illustrated in figure 1 has yielded some important additional considerations. The clear impression is that how adolescents adjust psychosocially to living with a sibling with ASCs is a complex process, incorporating a myriad of factors. There appear to be some commonalities amongst the participants in this study that are important features of promoting functional psychosocial adjustment. These factors include:

1. Gaining knowledge and understanding of ASCs and how these conditions impact on how the sibling with the diagnosis behaves and reacts in certain situations.
2. Such knowledge can facilitate empathy and sensitivity in adolescents which can foster increased tolerance and acceptance of their siblings with ASCs, thus promoting better conditions for improved sibling relationships.

3. Being able to find personal time and space to relax is vital for adolescents with regard to coping with their siblings with ASCs, particularly during times when their behaviours become challenging.

4. Social support systems, including friends, family, and other relatives are frequently relied on by adolescents as fundamental sources of comfort.

Notwithstanding the apparent significance of these factors, the negative hypothesis testing has also highlighted the importance of the idiosyncrasies of individual circumstances in determining how adolescents might adjust psychosocially to living with a sibling with ASCs. For example, several of the adolescents in this study reported that individual factors could influence their psychosocial adjustment and that specific strategies were required to mitigate against these factors. For example, Michelle experienced feelings of frustration at not being acknowledged for what she perceived as an ability to manage effectively her brother's challenging behaviours. This frustration was compounded by her reluctance to openly discuss this issue with her parents given her perception that she would not be heard. Martin did not enjoy spending time in his bedroom as it was undecorated so found it necessary to visit relatives to avoid his brother's challenging behaviours. Similarly, Sophie found it essential to visit friends as she shared her bedroom with her sister and experienced her ASCs as extremely challenging. To this end, social living circumstances influenced each of these adolescent's abilities to adjust psychosocially to living with a sibling with ASCs. In the case of Mark, his experience of seeing how difficult it was for his brother to receive a diagnosis of ASCs was the most challenging aspect of adjustment. Although Carole did describe some behaviours of her sister that were characteristic of ASCs, she appeared to genuinely accept her sister for who she was which seemed important in helping her to psychosocially adjust. Matthew reported aspects of his life that impacted on his sense of well-being but he did not attribute these to his brother's ASCs. In Davina's report she discussed a transitional process whereby she had adjusted psychosocially by developing creative ways to maintain friendships and also by reflecting on the positives that she could glean from her experiences of being responsible for looking after her sister. That Davina was older than the majority of the other participants in this study and that she had the most experience of living with a sibling with ASCs may also have been influential factors in the process of her psychosocial adjustment.

In conclusion, the negative hypothesis testing carried out has highlighted the complexities relating to how each of the participant's accounts fit with the proposed model. In light of this, whilst the conceptual model outlined in figure 1 can be helpful for providing an overview for some of the factors that appear to feature in how adolescents adjust psychosocially to living with a sibling with ASCs, it is ambitious to claim anything beyond this given that there are any number of factors specific to an individual's circumstances that will also influence how an adolescent adjusts psychosocially to living with a sibling with ASCs.

Strengths and limitations of the research

Throughout the process of this research steps were taken wherever possible to ensure that the study was conducted with integrity. There were, however, some limitations which need acknowledging.

The use of grounded theory in this study required a review of the literature prior to analysis of the data. This literature review was an integral and non-negotiable facet of the requirements for the doctorate. This knowledge of the area, and working in a clinical setting with ASCs, created potential for personal bias, which could have interfered with the analysis and interpretation of the findings. For example, the researcher became aware after the initial three interviews that there was a tendency to incorporate a clinical approach at times to the interview. On reflection the researcher was then able develop his interview skills accordingly. The researcher maintained memos to monitor perspective and used a journal to maximise the transparency of the decision making processes throughout the analysis. This is in line with key recommendations suggested by Elliot, Fisher, and Rennie (1999). Moreover, the researcher regularly received input through supervision to minimise the potential for misinterpretation or over-identification with the data. This joint checking of transcripts and discussion of themes as they developed formed an integral part of monitoring for discrepancies. Supervision served a further function of facilitating and enhancing the researcher's reflective and reflexive stance which is such a vital component of the grounded theory approach. The researcher also attended a qualitative research supervision group with fellow trainees who analysed interview extracts to monitor for differences in the cross referencing of codes, categories, and themes. Changes in thinking and alterations to codes and themes were occasionally made during this process of cross

referencing which helped strengthen the credibility of the research. Although these considerations were all helpful additions to the data analysis, inter-coder reliability was not attained for each of the eleven interviews. The absence of respondent validation for the researcher's interpretations of the themes identified in the analysis is a further consideration when considering the validity of the findings, as such credibility checks can enhance the validity of the analysis (Mays & Pope, 1995).

The interpersonal nature of the grounded theory approach may have influenced the content of the interviews depending on the relationship between the researcher and individual participants. That is, some of the adolescents might have felt more comfortable with the researcher and vice versa, allowing for a more fluent and open interview process. The researcher is aware that IPA could have been used appropriately in this study as a means of studying participants' individual experiences, with a focus on being concerned with the texture and quality of the participant's perspective rather than its social context, causes, or consequences. Equally, informed by a comprehensive literature review the researcher might have been able to adopt Q methodology to assess the subjective viewpoints of the participants' opinions and beliefs. Indeed Q methodology is perhaps a serious consideration for researchers who might wish to explore the findings yielded by this study. For example, a series of statements based on the proposed model could be generated and presented to adolescents of siblings with ASCs to measure for similarities and differences of opinions and beliefs.

The researcher chose grounded theory methodology on the understanding that this approach might facilitate the exploration of the experiences and perceptions of siblings living with children with ASCs whilst adopting an investigative process that remained open and curious to the data that emerged in the participants' accounts. To this end, the researcher did not intend to delve into individual experiences *per se* or to test a hypothesis but to set out to develop on how existing theory could account for the research situation as it was. Whilst this use of grounded theory appeared to achieve this objective, an unwanted additional effect of this approach is the potential for the sense of the individual to be lost in translation during the data analysis. The use of negative hypothesis testing highlighted this issue when, for example, it became apparent that 'Matthew's' story illustrated how there were factors other than living with a sibling with ASCs which may

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have had a more significant impact in his well-being. Such an observation would have emerged more clearly with an approach such as IPA.

The innovative decision to use the photo elicitation method alongside grounded theory was intended to allow the participants to feel free to discuss what they 'chose' in the context of what they saw as important aspects of their lives. Therefore, the researcher had an agenda within the framework of a semi-structured interview but this was only introduced within the interview process after the participants had discussed their photographs. In this way, as depicted in the 'findings' chapter, the photographs were instrumental in influencing some of the discussions during the interviews which ultimately led to the development of some of the themes which emerged from the data. For example, the photographs initiated conversations that brought about data which led to the emergence of the theme 'adolescent psychological factors', with regard to friends, hobbies, and aspects of school. In particular, the majority of the participants took photographs of family members (notably their sibling with ASCs), friends, and pets all of which featured as sub-categories of the theme 'social impact of ASCs on interpersonal relationships'. Photographs of family members, especially siblings with ASCs, were also prominent in discussions that developed the emerging theme 'adolescents' perceptions of siblings with ASCs'. An interesting observation here was that out of the eleven participants only the two participants who reported predominately negative experiences of living with a sibling with ASCs did not take a photograph of their sibling with ASCs. This was something that the researcher in hindsight would have liked to have explored further during the interviews. A lingering question exists around the possibility that some of the participants might have had important aspects of their lives which they might have chosen to avoid, or subconsciously ignored, when taking the photographs?

However, the researcher was careful to obtain feedback from the participants on how they had experienced the opportunity to use photographs as part of the research process. All of the participants reported that they appreciated the option of being given licence to discuss what mattered to them and that the photographs had facilitated the process. Some participants were particularly grateful for being given the chance to express their emotions openly with someone outside of the family. Most of the participants used the photographs in a considered manner, taking time to choose carefully which photographs would encapsulate the most important aspects of their lives. Only one

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participant reported that ten photographs were not sufficient to accommodate all of the important aspects of life. When given the opportunity to show other photographs, the participant chose a further three; each of the three photographs were of pets, an important area of the participant's life that had already been captured in the original ten photographs. In terms of managing the demonstration of the photographs during interview, one participant elected to use a digital camera and to display the photographs on a computer screen. This worked well. One other participant expressed a preference for writing down their ideas for photographs, as 'imagination' was not something that could obviously be photographed. As all participants are different, it is unlikely that one approach will work for all. Photo elicitation was a way of allowing the data generation to be open. Other avenues that could be considered as participatory methods for future researchers could include asking participants to write diaries to create a narrative about their lives, or to draw pictures to illustrate important aspects of their lives. Perhaps the most interesting piece of general feedback from the participants was that talking about what they saw as important aspects of their lives was a strange experience inasmuch as it was not something they had experienced much. Participants were honest enough to report that the photographs were instrumental in facilitating a variety of discussions and that they were ultimately 'surprised' they had been able to be so open with a stranger about such personal issues.

The selection of participants was based on the knowledge and at the discretion of the field supervisor. A consideration for future investigators with regard to the selection process in this study is that the researcher allowed for siblings with a diagnosis of autism or Asperger's. This decision was pragmatic, and in the knowledge that excluding one diagnosis would make the process of recruitment more difficult. There did not appear to be an obvious bias in the selection process, nor differences in adolescent experiences that could be accounted for by diagnosis.

A further consideration regarding the selection of this particular group of participants pertains to the question surrounding the heritability of autism. The heritability of autism is the proportion of autism that might be explained by genetic variation. Genetic links to autism have been inconclusive and it remains unclear whether ASCs can be explained more by multigene interactions or by rare mutations with major effects (Abrahams & Geschwind, 2008). Although some research evidence on adult siblings has

indicated that the risk of having one or more features of the broader autism phenotype might be as high as 30% (Folstein & Rosen-Sheidley, 2001), other evidence has suggested that the prevalence of ASCs in siblings of autistic children can be estimated to be much lower at 1.76% (Lauritsen, Pedersen, & Mortensen, 2005). Although the researcher was able to draw on clinical judgment prior to and during the interview process, no formal assessment was conducted with the participants regarding the potential for them to have ASCs or features of ASCs. This might be a worthy consideration for future researchers in this area, given that there is perhaps scope to argue that siblings of individuals with a diagnosis of ASCs may not be typically developed themselves.

The interviews were not always conducted alone with the adolescents. It is difficult to be certain of the potential impact of a parent being present during interviews but it is likely that there will have been an effect, given that some of the adolescents reported that they had enjoyed being interviewed alone as it had allowed them the opportunity to discuss things that they would not have revealed in the presence of their parents. To this end, several of the adolescents reported that they had valued the opportunity to take some photographs and that they had appreciated having the time and space to discuss them during the interviews as part of their subjective and meaningful experiences of living with sibling with ASCs.

The small sample size is typical of those recruited generally for qualitative research and therefore the findings need to be treated with caution and should not be generalised across developmental stages, such as early or middle childhood. In addition, there may be differences in gender that warrant further investigation as boys with ASCs may not necessarily behave in the same ways as girls with ASCs which is likely to impact on siblings' adjustment. The length of time that the adolescents had been aware of their siblings' diagnosis of ASCs could also be an important factor that requires further study. However, the findings in this study reflect the subjective perceptions and experiences of the adolescents that participated.

Contribution to the literature

Overall the findings from this study indicate that adopting a grounded theory approach alongside photo elicitation methodology has facilitated an in depth exploration of how living with a sibling with ASCs features in the context of what adolescents see as important

aspects of their lives. To this end, this combined methodological approach has elicited the following findings which contribute to the existing literature.

1. The general feedback from adolescents who participated in this study suggests that they valued an opportunity to open up and discuss their thoughts and feelings during the interviews. This seemed to be facilitated as much as anything else by the fact that the researcher was seen by the adolescents as someone that was outside of the family and therefore a 'safe' person to discuss issues about their siblings with ASCs, as there was little perceived chance of the discussion upsetting family dynamics. That is, some of the adolescents reported that they preferred to repress their worries or complaints about their siblings with ASCs as they did not want to 'contribute' to their parents' existing levels of stress. It seems important to emphasise this consideration here, as there appears to be a need or desire for adolescents to verbalise their thoughts and feelings which is compromised by the competing issue of them needing to protect their parents from further potential stress.

2. This research also supports existing literature (Petalas et al., 2009; Mascha et al., 2006) in that the majority of participants valued their relationships with their siblings with ASCs and that good relationships appeared to foster positive perceptions of their siblings with ASCs which allows for increased tolerance and acceptance of their siblings' more challenging behaviours.

3. Some participants in this study also highlighted an issue around not having sufficient knowledge or understanding of ASCs and that this made them feel anxious and inhibited about the idea of discussing ASCs with their friends. This is in line with previous research (Seltzer et al., 2009). Increased knowledge of ASCs correlated with participants' increased tolerance and acceptance of their siblings with ASCs which buffered against stress and feelings of resentment, promoting further understanding, sensitivity, and empathy for their siblings with ASCs. In addition, the accounts from some of the adolescents in this study correspond with previous research by Bayat (2007) indicating the presence of processes that appear to be associated with resilience, such as developing a greater appreciation of people who are different and making positive sense of disability.

4. Participants also described how they required a variety of coping strategies, particularly an option to 'escape' intermittently to find personal time and space, and this seemed to be a central tenet in facilitating relatively healthy sibling relationships when living with a sibling with ASCs.

5. The use of negative hypothesis testing has added uniquely to the literature in assessing and refining the existing theory development discussed here. Nuances of individual stories have been observed, adding to the strength and validity of the theory development.

Clinical Implications

The findings from this study indicate several implications for clinical practitioners and services. These implications can be beneficial for informing the future practice of professionals in areas of assessment, formulation, and intervention when considering the needs of siblings living with children with ASCs. It is hoped that these practical implications will also be of use in supporting and informing parents and caregivers.

Based on the findings from this study the remainder of this section highlights specific areas to be considered by clinicians. These areas include:

(1) Assessment of siblings' level of knowledge and understanding of ASCs.

(2) Assessment of family living circumstances (e.g. do siblings share rooms? Does sibling have opportunity to find personal time and space as and when required?).

(3) Information given to families on the importance of encouraging siblings to be open and honest about their thoughts and feelings regarding ASCs, whilst guarding against the propensity to repress emotions.

(4) Consideration of structured and professionally facilitated support groups for siblings living with a brother or sister with ASCs. Davies (1994) has developed useful information in this area.

(5) Introducing the concept of incorporating family-oriented assessments for children with ASCs alongside education around implementing interventions. This approach requires collaborative agreement with families and would need to be developmentally tailored to cater for varying sibling ages.

(6) Promoting the psycho-education of ASCs in schools (i.e. providing information and knowledge of the impact of ASCs to typically developing children and adolescents

who attend the same school as children and adolescents with a diagnosis of ASCs). This would seem to be particularly relevant with regard to secondary school pupils, given that the differences between typically developing individuals and those individuals diagnosed with ASCs become increasingly noticeable during adolescence.

The findings suggest that individual factors associated with how adolescents experience their siblings' ASCs in everyday life are important features in how adolescents adjust. Adolescents appear to benefit from increased knowledge about ASCs as this helps them to understand their siblings better which can lead to a more tolerant and accepting attitude. Although it is difficult to know for sure which comes first, adolescents with greater tolerance and acceptance of their siblings' ASCs in this study appeared to have more satisfying and fulfilling relationships with their siblings. Those adolescents with better sibling relations also showed signs that they perceived themselves as more able to manage their siblings challenging behaviour. Practitioners are well placed to highlight and feedback these important revelations to parents of children diagnosed with ASCs. The development of interaction and communication training for siblings of children with ASCs may prove beneficial in reducing conflict and improving relationships between siblings. Training in social behaviour and communication can be tailored to meet the developmental demands faced during adolescence so that they have a consistent level of support. Current practice in the Wakefield district CAMHS does not include siblings in diagnostic assessments or in follow sessions which provide parents with information and resources to help manage ASCs and to help the child to live with their ASCs.

Adolescents in this study emphasised the importance of social support networks in their ability to cope and adjust to living with a sibling with ASCs. Some of the adolescents felt that either their peers or extended family members were of more support than their parents. This is consistent with previous research (Laible, Carlo, Raffaelli, 2000). This sense of support from sources other than parents is helpful in some respects. However, adolescents can become reliant on friends, peers, and external family members to the extent that they become uncomfortable in expressing to their parents their emotions about their siblings with ASCs. The findings from this study suggest that adolescents need to have an open relationship with parents in which they can feel safe to express their

emotions in relation to living with a sibling with ASC. Feelings of loneliness and isolation in adolescents are not rare, particularly when they are faced with emotionally difficult experiences such as the stress of living with a sibling with a disability (Cotterell, 1996). Fear of rejection by parents, being overlooked by parents, or being alienated by peers in the presence of a sibling with ASCs can add to feelings of loneliness. The absence of a communicative relationship between adolescent and parent can manifest in the adolescent having to contain unexpressed emotions. This study yielded information that might suggest unexpressed emotions about their siblings with ASCs can contribute to internalised difficulties such as low mood or anxiety, as well as problems of an external nature such as aggression and self-harming behaviours. It is crucial for clinicians to understand the factors involved that may predispose referrals to CAMHS of siblings of children with ASCs; parents need to be aware both of the dangers associated with uncommunicative relationships with their children, particularly during adolescence, and of the significant benefits that can occur through transparent and accessible lines of communication. Parents can be encouraged to act as agents of increased support for adolescents, in helping them to understand the nature of their siblings ASCs and in teaching them ways to work around problematic and challenging situations during times when their siblings with ASCs are in distress.

The results of sibling-parent group interventions for siblings of children with chronic illness or developmental disability have produced positive results with regard to improvements in sibling connectedness and knowledge of the disability and behaviour problems (Lobato & Kao, 2002). Only one adolescent (Martin) reported attending a support group with other siblings who lived with children with ASCs. Martin appeared to benefit from attending the group, feeling less alone in the knowledge that there were others who were able to empathise with his difficult experiences. However, there seemed to be a skewed emphasis on the group being entrenched in negative discussions around their siblings challenging behaviours. Whilst it is perhaps helpful to express the frustrations created by living with a sibling with ASCs, there is further room for the inclusion of qualified facilitators in the development and advertisement of structured support groups that can account for the developmental level of siblings and target the demands of siblings in need of a supportive environment. Within this environment the findings from this study suggest that there appears to be a need for further consideration and discussion around

the potential benefit that can be gained from promoting positive perceptions and experiences of living with a sibling with ASCs. Support groups could also provide a forum for enhancing knowledge and understanding of ASCs. Together with the promotion of positive perceptions, increased knowledge of ASCs could help to nurture resilience in children and adolescents living with siblings with ASCs. This might have implications for enabling these children and adolescents to show greater appreciation and acceptance of people in society who are different (Bayat, 2007). This was apparent in some of the adolescents' accounts in this study; it appeared to be a key factor in how they perceived their relationships with their sibling with ASCs in a positive light and was linked to more adaptive psychosocial adjustment. There are several advantages of promoting resilience in children and adolescents who experience daily stressors of living with a sibling with ASCs which include the potential to develop positive self-esteem, a hardy temperament, and prosocial behaviour; increase opportunities to build a supportive family environment; and learn skills to develop wider sources of social support through extended family, friends, and peers.

Clinicians might consider the option of introducing family-oriented assessments and interventions when considering the diagnosis of a child with ASCs. In this way, clinicians can help families to acknowledge their individual skills, strengths, and abilities and promote the positive views that siblings might hold about living with a brother or sister with ASCs. The process of adjustment to any initial shock of finding out about their siblings having a diagnosis of ASCs may also be reduced if siblings are involved in the assessment from the outset; it would also be an effective way of increasing knowledge and understanding of ASCs. By facilitating a more systemic approach to the workings of ASC clinics, perhaps clinicians can open up helpful and informative channels of communication that adolescents can appreciate as positive opportunities to engage in satisfying and fulfilling family oriented activities. Providing psycho-educational information about ASCs in schools may be of particular value to adolescents who have siblings with ASCs, in helping to dispel some of the myths and reduce some of the stigma that surround this challenging and complex diagnosis.

Agenda for future research

The present study has revealed a number of salient findings that point towards several lines of enquiry for future research. The decision to restrict this study to adolescents precluded a number of other typically developing siblings in families of adolescents who participated. Further exploration of the similarities and differences in siblings of different developmental stages living in the same household could yield further valuable insights in to how siblings adjust psychosocially to living with a brother or sister with ASCs. The qualitative approach is an excellent method for acquiring subjective knowledge from participants but more quantitative investigation is needed across developmental stages that incorporates a tighter control over sibling characteristics (e.g. birth order, gender, levels of social support, family size, coping processes, understanding of ASCs,) and those characteristics of the family member diagnosed with ASCs (e.g. age, gender, functioning ability, diagnosis).

Finally, it would be interesting to implement and monitor any changes that might emerge as a result of the clinical implications indicated by the findings in this study to see if children, adolescents, parents and indeed the family member with ASCs can all benefit.

CONCLUSIONS

The findings interpreted from the data collected in this study suggest that adolescents do not view living with a sibling with ASCs in entirely negative terms. There were adolescents who participated in this study who found that living with a sibling with ASCs made life very difficult. However, it can be argued that many of the adolescents in this study were able to tolerate, accept, and have positive perceptions of their siblings with ASCs. The theoretical model developed from the findings in this study demonstrates that adolescents feel most able to cope with and adjust psychosocially to living with a child with ASCs when they experience open and collaborative channels of communication with parents; supportive social networks that include friends, peers, family, extended family; positive perceptions of their siblings, including realistic hopes for their siblings' development; knowledge and understanding of ASCs and a perceived sense of self-efficacy in being able to manage their siblings in times of distress. The reciprocal extent to which an adolescent accepts and is accepted by their sibling with ASCs has important connotations for the quality of relationship experienced between siblings, where increased acceptance seems to correlate

with improved sibling relationships. Although the factors incorporated within the model do impact on how adolescents adjust psychosocially to living with a sibling with ASCs, negative hypothesis testing of the model suggests that the complex process of psychosocial adjustment to living with a sibling with ASCs is mediated and complicated further by any number of idiosyncrasies relating to an individual's circumstances.

Final reflections

I am a novice in the world of ASCs except for my clinical experiences in the assessment of children for diagnosis of ASCs and in feeding back the results of these assessments. My knowledge and understanding of the real impact of ASCs is therefore second hand. Throughout this research process I have marvelled at the impressive human qualities of all of the adolescents who were kind enough and motivated to join in with this study. I have always held the view that as clinicians we are in a privileged position to learn from those who sit in front of us in the therapy room. I often discuss with parents the notion that they are the 'experts' when it comes to knowing their children and that clinical practitioners can merely compliment this parental expertise by providing some theoretical knowledge to help clarify why some problems develop and even how they are maintained. Occasionally, I might get lucky and offer some information or an interpretation that leads to a reduction in the presenting problems. I sincerely hope that the findings from this study might be of some use for clinical practitioners when they also find themselves in the privileged position of offering some theoretical insight to a family of experts waiting to be heard.

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APPENDIX ONE

Ethical approval

Leeds (East) Research Ethics Committee

Yorkshire and Humber REC Office
Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4EP

Telephone: 0113 3050108
Facsimile:

17 June 2010

Mr James Edward Hoskinson
Psychologist in Clinical Training
The Leeds Teaching Hospitals NHS Trust
DClinPsych Admin Office
Charles Thackrah Building
101 Clarendon Road, Leeds
LS2 9LJ

Dear Mr Hoskinson

Full title of study:	**How does having a sibling with autism spectrum conditions impact on adolescents' psychosocial adjustment?**
REC reference number:	**10/H1306/30**

Thank you for your letter of 15 June 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 14 June 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Assent form (adolescent)	2	15 June 2010
Participant Information Sheet: Adolescent	3	15 June 2010
Participant Consent Form: Adult	3	15 June 2010
Participant Information Sheet: Parent	3	15 June 2010
Participant Consent Form: Adolescent	3	15 June 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/H1306/30	**Please quote this number on all correspondence**

Yours sincerely

Rachel Bell

APPENDIX TWO

Participant information sheets

Adolescent Information Sheet (Version 3 – 15/06/10)

How does having a sibling with autism spectrum conditions impact on adolescents' psychosocial adjustment?

My name is Jim Hoskinson. I am a Psychologist in Clinical Training studying at the University of Leeds. As part of my training, I am required to conduct an educational project. I am therefore inviting you to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Some of what is written below might be difficult to understand so please feel free to ask if there is anything that is not clear or if you would like more information.

Purpose of research
The research aims to explore the experiences of adolescents whose siblings (brothers, sisters, step-brothers, or step-sisters) have autism or Asperger syndrome with a view to uncovering how these experiences might impact on these adolescents' psychosocial wellbeing (how they think and feel about themselves and in relation to others around them, such as friends and family members) and thereby assessing any possible implications for service delivery (whether there is a need for support from services).

Why choose you?
You have been chosen for the following reasons:

(1) You have a brother or sister diagnosed with autism or Asperger Syndrome.

(2) You are between the ages of 12-18 years-old.

(3) You, or your brother or sister has attended NHS Wakefield District (Child and Adolescent Mental Health Services (CAMHS).

Do you have to take part?

It is up to you whether you would like to take part. If you do decide to take part, you will be asked to sign a consent form. If you agree to take part, you are free to withdraw without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the quality of care given to any aspect of any of your healthcare needs now or in the future.

What will happen to you if you do take part?

If you choose to take part, I will be giving you a camera and asking you to take 10 photographs of anything that you see as important in your life. It is very important that you make sure you do not put yourself in any danger when you are taking your photographs. It would be a good idea to tell your parents if you are taking photographs that are away from your house. I advise that you do not take pictures of strangers and that you ask permission if you wish to take pictures of your friends and family members. If you do choose to take pictures of friends or family members, then it would be helpful to let them know about this study and to reassure them that you will have the pictures in your possession when the interview is finished. When you have taken the photgraphs I will come and collect the camera from you so that I can get them developed for you. I will not be looking at any of the photographs until we meet up again. I will then be asking you some questions about the photographs in your home or any other place in which you would feel comfortable. At least one of your parents, or caregivers, will be in the house during the interview and can also be present in the room during the interview if this is what you would prefer. You can keep the photographs when we have finished talking about them. I will need about an hour to ask you my questions. I will be recording our conversation on a digital audio recorder. This is so that I can listen to what we have talked about afterwards. I will be asking you to sign a form which agrees to this process. I will ensure that the audio recorder is stored in a secure place and that no one else will listen to what we talked about. When I have listened to our conversation and transferred the data to a confidential (private) university server so that it is anonymised (made so that no one else apart from you and I will know that it is you who has had the conversation with me), I will ensure that it is erased from the recorder.

What are the possible disadvantages and risks of taking part?

I hope that our conversation will be enjoyable and that it will give me useful information that may be of benefit to you and your family. However, it is difficult to say for sure that there are no possible risks involved in taking part in the study. You may or may not find that some of the things that you choose to talk about upsetting. If this happens, I will make sure that we can find a way of making things less upsetting for you and, of course, we can stop and talk about something completely different should that be your wish.

What happens when the research finishes?

Once the research has finished and I have the results and recommendations, I will give you a summary of the results. Some of what you say may be written in my report. Where this occurs, I will make sure that only you and I know that you have said certain quotes.

Contact for further information

This project is being co-ordinated by: James E. Hoskinson,
Leeds Institute of Health Sciences
Charles Thackrah Building,
101 Clarendon Road,
Leeds LS2 9LJ

Tel: 0113 343 2732

Under the supervision of: Cathy Brennan
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Tel: 0113 343 0810

Thank you for taking the time to read this information.

Jim Hoskinson

Parent Information Sheet (Version 3 – 15/06/10)

How does having a sibling with autism spectrum conditions impact on adolescents' psychosocial adjustment?

My name is Jim Hoskinson. I am a Psychologist in Clinical Training studying at the University of Leeds. As part of my training, I am required to conduct an educational project. I am therefore inviting your son or daughter to take part in this research study. Before you decide on whether to give permission for your son or daughter to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information.

Purpose of research
The research aims to explore the experiences of adolescents whose siblings have ASCs with a view to uncovering how these experiences might impact on these adolescents' psychosocial wellbeing and thereby assessing any possible implications for service delivery.

Why choose you?
You have been chosen for the following reasons:

(1) You have a child/ren who has a brother or sister diagnosed with ASCs.

(2) You have a child/ren is/are between the ages of 12-18 years-old not diagnosed with ASCs.

(3) Your child with ASCs has attended NHS Wakefield District (Child and Adolescent Mental Health Services (CAMHS).

Do you have to take part?
It is up to you whether you would like your son or daughter to take part. If you do agree to him or her taking part, you will be asked to sign a consent form. If your son or daughter is under 16 years of age and you agree for him or her to take part, you are free to withdraw him or her at any time and without giving a reason. Your will not affect the quality of care given to any aspect of any of their healthcare needs now or in the future.

What will happen to your son or daughter if you permit them to take part?
If you choose to take part, I will be asking permission to give your son or daughter a disposable camera so that they can take 10 photographs of anything that they regard as important in their lives. I would advise your son or daughter not to put themselves at risk when taking any of the photographs. I advise that your son/daughter does not take pictures of strangers and that he/she asks permission if they wish to take pictures of their friends and family members. If he/she does choose to take pictures of friends or family members, then it would be helpful to let these friends and/or family members know about this study and to reassure them that your son/daughter will keep possession of the pictures when the interview is finished. When your son/daughter has taken the photgraphs, I would be responsible for collecting the camera and having the camera processed before returning the photographs unopened. I would then want to ask your son or daughter some questions about the photographs in your home or any other place in which you and them would feel comfortable. At least one of you, as parents or caregivers, will need to be in the house during the interview and you can also be present in the room during the interview if this is what your son/daughter prefers. I will need about an hour to ask him or her my questions. I will be recording our conversation on a digital audio recorder. This is so that I can listen to what we have talked about afterwards. I will be asking you to sign a form which agrees to this process. The photographs will be the property of your son or daughter and will be for them to keep when the interview finishes. I will ensure that the audio recorder is stored in a secure place and that no one else will listen to what we talked about. When I have listened to our conversation and transferred the data to a confidential university server, I will ensure that it is erased from the recorder. The data that are stored on the university server will also be anonymised so that they cannot be identified.

What are the possible disadvantages and risks of taking part?
I hope that our conversation will be enjoyable and that it will give me useful information that may be of benefit to you and your family. Your son or daughter may find that some of the things that he or she chooses to talk about upsetting. If this happens, I will make every effort to make sure that we can find a way of making things less upsetting for them and, of course, we can stop and talk about something completely different should that be their wish. There will also be an option for your son or daughter to be referred to CAMHS via the GP in the unlikely event that this is necessary.

What happens when the research finishes?
Once the research has finished and the results and recommendations are established, I will give you a summary of the results. Some of what your son or daughter says may be presented as evidence for some of my recommendations. Where this occurs, I will ensure their confidentiality so that only they and I know that they have said certain quotes.

Who has reviewed this study?
The National Health Service Research Ethics Committee and the University of Leeds Research Committee for the Clinical Psychology Doctorate Programme have reviewed and approved this research proposal.

Contact for further information
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Thank you for taking the time to read this information.

Jim Hoskinson

Informed consent forms

Adolescent consent form – Version 3 (15/06/10)

How does having a sibling with autism spectrum conditions impact on adolescents' psychosocial adjustment?

ID Reference No:_____   Age:_____

Please Initial

Have you read the Participant Information Sheet?

☐

Have you had the opportunity to ask questions and to discuss the study?

☐

Have you received satisfactory answers to all of your questions?

☐

Have you received enough information about the study?

☐

Have you spoken to Jim Hoskinson?

☐

Do you understand that you will be interviewed by Jim Hoskinson?

☐

Do you understand that you are free to stop the interview, can choose not to answer a question, or can change your mind about taking part in the study?

☐

Please Initial

At any time

☐

Without having to give a reason

☐

Without it affecting your present or future health care

☐

Do you agree to take part in this study?

☐

Please Initial

Do you agree to the interview being audio recorded?

☐

Do you give me permission for the things that you say in the interview to be used in reports of the research, knowing that your name will not be used?

☐

Signed   _____

Date   _____

Identification No.   _____

Signature of witness   _____

Date   _____

Name in block letters   _____

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Chief Executive: Alan Wittrick
Chair: Roger Grasby
WDCHS Chief Operating Officer: Andrew Irvine

Adult consent form – Version 3 (15/06/10)

How does having a sibling with autism spectrum conditions impact on adolescents'
psychosocial adjustment?

ID Reference No:_____

**Please
Initial**

Have you read the Participant Information Sheet?

☐

Have you had the opportunity to ask questions and to discuss the study?

☐

Have you received satisfactory answers to all of your questions?

☐

Have you received enough information about the study?

☐

Have you spoken to Jim Hoskinson?

☐

Do you understand that your son or daughter will be interviewed by Jim Hoskinson?

☐

Do you understand that your son or daughter is free to stop the interview, choose not to answer a question, or change their mind about taking part in the study?

Please Initial

At any time

☐

Without having to give a reason

☐

Without it affecting their present or future health care

☐

Do you agree for your son or daughter to take part in this study?

☐

Please Initial

Do you agree to the interview being audio recorded?

☐

Do you agree to anonymised data from this study being published?

☐

Signed   _____

Date   _____

Identification No.   _____

Signature of witness   _____

Date   _____

Name in block letters   _____

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Interview Schedule

Introductory comments

Initial general conversation to help the participant to feel comfortable and at ease with the researcher.

Outline of the process of the interview; introduce participants to the audio-recording equipment and reiterate that the interview should not take longer than 90 minutes.

Remind the participant that he or she can choose to stop the interview whenever he or she feels like it.

Ensure that interviewee is content to proceed (signatures on form).

Opening question:

You have taken some interesting pictures since I last saw you. I wonder if you could tell me a bit about why you chose to take these particular photos? You can start with whichever photograph you want.

General questions:

What did you think/feel when you took this photo?

What do you think/feel about that now?

Can you tell me more about that please?

Specific questions?

How would you describe yourself?

Tell me about you brother/sister

How do you find having a brother/sister with ASCs?

What else can you tell me about having a brother/sister with ASCs?

Concluding questions:

Is there anything that I haven't asked about any of the photographs that you think is

important and that you would like to talk about some more?

How have you felt talking about these photographs today?

Are there other things that are important to you that you didn't manage to include with

your photographs?

Debrief

APPENDIX THREE

Illustrative example of worked transcript analysis (4th interview)

Theme: Social impact of ASCs on interpersonal relationships

Category: *Relationships with extended family*

Illustrative quotes	Coding: line-by-line	Focused coding
"...I chose my Granddad because I love him, and me and him will go all over together, and I spend time with him more than I do in my house."	Family member; emotional bond, sense of togetherness	Emotional closeness with extended family; meaningful relationship; coping strategy/avoidance

Recorded memo: The adolescent talked about how he had found it very useful to be able to talk with me about some of the difficulties that he experiences whilst living with his sibling with ASCs. I wonder whether he stays away from the family house to help manage his emotions during times of distress. He was also very complimentary and understanding of his brother during the interview so it may simply be that he has a really special bond with his Granddad.