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Siblings of children with autism spectrum disorder

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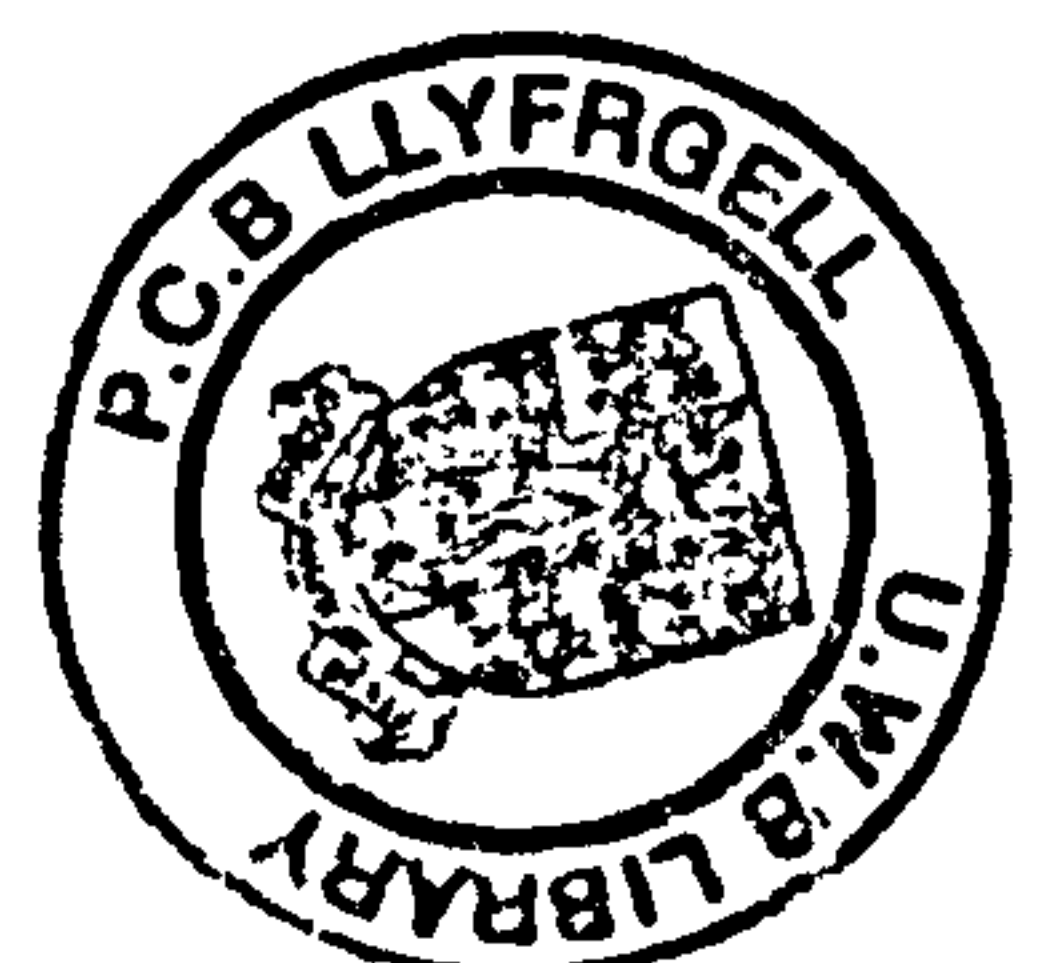
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Siblings Of Children with Autism Spectrum Disorder.

Michael Anthony Petalas

Thesis submitted to the School of Psychology, Bangor University, in partial
fulfilment for the degree of Doctor of Philosophy

March, 2009



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Diolch.

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Summary

Research with typically developing siblings of children with autism spectrum disorder (ASD) has often yielded mixed findings. Some of the inconsistencies in study outcomes have been attributed to methodological issues. This thesis attempts to expand upon the existing knowledge base on sibling adjustment and relationships, where one child has ASD, by addressing some pertinent methodological issues.

In Chapter 1, a review of extant literature is undertaken, outlining key methodological considerations and highlighting areas for future research. Four empirical investigations follow (Chapters 2,3, 4, 5.), attempting to address some of these methodological considerations. In Chapter 2, siblings of children with autism and ID were compared to siblings of children with ID only, on a measure of emotional and behavioural adjustment. Siblings of children with autism and ID had increased emotional difficulties compared to the comparison group (ID only) as well as normative data from typically developing children in the UK. Correlation analyses revealed that a number of environmental and demographic variables were associated with increased adjustment difficulties in siblings of children with autism and ID.

In Chapters 3 and 4, the subjective accounts of siblings growing up with a brother with ASD were explored. Interpretative phenomenological analysis was used to analyse data collected via semi-structured, face-to-face interviews. Chapter 3 presents findings from interviews with siblings in middle childhood with a brother with ASD. Chapter 4 presents the analysis from interviews with adolescent siblings with a brother with ASD. Taken together the findings from these two exploratory studies introduce a developmental perspective to the research area; the findings are indicative of qualitative differences in the perceptions and experiences of having a brother with ASD between siblings in middle childhood and adolescent siblings.

Chapter 6 examined a diathesis-stress model of sibling emotional and behavioural adjustment and relationships. The results showed that autistic characteristics in the siblings predicted behavioural and emotional adjustment outcomes in the siblings and the children with ASD. Emotional and behavioural problems of the children with ASD, predicted emotional and behavioural adjustment outcomes in the siblings and sibling relationship outcomes. Autistic characteristics in the siblings also moderated the relationship between emotional and behavioural problems in the children with ASD and emotional and behavioural problems in the siblings, as well as the relationship between parent mental health problems and emotional and behavioural problems in the siblings. A number of environmental variables significantly predicted sibling relationship outcomes. The findings presented throughout the thesis are summarized and discussed in Chapter 6.

Chapter 1. Siblings of Children With Autism: A Review of the Literature

There is a well-established literature on family functioning reporting group differences in parental distress across different types of children's disabilities. Research with mothers and fathers of children with autism tends to report significantly more stress than for parents of typically developing (TD) children (Rodrigue et al., 1990, 1992; Wolf et al., 1989), children with Down syndrome (Dumas, Wolf, Fisman, & Culligan, 1991; Rodrigue et al., 1990, 1992; Sanders & Morgan, 1997; Wolf et al., 1989) other developmental disabilities or chronic illness (Bouma & Schweitzer, 1990; Donovan, 1988; Fisman et al., 1989; Fombone et al., 2001; Kasari & Sigman, 1997; Koegel et al., 1992; Konstantareas, 1991; McKiney & Patterson, 1987), or children from psychiatric outpatient facilities (Holroyd & McArthur, 1976).

From a family-systems and ecological point of view (Bronfenbrenner, 1979; Crnic, Freidrich, & Greenberg, 1983; Fisman & Wolf, 1991; Kazak, 1989; Minuchin, 1985), the broader familial and societal environments are interlinked and play an important role in the psychological development of the individual members. Therefore, we might expect siblings in families of children with autism to be affected in at least two ways. First, their parents might be experiencing significant amounts of stress. Second, like parents, siblings may have to cope with a sibling with considerable social and communication impairments, and behaviour problems.

In the present review, our main focus is to bring together research evidence on the psychological and behavioral adjustment of child and adolescent siblings of children with an autism spectrum disorder (ASD). In addition we review studies reporting on the relationship outcomes in siblings of children with ASD and factors affecting these outcomes. We will briefly explore the evidence base for support interventions aimed

at siblings of children with ASD. We also discuss methodological and conceptual challenges for research on siblings of children with ASD, including the putative role of the broader autism phenotype. We will not review this latter question in detail and refer the reader to alternative sources for a more complete treatment of the issues (Bailey et al., 1995; Fombone, Bolton, Prior, Jordan, & Rutter, 1997; Hughes, Plumet, & Leboyer, 1999).

Autism is a pervasive developmental disorder with onset by age three in an individual. Autism is currently defined by a triad of impairments relating to difficulties in social interaction, language and communication, and restricted, repetitive, or stereotyped behaviors (APA, 1994). The use of the term autism spectrum disorders (ASD), throughout this paper, includes children with autism, Asperger syndrome, and pervasive developmental disorders. These disorders share impairments in communication and social interaction, and are characterized by the presence of restricted and repetitive behaviors (APA, 2000). We refer to the siblings of children with ASD as TD as these children reportedly did not have a diagnosis of an ASD at the time that the research was carried out. The term 'adjustment' as used throughout this paper refers to the psychological, emotional and behavioural outcomes of siblings, as captured by outcome measures employed in the literature reviewed in this paper. We have selected studies on siblings of children with autism from the year 1970 forward. Prior to that, studies used different terminology (e.g. Creak & Ini, 1960) and autism was generically referred to as childhood schizophrenia (Eisenberg & Kanner, 1956). Although our knowledge of the autistic disorder is still today growing and changing, it was in the 1970s that researchers and clinicians began to recognise the disparateness between autism and schizophrenia

(e.g. Kolvin, 1971), as well as the diagnostic broadness of the autism phenotype. Reports of prevalence rates of the autistic disorder between studies that include children born before or after the year 1970 show a 50% increase in prevalence of autism for the latter group (Gillberg & Wing, 1999). It is also important to note that since the sibling adjustment literature reviewed in this paper stretches as far as the 1970s, it is possible that some siblings that participated in the earlier studies as TD may have since qualified for an ASD diagnosis, given the broadening of diagnostic concepts over the years.

The adjustment of siblings of children with ASD

Within the literature reporting findings from research on the adjustment of siblings of children with autism, many researchers make comparisons between siblings of children with autism and siblings of children in various other diagnostic categories or typically developing (TD) children. Most researchers also address relationships between variables and factors associated with sibling adjustment within the samples. The aim of such methods is twofold and attempts to answer two important questions:

- 1) whether siblings with a brother or sister with autism differ from typical sibling pairs or siblings of children with other disabilities and if so in what ways they differ?
- 2) Assuming that siblings of children with autism as a population are unique, what makes some siblings, within that group, cope better than others and what factors underlie these different adjustment outcomes?

Group-comparison outcomes

The results from studies reporting on group comparison outcomes between siblings of children with ASD and other sibling groups or normative data are mixed. Bågenholm

and Gillberg (1991) found more siblings, aged 4 to 20 years, of children with autism reporting feelings of loneliness and social isolation compared to siblings of children with an intellectual disability (ID). A number of researchers have found siblings of children with ASD to be as socially competent as siblings of children with Down syndrome or siblings of TD children (Gold, 1993; Kaminsky & Dewey, 2002; Rodrigue, Gefken, & Morgan, 1993). Some researchers even found social competence in siblings of children with ASD, aged 6 to 13 years, to be at an advantage compared to siblings of children with diabetes or no disability (Ferrari, 1984).

The majority of studies into siblings' well-being have compared siblings on their behavioural and emotional adjustment. In one of the earliest studies, mothers rated siblings to have the highest internalizing, personality problems but no increased risk for behaviour problems compared to siblings of children with Diabetes and TD children (Ferrari, 1984). Bågenholm and Gillberg (1991) found higher levels of externalizing behaviour problems for siblings of children with autism, compared to siblings of TD children. In a subsequent study, siblings of children with autism had significantly more internalizing and externalizing behaviour problems compared to siblings of TD children (Rodrigue & Gefken, 1993); these children furthermore had more internalizing and externalizing behaviour problems compared to siblings of children with DS, however this difference was not statistically significant. Similarly, Verte et al. (2003) reported higher rates of internalizing and externalizing behaviour problems in siblings of children with high functioning autism between 6 and 16 years of age, compared to siblings of TD children. Fisman et al. (1996) also found siblings of children with PDD, aged 8 to 16, to present with more internalizing behaviour problems according to reports from both parents and teachers, than siblings of children with DS and TD children. Furthermore, in this study, parents additionally

reported increased externalizing problems in the siblings. At three year follow up these siblings displayed only increased externalizing problems, according to parent reports (Fisman et al., 2000). Yet in a later investigation Hastings (2007) did not observe any significant differences between siblings of children with autism, aged 3 to 18 years, and siblings of children with DS and other disabilities on the strengths and difficulties questionnaire. Kaminsky and Dewey (2002) also found no group differences on siblings' behavioural adjustment, between siblings of children with autism, DS, and TD children. Pilowsky et al. (2004) also observed that group differences were absent in siblings of children with autism compared to TD children.

In another study where the emotional and behavioural adjustment of siblings of children with ASD, ages 6 to 16 years, has been compared to normative data, siblings of children with autism were found to have more peer problems, less prosocial behavior, and more overall adjustment problems (Hastings, 2003a). In subsequent research from the same author, using the same outcome measure of adjustment (SDQ), siblings of children with autism aged 4 to 16, from families engaged in ABA programmes, were found to have better adjustment outcomes on the domains of conduct problems, hyperactivity, peer problems, and overall adjustment problems compared to normative data (Hastings 2003b). In a study by Ross and Cuskelly (2006), mothers reported that 40% of siblings of children with autism had significantly more internalizing difficulties compared to normative data. Previously, Mates (1990) also found no differences in siblings home or school adjustment compared to normative data. More recently Benson and Karlof (in press) also showed that siblings of children with autism were not at an increased risk for adjustment problems as measured by the SDQ.

Research has in addition compared the self-concept of siblings of children with autism to other comparison groups. Both Verte et al. (2003) and Mates (1990) did not find a difference against siblings of TD children. Berger (1980) found siblings of children with autism to have higher self-concept scores compared to normative data. Macks and Reeve (2007), similarly found siblings of children with autism comparing favourably to siblings of TD children on their self-concept.

Studies have furthermore compared siblings of children with autism on measures of depression. Gold (1993) found higher scores for siblings of children with autism, from 7 to 17 years of age, compared to siblings of TD children, using the child depression inventory (CDI; Kovacs & Beck, 1977). In this study adolescent siblings (13 to 17 years) of children with autism had significantly higher scores of depression than child siblings. In a more recent investigation (Orsmond & Seltzer, 2006), over one third of adolescent siblings (12 to 18 years) of children with autism reported depressive symptoms at or above the clinical cut-off score of 16 on the Center for Epidemiological Studies Depression Scale (Radloff, 1977). These symptoms were similar to those found in adolescent community samples (Radloff, 1991). Macks and Reeve (2007) found no such group differences between siblings of children with autism, aged 7 to 17 years, and siblings of TD children, using the short-form version of the CDI (Kovacs, 1992).

Summing up, the findings from group comparisons are often equivocal. The self-concept of siblings of children with autism seems to be unaffected. Findings on sibling's social competence are less clear from the existing literature. There appears to be an increased risk for siblings of children with autism, especially for internalizing difficulties, however this risk does not present consistently.

Methodological reasons that might underlie the variability in findings include small sample sizes, and lack of adequate matching and control procedures. These and other issues are discussed in the following sections. Notably, none of the aforementioned studies have specifically focused on siblings of children with ASD during the preadolescence years, without also including the adolescent years.

Issues in relation to group comparisons

Provided that groups are matched on demographic factors and potential confounding variables are controlled for, comparative findings that show a difference between siblings of children with autism and other sibling groups hold implicit the assumption that places the locus of the factor responsible for group differences directly with the child with autism. Children with autism frequently engage in a constellation of challenging behaviours such as aggression, self-injury, impulsivity, hyperactivity, limited play repertoire, lack of social/affective behaviour, impaired communication ability, temper tantrums, destructive behaviour and obsessive ritualistic behaviours (Grey, & Holden, 1992; Harris, 1994; Knott, Lewis, & Williams, 1995; Sanders, & Morgan, 1997), that might be expected to have a negative impact on the TD sibling and the dyadic relationship. It therefore seems not unreasonable to assume that siblings of autistic children can sometimes be negatively affected by their experiences as they face great and possibly unique challenges (Morgan, 1988).

In a group design that compares the adjustment of siblings of children with autism to another sibling group, any group differences that appear between the two groups may become the basis for inferring a causal relationship between the experimental conditions and the outcome measures of adjustment. The first problem with this line of reasoning is that comparisons of siblings of children with autism to

other groups of siblings, are attempting to replicate true experimental designs in order to make causal inferences. Hastings (2008) notes how research into the wellbeing of parents of children with autism lacks the essential criterion of random allocation of participants to the experimental conditions that is so crucial in a true experimental design. Group designs with siblings of children with autism face the exact same impossibility in that it is not realistic to randomly assign some siblings to a brother or sister with autism and other siblings to children with other or no disabilities. Hastings (2008) discusses the problem of causal evidence in adjustment research with parents of children with autism. In a similar manner, research with siblings of children with autism that endeavours to demonstrate a causal pathway between a given variable and outcomes of adjustment, should do so in accordance with the proposed criteria of causality set for research where true experimental approaches are not present (Haynes, 1992; Kazdin, et al., 1997). This means that if a causal association is to be made, first, a reliable association between having a sibling with autism and an outcome of adjustment must be established. Second, competing explanations must be eliminated, third, the research needs to be able to demonstrate that the cause temporally precedes the effect. Finally, there needs to be a conceivable psychological process by which causality can be demonstrated.

Factors underlying sibling adjustment

We saw earlier why evidence causally linking siblings of children with autism to maladjustment is not compellingly convincing. An additional drawback with findings derived from group designs refers to falling short of the second criterion of causality: eliminating alternative explanations; group designs can overlook other pertinent sample characteristics, apart from having a sibling with autism, that may also be

contributing to the differences between sibling groups. These include characteristics of the familial environment, the dynamic interactions between its members, and the broader interfaces of the social climate, as well as the genetic aspects of the broader autism phenotype that may be present in relatives of children with autism. It is important therefore to move beyond the group findings.

A more substantial question concerns what factors moderate, and what processes mediate the relationship between having a brother or sister with autism and TD siblings' adjustment outcomes. Analysis on the within group level explores within group differences, relationships between factors, predictive power and interaction effects, to determine how certain variables are associated with or predict adjustment among siblings of children with autism. This allows researchers to move away from the assumption that siblings are uniformly affected, to focus on other factors in addition to the child with a disability. Such factors include characteristics of the child with autism and the TD sibling, the parents/carers and marital dyadic relationship, and the effects of the wider social and familial context. Research investigating factors underlying behavioural adjustment difficulties in siblings have yielded mixed findings. While some researchers have not found a relationship between symptom severity of the child with autism and sibling behavioural adjustment (Brady, Hoffman, & Sweeney, 2005), others have shown that severity of symptoms and behaviour problems of the child with autism predicted increased behavioural adjustment problems in the TD siblings (Benson and Karlof, in press; Hastings, 2007). Rodrigue and colleagues (1993) found siblings older than the child with autism to experience more adjustment difficulties. They speculated that this might be, due to older siblings suddenly having to cope with the introduction of a developmentally disabled sibling, and perhaps having to assume more care and domestic responsibilities. Other research

however, has shown that siblings younger than the child with autism were found to be more at risk (Gold, 1993; Hastings, 2003a). Hastings (2003a) postulated that older children could have had time to develop attachment relationships with their parents prior to the birth of the child with autism that might act as a buffer to the deleterious affects of growing up with a sibling with autism.

Static factors and constellation variables

In general research exploring static factors such as age, birth order, gender, and number of children in the family, in isolation, has not demonstrated significant effects of these variables on sibling adjustment (Breslau, 1982; Gold 1993; Mates, 1990; McHale et al., 1986; Pilowsky et al., 2004). Kaminsky and Dewey (2002) did find a positive correlation between the number of children in the family and siblings' behavioural adjustment. Pilowsky et al. (2004) however noted that increased family size correlated with decreased prosocial skills in the TD siblings. An older diagnosis of the child with autism has been shown to positively correlate with sibling behavioural adjustment (Ferrari, 1984). More recently, Macks and Reeves (2007) found that older brothers of children with autism, from two-child families, that were socioeconomically deprived, had higher scores of depression and lowered self-concept. Gold (1993) noted that different variables correlated with different adjustment outcomes for brothers and sisters of boys with autism; brothers had higher scores of depression when they reported that there was nothing good about their brother with autism, sisters' depression scores positively correlated with the age and time elapsed since diagnosis of the child with autism, and also being younger than the child with autism.

Process variables

Research has also focused on *processes* rather than *family constellation variables* and *individual characteristics*. Parental and marital satisfaction was positively correlated with siblings' perceived competence (Rodrigue et al., 1993). Fisman et al. (1996; 2000) reported parental distress to mediate the relationship between having a brother or sister with autism and sibling's behavioural adjustment. Higher levels of parental stress have also been associated with delays in sibling socialization skills (Pilowsky et al., 2004). More recently, the importance of the familial climate (family connectedness, parent agreement, and perceived child-marital impact) was further highlighted when it was shown to significantly predict sibling prosocial behaviour (Benson & Karlof, in press). The perception of parental partiality, specifically being preferred over the child with autism, was related to internalizing behavior problems in the TD siblings (Wolf et al., 1998). Hastings (2003b) showed family social support to moderate the relationship between severity of disability in the child with autism and emotional and behavioural adjustment of the TD sibling. Kaminsky & Dewey (2002) found social support from classmates and friends to be related to decreased levels of loneliness. Social support from parents and teachers has additionally been related to decreased behaviour adjustment problems in the TD siblings (Wolf et al., 1998). Parents increased involvement in educational programmes, such as intensive home-based ABA services (Hastings, 2003b), has been shown to benefit siblings in their behavioural adjustment (Benson & Karlof, in press; Hastings, 2003b).

Self-concept

Ferrari (1984) found siblings' self-concept score to be the best variable for predicting the child's overall behaviour problem score. The author found no differences in siblings' self concept, between siblings of children with PDD, siblings of children with diabetes and siblings of TD control children. Siblings' concept of self has also been related to their social competence skills (Verte et al., 2003). Despite the common sense link between *social competence* and *concept of self* it is important to recognise that the two constructs are distinct and should therefore be examined separately. This distinction is particularly important in the context of the broader autism phenotype that has been shown to include deficits in social interaction and friendship formation (Losh & Piven, 2007). Furthermore, Wolf et al. (1998) found sibling's feelings of self-competence, as measured by the Harter (1985) self-perception profile, to be related to parent reports of sibling internalizing and externalizing behaviour problems at Time 1 and these relationships were still evident three years later when there was evidence for an additional relationship between feelings of self-competence and teachers reports of internalizing difficulties in the siblings. Verte and colleagues (2003), found elevated scores in the self-concept scores among sisters aged between 12 and 16 years of children with high functioning autism.

Different measures of self-concept however, have been used across studies.

Verte et al. (2003) used a Dutch version of the Self-description Questionnaire I and II (Marsch 1992; Van der Steene 1998; Verte & Royers, 1998), while the majority of studies with siblings of children with ASD employed the Piers-Harris Self Concept Scale (Piers & Harris, 1969), and Fisman et al. (1996, 2000) and Wolf et al. (1998) used the Self Perception Profile for Children (Harter, 1985). The study by Verte et al.

(2003) also restricted their sample to siblings of children with high functioning autism, a methodology that is not shared by most other studies.

Statistical significance in within group findings

The within-group studies present mixed findings, it is therefore important to ask whether some of the studies are failing to detect effects when these are present due to issues such as different outcome measures employed and different age groups of participants or small sample sizes used. Hastings (2007) recently examined the relationship between the behaviour problems of the child with a disability and the behavioural adjustment of the TD siblings in 75 families of children with autism and intellectual disability, Down syndrome and mental retardation, and mental retardation and no other additional diagnosis. Hastings (2007) followed up this sample two years later where data was available on 56 families. Longitudinal data analyses showed that increased behaviour problems in the siblings with a disability predicted increased behaviour adjustment difficulties of the TD sibling. These results do not replicate earlier research (Hastings, 2003a) where the behavioural problems of the child with autism did not significantly add to the prediction of siblings' behavioural adjustment. One key difference between the two studies is that in the more recent longitudinal investigation the sample is much larger and at time 1, the association between the behaviour scores is significant but the correlation is weak ($r(75) = .24, p = .043$). Even longitudinally the sample in the Hastings (2007) paper is much larger meaning that although it is important, the behaviour problems of the disabled child are not a massive contributor. The above example, raises questions regarding the strength and significance of statistical findings and how well these findings represent outcomes that are clinically meaningful.

The problem with associations

A potential strength of the present paper is its narrow focus on research with siblings of children with autism. However, given the broad diagnostic classification of ASDs, the diagnosis of the child with autism varies greatly from one study to the next. Studies have included samples of children with HFA (Verte et al., 1993), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (Ferrari, 1984; Fisman, et al., 1996, 2000), as well as children with varying forms of Aspergers', and autism with or without learning disabilities (Bagnholm & Gillberg, 1991; Mates, 1990; Rodrigue et al., 1993) or even mixed samples (Giallo & Gavidia-Payne, 2007; Ross & Cuskelly, 2006). Findings from research that does not differentiate between the varying phenotypes of ASDs limits the generality of outcomes and precludes the corroboration of evidence toward a direction.

The majority of the research on sibling adjustment reports on findings from studies that collect data at one point in time (See Fisman et al., 2000; Hastings, 2007), falling short of meeting the causality criterion of temporal precedence. Longitudinal investigations are the most viable means of demonstrating that specific characteristics or changes in these characteristics, which pertain to the child with autism, predict siblings' adjustment over time. Studies that are longitudinal in nature are more qualified to make causal attributions by looking at temporal precedence between putative causal variables (Hastings, 2007) and are better able to address the issue of confounding variables by equating groups through close matching (Stoneman, 1989). Finally, research attempting to identify factors that influence sibling adjustment should always adopt an ecological perspective considering factors within as well as outside the family where there is a child with ASD. Benson and

Karlof (in press) found stressful life events, such as the death of a loved one, or financial hardship to be significant predictors of sibling prosocial behaviour.

The sibling relationship

Research investigating sibling relationships where there is a child with autism is beset with the same methodological difficulties surrounding causal inferences that have been covered in the preceding sections. Despite this, the importance of the sibling relationship between the TD sibling and the child with autism is a subsystem with a direct and pertinent role in the TD sibling's development and subsequent adjustment.

In siblings of TD children, a positive sibling relationship is related to a positive concept of self (Dunn and Plomin, 1990). In addition siblings who reported less warmth, intimacy, and lacking friendly behaviour in their sibling relationships, showed increased internalizing and externalizing behaviour problems (Dunn et al., 1994).

Historically the research investigating relationships between brothers and sisters where there is a child with a disability has developed from the perspective of pathology (Abrams & Kaslow, 1976; Adams, 1969; O'Hara & Levy, 1984). A number of the studies have found evidence for negative relationship reports and outcomes such as: role asymmetries in the domestic or care responsibilities (Bägenholm & Gillberg, 1991; Gold, 1993; Miller, 2001), impoverished interactions, aggression and conflict (Bägenholm & Gillberg, 1991; Kaminsky & Dewey, 2001; Knott et al., 1995, Mascha & Boucher, 2006, Ross & Cuskelly, 2006), as well as reduced warmth and positivity (Gold, 1993; Kaminsky & Dewey, 2001; McHale et al., 1986). Kaminsky and Dewey (2001) for example, investigated sibling relationships between three groups of 30 siblings with a brother or sister with autism, Down syndrome, and TD

children. The researchers used the Sibling Relationship Questionnaire (SRQ; brief version, Buhrmester & Furman, 1990), a self-report questionnaire to examine aspects of the siblings' relationships across the three groups. They found that siblings of children with autism experienced reduced intimacy, nurturance, and prosocial behavior in their relationships compared to the other two groups. In the majority of studies however, where siblings report on their brother or sister with autism, they provide positive descriptions of their siblings (Bägenholm & Gillberg, 1991; McHale et al., 1986; Miller, 2001) and sometimes describe warm relationships with less conflict compared to siblings of TD children (Fisman et al., 1996, 2000; Kaminsky & Dewey, 2001; Roeyers & Mycke, 1995).

The role of static factors such as age, gender and family size on the sibling relationship has also been explored (McHale et al., 1986; Miller, 2001; Roeyers & Mycke, 1995). McHale, Sloan and Simeonsson (1986), for example, found that siblings younger than the child with autism reported increased feelings of rejection toward their brother/sister with autism, and siblings with a brother with autism were less positive about their brother's role within the family. In this study, mothers' rated same gender sibling dyads as less supportive. In addition, both McHale et al. (1986) and Miller (2001) reported that greater family size was associated with fewer feelings of embarrassment and burden in the TD siblings. Roeyers and Mycke on the other hand found that siblings that were over three years older than the child with autism had more negative relationships and a higher amount of stressors had a more negative sibling relationship.

Studies investigating factors that influence the sibling relationship have also included such processes as siblings' coping styles and child temperament. Roeyers and Mycke (1995), found that a higher affective reaction to stressors, and increased

copied efforts to deal with a brother or sister with autism, were both associated with a more negative sibling relationship. Ross and Cuskelly (2006) identified emotional regulation and wishful thinking as the most common coping mechanisms employed by siblings of children with autism, evidencing increased introspection and a desire for change of circumstances. Recently, Rivers and Stoneman (in press) found increased levels of persistence, in the TD sibling and the child with autism, to be associated with a more positive sibling relationship and greater satisfaction in the sibling relationship. High persistence behaviour involved persisting to work on tasks even when these are difficult or frustrating, returning on task after being interrupted, and becoming engrossed in tasks ignoring distractions. The authors additionally report that high persistence may protect against the impact of a temperamentally difficult child, and particularly in the TD sibling, may act as a buffer against parental differential treatment.

Siblings' knowledge of their brothers'/sister's condition has been linked to sibling relationship outcomes (Dellve et al., 2000; McHale et al., 1986; Roeyers & Mycke, 1995). Roeyers and Mycke, for example, found that TD siblings' knowledge that autism was an organic disorder and not a psychogenic disorder was associated with a more positive sibling relationship. Research has also shown increased marital stress, and parental differential treatment, to be associated to less satisfaction in the sibling relationship as well as decreased levels of positive sibling interactions (Rivers & Stoneman, 2003; Rivers & Stoneman, in press). In this study, parents who sought formal and informal social support saw a positive impact on the sibling relationship. This protective effect of social support however, was not present in circumstances of high marital stress.

At present, studies of siblings and their brother or sister with autism are few and overly reliant on interviews or rating scales (See Knott et al., 1995; 2007 for exceptions). Future research should employ direct observations in conjunction with the use of other methods of collecting data. Observational studies may provide a more comprehensive panorama of the family dynamics and offer a relatively independent picture of the relationship between siblings, free of any social desirability or other biases that might operate in parental or sibling reports. Future research also needs to address the question of whether there is a direct relationship between sibling relationship outcomes and sibling adjustment outcomes in siblings of children with ASD.

We have described a number of findings, many times contradictory, using different methodologies and measurement constructs, with varying sampling populations and methods of control. Although some of the inconsistency in research findings may arguably be a product of over four decades of research employing differing methodologies, these findings may well document a very real story; having a brother or sister with autism can mean having to face a variety of difficulties that can be exaggerated under certain circumstances and conditions. Having a sibling with autism however is not in itself necessarily a predictor of increased stress being placed on the TD sibling, or a precursor of negative impact on the sibling relationship.

The concept of stress

The conceptualization of stress itself has been surrounded by controversy, it is generally agreed however that one or more identifiable antecedents (stressor) precede the resulting constellation of behavioural consequences that we could term as "stress".

The distinction is made depending on whether the stressor is perceived as an external stimulus, an internal biological/psychological response, or a transactional interaction between the person's internal response and their environment (Lazarus and Folkman, 1984). Gamble & Woulbroun (1993) discuss each of these perspectives in relation to siblings of children with disabilities. The implications of this triadic model for siblings of children with autism are especially interesting in the context of how we conduct research with this population. For example, researchers employing a stimulus-oriented perspective of stress for siblings of children with autism can focus directly on the child with autism, or the affected parent(s) (who might be impacted by raising a child with autism or who might themselves exhibit traits of the broader autism phenotype). Research adopting a response-oriented view could focus on specific coping strategies used by siblings, and other internal psychological states or traits that might be the result of environmental or genetic influences. The transactional approach is more inclusive and encompasses both of the approaches described above and how they might interact.

The research that will be described in the present thesis draws on a number of theoretical models and frameworks. In line with the transactional model (Lazarus and Folkman, 1984), we will draw attention to the relationship between the person and the environment, and the interaction between living in a family environment with a child with ASD and a sibling's appraisal of the situation, which implies that different individuals may have different experiences and outcomes of adjustment, including positive outcomes. This thesis furthermore incorporates family systems principles (Minuchin, 1985) such as circularity, and the notion of distinct yet interdependent subsystems, with a specific focus on the sibling and parent-child subsystems. Models of stress and adjustment that operate beyond the level of the individual therefore

implicitly underlie our research. The double ABCX model (McCubbin & Patterson, 1983) describes coping at a family system level. In the ABCX model, family resources (B) and the family's appraisal of the situation (C) determine the family response (X) to a stressful situation (A). In the double ABCX model, the stressful situation (A) reflects an accumulation of experiences over time, forming a cumulative effect of the stressor (A), to which the family repeatedly adapts (Cherry, 1989). Our research also highlights the need for longitudinal and developmental perspectives. Finally, we also take a diathesis-stress viewpoint on sibling adjustment, highlighting the contribution of ecological and genetic factors in sibling adjustment. One of the benefits of elucidating the stress-buffering role of various factors and mechanisms lies in their potential as evidence that might inform the design of future supports or interventions for siblings with unmet needs.

Intervention or support for siblings

Regrettably only a small pool of published research currently reports on support or intervention outcomes for siblings of children with ASD. We provide a brief overview of support evaluation research for siblings of children with ASD that has focused on improving sibling adjustment and the future implications that can be derived from the current status of this evidence-base.

Early research used behavioural training techniques with siblings to improve interactions between children with autism and their TD brothers or sisters (Celiberti and Harris, 1993; Clark, Cunningham & Cunningham, 1989; Colletti & Harris, 1977; Schreibman, et al., 1983; Strain & Danko, 1995). For example, Schreibman, et al. (1983) investigated the effectiveness of a behavioural training programme using a multiple baseline design with three TD siblings of children with autism. Their

intervention was aimed at teaching behaviour modification procedures (e.g. reinforcement, shaping, chaining, and discrete trial techniques) to siblings and evaluating their effectiveness and generalization. Results showed improved behavioural teaching skills in the siblings of children with autism and that the siblings were able to apply these skills beyond the structured training sessions to various environments. Parental reports of comments made by the siblings toward their brother or sister with autism showed that post training, siblings made more positive comments. It is vital to note that interventions in the above studies were not designed specifically to have an impact on the TD siblings.

Despite the evidence-based efficacy of such procedures described in the studies above, the support and benefit for the TD siblings is indirect and, at best modest. All studies had small sample sizes and none of these studies used a validated measure of adjustment for the TD siblings. Furthermore, Celiberti and Harris (1993), in their discussion, mention that a possible drawback of such behavioural interventions is the possibility of parents raising their expectations and inadvertently placing increased demands on the TD siblings, who might already be experiencing the difficulties of growing up with a brother or sister with autism. To professionals working with families where there is a child with a disability, it very quickly becomes apparent that siblings of children with autism experience difficulties of their own, and that their needs call for support with a specific focus on the sibling rather than their interactions with their brother/sister with autism.

In an attempt to directly support siblings, Lobato and Kao (2002) developed an integrated parent and sibling group intervention for 54 TD siblings (ages 8 to 13 years) of children with chronic illness and disability, a proportion (23%) of whom were diagnosed with ASD. The intervention aimed to improve sibling knowledge and

adjustment to the disability of their affected brother or sister, through six 90-minute group sessions that took place over a 6 to 8 week period. Sessions involved improving sibling knowledge, identifying and managing sibling emotions and balancing individual needs of siblings. Results showed improvements in siblings' knowledge of the disorder and increased relatedness amongst participating siblings. Furthermore, there was a decrease in negative reports by the TD siblings as well as parental reports of sibling behavioural problems as measured by the Child Behaviour Checklist (CBCL; Achenbach, 1991). In this study, while improvements in externalizing problems were maintained at three-month follow-up, internalizing difficulties regressed to pre-intervention scores. Interestingly, at baseline siblings of children with physical disabilities or medical disorders expressed increased knowledge of these conditions compared to siblings of children with ASD, intellectual disabilities or psychiatric disorder.

In a subsequent investigation the same researchers employed a family based group intervention using a similar parent-sibling model as previously, with 43 siblings of children with a disability, the majority of whom had a diagnosis of ASD (Lobato & Kao, 2005). This time the sample of sibling participants was younger (ages 4 to 7 years) than the sample in the previous study by Lobato and Kao (2002). Furthermore, as well as measuring sibling adjustment at pre and post intervention, a measure of perceived competence the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1983), was also used. This measures children's perceptions of their cognitive and physical competence as well as peer and maternal acceptance. Increases were observed in sibling knowledge of the disorder and sense of relatedness to other siblings facing similar circumstances as well as their self-perceptions of cognitive and physical competence. These findings, although

encouraging for future intervention research utilizing a parent-sibling integrated support group intervention, should be considered in the context of the narrow demographic profile to which the samples were skewed, that is, white middle class families, and the lack of a control or comparison group. Furthermore, where integrative parent-sibling groups have been used, it is worth asking who is driving the agenda in such groups and whether these groups offer the best possible environment for siblings to openly express thoughts and feelings and have maximum input.

Smith and Perry (2005) examined the effectiveness of a support group for 26 siblings of children with autism that targeted sibling self-concept, knowledge of autism, and sibling adjustment. The support group met on a weekly basis over a period of eight weeks. Siblings engaged in group exercises, games, and activities that aimed: to address siblings' knowledge of autism, providing a discussion forum for siblings to share feelings and coping strategies, and to enhance siblings' self-concept. Coping/adjustment, self-concept and knowledge of autism were examined at pre and post intervention time. At post-intervention phase, siblings demonstrated improved self-concept and knowledge of autism. There was no change however, in the siblings' reports on anger/resentment with their family circumstances. The authors point out the limitations to the internal validity of the data due to the absence of a control group. Nevertheless these findings have several important implications for future research that relate to methodological aspects, such as the future employment of measures that are reliable, valid, and sensitive to changes over short temporal intervals and that measure not only sibling outcomes but capture the wider picture of the effect of such support groups within the familial context.

Every sibling relationship is unique and there is evidence to suggest that in siblings of children with autism, as a group, their experiences and relationships differ

from siblings of children with another disability (Wolf et al., 1998). Even within a given group however members differ at the level of the individual. It therefore makes sense to select and evaluate interventions that can be applied to groups with shared characteristics and to provide support that is tailored to the individual needs of siblings. Nevertheless, the literature on intervention for siblings of children with a disability not specific to autism, comprise an additional useful resource that we can draw upon for the design of effective support interventions. Evans, Jones and Mansell (2001) report on findings following a sibling support group for brothers and sisters of children with a learning disability and challenging behaviour. An initial pilot group comprised ten children between the ages of 6 and 12 years, and two subsequent groups of 9 children between the ages of 7 and 12 years. Each child received individual assessment at pre-intervention level and again at post-intervention that measured involvement between siblings and self-esteem of the TD siblings. The support group met initially at a pre-group meeting and then ran for three consecutive days during half-term and on a weekly basis for six weeks during school time. The final day entailed a visit at a theme park. The support-group addressed knowledge of their disabled brother's or sister's disability and behaviour, coping with as well as communicating these to others, relaxation techniques and ways of interacting with their brother/sister. Results showed increased understanding of their siblings' disability, and enhanced ability to play and relax with their siblings. The parents further supported these findings.

Burke and Montgomery (2000) reported on initial results from the pilot stage of research investigating the needs of siblings of children with autism. The study included initial comments by siblings for the provision of a support group. Findings are derived from eight questionnaires from families of children between the ages of

1.6 to 13 years where there were one or more children with a disability and four interviews with the TD siblings. Despite the obvious sample size limitations the results present interesting findings. Parents reported on their TD children relative to aspects of having a sibling with a disability. These included being more caring and tolerant than other children but also receiving less attention because of increased demands placed by the child with a disability. Both parents and siblings viewed the sibling support group positively. Siblings identified positive aspects of the support group they attended and these included engaging in fun and recreational activities.

In a more recent evaluation study, D'arcy and others (2005) ran a sibling group based on the Sibshops model (Meyer and Vadasy, 1994); a support group for siblings aged between 8 and 13 years, that brings siblings of children with a disability together to exchange information and engage in fun activities. In accord with the Sibshops model the support group aimed for the children to interact, relate and share information with other siblings who faced similar life situations with their brother/sister with a disability and also to increase their knowledge about the nature and implications of their siblings' disability. Sixteen siblings aged between 8 and 10 years were initially individually assessed at home using psychometric testing and the Piers-Harris Children's Self Concept Scale (Piers and Harris, 1984), six weeks at most prior to the first Sibshop. Siblings also received a pre-Sibshop interview that evaluated children's knowledge, attitude and feelings toward their disabled sibling. The Sibshops took place on a monthly basis, on a Saturday from 10:00am until 1:00pm and ran for four consecutive months. Results showed that the majority (81%) of children expressed a wish to continue meeting up with the group, and reported finding the activities enjoyable. A large number of children (75%) were able to talk much more about and better explain their circumstances. There was an increase in

negative comments from the siblings, which the authors saw as a positive aspect of being able to vent thoughts and feelings of frustration in a safe environment.

In general sibling support groups have tried to support children by providing social support through group meetings and an environment to meet and interact with other siblings with similar needs. Sibs, a UK based charity for siblings who grow up with a brother or sister with a disability, have developed a group work model (F.R.A.M.E.) aimed at alleviating emotional and behavioural problems in siblings (Sibs, 2008). The model operates by providing a sense of enjoyment; increasing social networks; offering an open channel for communicating negative thoughts and emotions; enhancing coping mechanisms; and offering and increased understanding of disability to siblings.

The literature has also documented putative negative outcomes that may be associated with attendance at a sibling support group compared to siblings that had not previously attended a support group (Giallo & Gavidia-Payne, 2006). In this study sibling group attendance strongly predicted adjustment difficulties. The researchers offer two possible explanations: 1) It might be that siblings with increased difficulties are being referred to access such support groups. 2) Alternatively, the benefit of support groups for siblings should be questioned. Regrettably, there are only a small number of published studies evaluating interventions specifically for siblings of children with autism. The existing studies go some way toward providing evidence for improving siblings' self-concept and knowledge of autism. Siblings' behavioural adjustment, however, has not been directly targeted to date, and needs to be a priority for future intervention research. There is also a need for future interventions that are more closely linked to the current research findings pertaining to sibling adjustment and that consider a broader range of outcome measures.

Methodological issues and future research

In the section that follows we focus on methodological issues and themes that necessitate greater awareness for future exploration in this area. The issues we discuss are: 1) The broader autism phenotype as an additional contributor to sibling adjustment beyond the familial environment of the TD sibling; 2) constellation variables related to outcomes of adjustment for siblings; 3) the use of control groups in sibling adjustment research where there is a child with autism; 4) defining the target sample, as well as; 5) measurement issues; 6) and areas where research is at present lacking.

The contribution of the broader autism phenotype

Siblings of autistic children with no diagnosis may fall short of meeting the full diagnostic criteria for ASDs but nevertheless may exhibit developmental abnormalities closely resembling autistic characteristics and these children may be different to TD children. Loosely defined as a combination of impairments in language, communication, social interaction and stereotyped behaviours, clinicians and researchers have defined the presence of such abnormalities in the relatives of persons with autism as the broader autism phenotype. Such traits have been shown to include: difficulties in language abilities (Hughes et al., 1999; Plumet et al., 1995; Tomblin et al., 2003) communication (Bishop et al., 2006) and socialization difficulties (Piven et al., 1997), impairments in cognition (August, Stewart, & Tsai, 1981; Baird & August, 1985; Fombone et al., 1997; Minton et al., 1982) such as planning (Ozonoff, Rogers, Farnham, & Pennington, 1993) and executive functions (Hughes et al., 1999) as well as other autistic traits including theory of mind abilities (Dorris et al., 2004). For the siblings, this might mean being genetically predisposed

to a number of psychosocial difficulties, as well as growing up in a family environment that possibly includes other members with the same genetically imposed handicaps and syndrome specific characteristics. At present, there are no formal statistics on the prevalence or incidence of the BAP in the TD siblings of children with ASD. This is because the BAP does not constitute a diagnosis, and is therefore difficult to quantify. It is furthermore difficult to ascertain whether autistics characteristics in infant siblings of children with ASD are indicators of the BAP or a future ASD diagnosis; it is equally difficult to establish if BAP characteristics in TD child siblings of children with ASD represent genetic liability or learned behaviour.

Future research needs to see the merge of genetic research and studies on psychosocial adjustment of siblings of children with autism; two schools of thought that have proceeded in parallel directions up until this point. No study to date that looks at the adjustment of TD siblings of children with autism has tried to measure and include the level of autism variant as a contributing factor in the outcomes of adjustment, this, despite the overwhelming evidence that points to a disorder with perhaps the strongest genetic basis of all other multifactorial psychiatric disorders (Bailey et al., 1996). Group comparison designs that are not controlling for the effects of the broader autism phenotype may be allowing this invisible confound to compromise the internal validity of their research designs.

Constellation variables: A paradigm shift

Researchers have been increasingly advocating a general ideological shift in the focus of research addressing predictors of sibling adjustment away from status variables towards more social, dynamic and transactional variables (McHale et al., 1986; Miller, 2001; Ross & Cuskelly, 2006; Verte et al., 2003). The arguments supporting

this change in direction are routed in conflicting findings of the research, the fact that static variables like age and sex cannot be targeted for change or intervention (Cuskelly, 1999), and the understanding that sibling adjustment as well as maladjustment is not the result of a simplistic linear relationship between two variables but rather a more complicated interplay of demographic, environmental, personality and relationship variables. Though not an argument without basis, future investigations on this trail of logic, risk the inherent danger of neglecting the possibly significant effects of variables such as gender and relative age on sibling adjustment (Hastings 2003a). Static factors may identify characteristics in siblings of children with autism that act as risk or protective factors. Moreover, while status variables might not be alterable, these factors should always be included in the research with siblings of children with autism because of their possible moderator effects on relationships between more dynamic variables that can be the focus of intervention.

Use of control groups

Research investigating sibling adjustment where there is a child with autism has traditionally, and in majority, used siblings of children with Down syndrome followed by siblings of children with mental retardation of unknown aetiology, with the exception of Ferrari (1984) who employed siblings of children with diabetes as a comparison group. Only two studies to date have employed multiple comparison groups of siblings of children with disabilities; Hastings (in press), included siblings of children with Down syndrome and developmental disabilities, and Pilowsky et al., (2004) included siblings of children with mental retardation and developmental language delay in their research. Siblings of children with Down syndrome provide a useful control/comparison group in as much as such designs allow for the control of

some of the environmental effects of siblinghood where there is a child with a disability, however, they do not control for the genetic element that is strongly associated with autism and neither do control groups of siblings of children with mental retardation of unknown aetiology.

Seltzer et al., (2004) suggest the inclusion of two additional disorders from which control groups can be derived for comparative research with families of children with autism, namely, fragile x syndrome and schizophrenia. Such samples may provide adequate control for the genetic vulnerabilities that may lead to behavioural, cognitive or psychiatric problems that are shared by some biological relatives of individuals with autism as well as some of the contextual circumstances that may operate in families of children with autism, such as time and ambiguity of diagnosis. Bauminger & Yirmiya (2001) propose the use of adoptive populations of siblings of children with autism as a prime candidate for a control/comparison group in genetic studies of siblings of children with autism to effectively identify the presence of a genetic component in the unaffected siblings. The advantage of using such a comparison group is that essentially, after careful matching, one has a group that is stripped of the environmental component of growing up with a brother or sister with autism and other members with possible variant expressions of the disorder, and left with the pure genetic influence. An additional control group that has, to date, not been used in research with siblings of children with an autism diagnosis, concerns siblings of children with conduct disorders or severe behavioural problems such as attention deficit hyperactivity disorder (ADHD). This is surprising considering the pronounced behavioural expression of externalizing problems in children with ASDs and the literature linking stress outcomes to child behavioural problems.

Defining the target population

Focusing on a single diagnostic category has been recognized as good practice in psychological research in that this method acknowledges the unique impact of a specific disability (Cuskelly 1999). Autism in itself, however, is a spectrum disorder with a chronic prognosis. Diagnosis can be delayed and surrounded by ambiguity. Onset can be immediate or delayed and the course of the disorder in an individual's lifetime fluctuates, as does the degree of impact. It has a strong genetic basis but no aetiology identified as yet, moreover, the often physically invisible nature of this disorder that is frequently contrasted by its accompanying severe behavioural manifestations, set ASDs apart from other developmental disabilities. The manifestation of autism symptomology depends in part on the functioning level of the individual; future studies should always include critical information on the child with autism such as cognitive and adaptive skill levels, and any co-morbid developmental, neurological, or psychiatric conditions. Therefore, restricting research to a diagnostic category as broad as autism may be problematic by way of sample heterogeneity. Researchers need to consider sectioning their target samples in homogenous groups according to the level and form of the autism phenotype in the affected child. To date, very few studies have selected their sample of children with autism using a firmly defined category of autistic characteristics (e.g. Brady et al., 2005; Verte et al., 2003). Clearly defined samples of children with autism matched across multiple domains such as behavioural problems, cognitive level and social interaction deficits should be used in future research investigating the impact of a child with autism on the adjustment of TD sibling.

Issues of measurement

One may argue that the multifaceted construct of adjustment is best captured from a number of different angles and this is best served through the use of multiple measures for adjustment. The different findings produced from studies measuring adjustment however call for a rethink in the varying methodologies used to address this matter. Replication using narrowly defined, matched samples and established instruments to measure adjustment may provide the consistency that is lacking within this body of literature. This underlines the importance of using standardized measures of adjustment, with good psychometric properties, that also include clinical cut-off scores. Measures of adjustment such as the SDQ (Goodman, 1997) and CBC (Achenbach & Edelbrock, 1979) or CBCL (Achenbach & Edelbrock, 1983; Achenbach & Rescorla, 2001), that look at behavioural and emotional adjustment, possess good validity and reliability and have been standardized allowing the use of clinical cutoff scores to be used for the identification of clinical levels of difficulties. Furthermore, even when cut-off scores are available on different measures, often these do not reflect true levels of diagnostic conditions. These points raise questions as to the alleged risk that is being detected in some siblings of children with ASD.

In studies investigating various domains of sibling adjustment, the source of information should be considered carefully. The majority of studies reporting on adjustment outcomes for siblings of children with ASD derive their information from three sources, the parents, the teachers, and the siblings themselves. Inconsistencies between parent and sibling reports of adjustment have been previously reported in the family and child disability research literature (Cuskelly & Gunn, 2003; Mandleco et al., 2003). Brady et al. (2005) emphasizes the importance of seeking more than one source of information after failing to identify a relationship between parent reports

and sibling self-reports on adjustment. Bågenholm and Gillberg (1991) found that parents of children with a disability complained more about the behaviour problems of their TD children than parents of siblings where none of the children had a disability, despite the same parents reporting no differences in the ways the TD siblings treated the disabled children compared to sibling dyads where there was not a child with a disability. Although many studies include sibling self-reports on measures of sibling relationship and self-concept, only one study includes a self-report measure of children's perceived adjustment to the disability of their sibling (Lobato et al., 2005). This is despite the fact that most studies include participants whose age-span extends into the mid or late teenage years and who could ably provide information on such more direct measures of their adjustment.

Research areas for future development

When siblings report on their relationships with their brother or sister with ASD, more often than not they are positive (Bågenholm & Gillberg, 1991; Fisman et al., 1996; Kaminsky & Dewey, 2001; Mascha & Boucher, 2006; McHale et al., 1986; Miller, 2001; Royers & Mycke, 1995). However we still know that in many sibling relationships where there is a child with autism, often the TD sibling will face challenges that are not characteristic of typical sibling interactions. Fortunately, although sibling relationships where there is a child with autism can be demanding, given the appropriate and adequate support there is also the potential that they can be profoundly rewarding and provide the context for the TD siblings to emerge as more understanding, empathic, and caring adults. Hastings (2003b) in his discussion comments on the importance of self-reports coming from the sibling participants themselves as well as focusing more broadly on the experiences of siblings of

children with autism. McHale et al., (1986) furthermore noticed that while group mean scores did not reveal a great number of statistically significant differences, closer inspection of within groups data of children with a disabled sibling contained highly variable accounts of their sibling relationship, ranging from fairly negative to very positive reports, that were being masked by the overall averaged score. At present there is a reasonably sized published literature base that lacks the most rudimentary of all informative displays, that is, exploratory and descriptive research with siblings of children with autism. If research into the effects of having a brother/sister with autism on the TD sibling will successfully identify the underlying factors and variables that shape the different relationship and adjustment outcomes, there is a need to start from the micro level, by observing or interviewing siblings to get an idea of the varied accounts that a sibling has to share from his/her individual experiences. Mascha & Boucher (2005) recently conducted a preliminary qualitative investigation of examining subjective experiences and feelings of typically developing siblings with a brother/sister with autism. There is a need for future research to acknowledge and carefully examine the value that can be found within subjective and qualitatively different accounts obtained from the individual.

Finally, from the individual to the broader cultural context the prevalence of autistic symptomatology and the subsequent adjustment of families where there is a member with autism across different cultures, races and ethnicities is an area of research that has received little attention in the literature. Just as one family unit may differ from another on home values and family traditions, cultures are distinct in several different ways and this may in turn influence how individuals appraise and adjust to having a brother or sister in the family. The role of social support for example has been examined extensively within Anglo families in the research

literature. Levels of community supports and organizational resources will vary in nature and availability across different cultural groups. The Lobato and Kao study in 2005, comparing Latino siblings to non-Latino siblings of children with disabilities that included autism, provides evidence in support of broadening the scope of sibling investigation to include familial and cultural variables, where the current research ground with siblings of children with autism is thin.

Sibling research where there is a child with autism can potentially highlight positive aspects, advantages, and competencies that might be present in this group. At present researchers are still striving to delineate psychological, biological and social factors that play a role in siblings' adjustment and adaptation. The accurate dissemination of research findings to a wider audience is crucial to avoid elevating, "having a brother/sister with autism", to the status of explanation for various adjustment difficulties. Characteristics that are sometimes observed in relatives of individuals with ASD such as preference for routine, reduced interest in non-purposeful social interaction, and fewer friendships might be useful in the identification of underlying neuropsychological processes, however, such findings in no way constitute clinical outcomes of maladjustment. While research findings might raise cautions about populations that might be at risk for a number of psychological difficulties, we can never really capture the abounding complexity of individuals, their strengths, weaknesses, and life circumstances. These considerations are also important in thinking about how to best support those siblings that are at risk. Setting up a support group, for example, broadly intended for siblings of children with autism may dilute its effectiveness and those siblings most in need may be deprived the benefits. Service providers have a duty to recognise that where adjustment difficulties

exist in siblings these are likely to be multidimensional and multifunctional; supports aimed at group level might therefore not be relevant for some siblings. Services and supports need to be designed around individuals themselves rather than categories.

Structure of thesis

The four empirical investigations reported in this thesis aim to address some of the methodological issues discussed thus far. By employing a mixed methods design, this research takes two distinct methodological routes, one is a quantitative research approach in Chapters 2 and 5, aiming to address issues such as potentially confounding and previously uncontrolled variables including the comorbid ID in the child with autism, and the BAP in the sibling; static as well as process variables affecting sibling adjustment and relationships; and longitudinal outcome-data on sibling adjustment. The second route, taken in Chapters 3 and 4, deals with the lack of sibling-self reports, which characterizes the literature on sibling adjustment, by employing qualitative phenomenological methodologies to explore sibling's subjective accounts of their experiences. Below we introduce each empirical study in more detail.

The first study is a secondary analysis of a pre-existing data-set used in previous research investigating parental adjustment to child disability, which also included data on siblings of children with a disability. The author of this thesis extracted the sibling data and conducted the analysis by employing a group comparison design comparing the siblings of children with intellectual disability (ID) with or without an additional diagnosis of autism. The current *DSM-IV-TR* manual states: "in most cases, there is an associated diagnosis of mental retardation, which can range from mild to profound" (APA, 2000, p. 71). In fact some versions of the

manual, note that 70% to 75% of children with autism, also present with comorbid ID (APA, 1980, 1994). The first study therefore addresses the question of whether autism per se, or the comorbid ID of the child with autism, is associated with increased emotional and behavioural difficulties in the TD sibling?

The second and third studies are exploratory in nature and aim to examine the perceptions and experiences of children and adolescents growing up with a brother with ASD using qualitative methods. Three theoretical perspectives inform the context of these studies: 1) TD sibling relations from childhood to adolescence, 2) the stress and coping literature, and 3) the adjustment of siblings of children with autism. We know that middle childhood and adolescence are associated with different sibling relationship dynamics in TD children (Buhrmester, 1992). There is a greater need to understand how individuals assign meaning to stressful events, enabling them to reframe their experiences in more adaptive ways (Rutter, 1993). This is particularly important in the context of the adjustment of siblings of children with ASD, where findings are mixed. At present, there is limited empirical research reporting on the experiences of siblings of children with ASD. Our exploratory studies also allow the participants to offer their personal accounts, where previously research has used other sources of information.

The final empirical study forms part of a larger collaborative research project led by the author of this thesis and facilitated by two clinical psychologists in training, in which data were collected on siblings and parents of children with an ASD. For the purpose of this paper, the author of the thesis focuses on data collected on siblings of children with ASD in an attempt to investigate what factors contribute to emotional and behavioural adjustment in the TD siblings of children with autism, by applying a diathesis-stress model (Burke & Elliott, 1999; Orsmond & Selzer, 2006). In addition

to stresses that may be exerted from the presence of a child with ASD in the family, the well being of some TD siblings of children with ASD may also be compromised by a genetic liability, due to the BAP. Difficulties have been shown to include social and language impairments as well as emotional and behavioural difficulties (Bolton, Pickles, Murphy, & Rutter, 1998; Smaley, McCracken & Tanguay, 1995). It is therefore important that research into the adjustment and well-being of TD siblings of children with ASD takes into account as much the environmental as the biological and genetic factors. We use a well-established measure of the BAP (Baron-Cohen et al., 2001), along with a number of other environmental factors, previously indicated to play a role in sibling well-being, to explore their contribution on siblings' emotional and behavioural adjustment.

Chapter 2. Emotional and Behavioural Adjustment in Siblings of Children With Intellectual Disability With and Without Autism*

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Abstract

Siblings of children with autism may be at greater risk for psychological problems when compared with siblings of children with another disability or with typically developing (TD) children. However, it is difficult to establish whether autism or the presence of intellectual disability (ID) explains the findings in previous research.

Mothers rated the emotional and behavioral adjustment of siblings of children with ID with (N = 25) or without (N = 24) autism. Data were also available 18 months later for siblings of children with autism and ID (N = 15). Siblings of children with autism and ID had more emotional problems when compared with siblings of children with ID only and also with normative data. Three variables had independent relationships with emotional problems in siblings of children with autism and ID, namely: The increasing age of the child with autism, having a brother with autism, and being younger than the child with autism. Behavioural and emotional difficulties of siblings of children with autism and ID were relatively stable over 18 months.

Parenting a child with autism can be an emotionally burdening experience, more so than parenting a child who is typically developing (TD) or with another disability (Hastings, 2007). For example, in a recent meta-analytic review of research on maternal depression in families of children with or without developmental disabilities, Singer (2006) found elevated levels of depression as indicated by higher effect sizes in studies of mothers of children with autism compared with studies of mothers of children with intellectual disability or spina bifida. From a family systems perspective (Minuchin, 1985) members of a family are interrelated, so what affects one family member will have affects across the whole system as well as the individual members of that system. Therefore, autism may also have an impact on other members of the family and researchers have also studied sibling emotional and behavioral adjustment to having a brother or sister with autism (e.g. Hastings 2003; 2007).

Although not a universal research finding, siblings of children with autism have often been found to present with more psychological problems in comparison to siblings of children with other disabilities or siblings of TD children. Siblings of children with autism have been shown to be at an increased risk for externalizing problems (Bagenholm & Gillberg, 1991; Fisman et al., 1996, 2000; Hastings, 2003; Rodrigue, Geffken, & Morgan, 1993; Verte et al., 2003; Wolf et al., 1998), and internalizing problems (Ferrari, 1984; Fisman et al., 1996; Gold, 1993). For example, Gold (1993) compared the levels of depression in siblings with a brother with autism to siblings with a brother without a disability. Siblings who had a brother with autism scored significantly higher on the Children's Depression Inventory (CDI; Kovacs & Beck, 1977), and their scores as a group reached clinical levels on two of the three recognized cutoff points explored.

Some researchers have found that siblings of children with autism may not be at increased risk for negative adjustment outcomes compared to siblings of children with another disability or TD children (Ferrari, 1984; Hastings, 2007a; Kaminsky & Dewey, 2002; Pilowski et al., 2004). Hastings (2007a) investigated the behavioural adjustment of siblings of children with autism, siblings of children with Down syndrome, and siblings of children with mixed aetiology intellectual disability (ID) over two years. Mothers completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) as a measure of the siblings' behavioural and emotional adjustment. There were no group differences on maternal reported behavioural and emotional adjustment between the siblings of children with autism, Down syndrome, and ID.

There are a number of methodological characteristics of previous research with siblings that make it difficult to draw strong conclusions. First, some studies make comparisons with comparison groups (Kaminsky & Dewey, 2001, 2002; Pilowsky et al., 2004; Wolf et al., 1998) and others with normative data (Hastings, 2003; Mates, 1990; Ross & Cuskelly, 2006). A number of studies include a comparison group of siblings of TD children (Bagenholm & Gillberg, 1991; Kaminsky & Dewey, 2002; Rodrigue et al., 1993;) although it is not always clear how representative these groups are and in most cases they are of small sample size ($N < 25$). Meta-analytic evidence relating to siblings of children with ID suggests that comparisons with normative samples estimate higher levels of psychological problems than comparisons with comparison groups (Rossiter & Sharpe, 2001). Therefore, to fully explore the emotional and behavioral adjustment of siblings of children with autism it is important to make comparisons both with a suitable

comparison group and a normative sample. We could find only one study of siblings of children with autism making both of these comparisons (Hastings, 2007a).

A second methodological dimension is the choice of comparison group in previous research. Siblings of children with autism have been compared with siblings of children with Down syndrome (Fisman et al., 1996, 2000; Kaminsky & Dewey, 2001, 2002; Rodrigue et al., 1993; Wolf et al., 1998), non-specific ID (Bagenholm & Gillberg, 1991;), diabetes (Ferrari, 1984), and Developmental Language Delay (Pilowsky et al., 2004). Given the overlap between autism and ID, it is not clear from previous research whether autism or associated intellectual disability might explain any observed sibling group differences in these studies. To address this problem, a design comparing the siblings of children with ID with or without an additional diagnosis of autism is needed. We found only one study using this design (Hastings, 2007a), so more are needed.

A third methodological characteristic of previous research is the lack of longitudinal data available on the psychological adjustment of siblings of children with autism. There are few longitudinal studies of the adjustment of siblings of children with intellectual disabilities generally (Hastings, 2007a) and we could find only two other longitudinal studies specifically of siblings of children with autism (Fisman et al., 2000; Wolf et al., 1998), both reporting on the same sample of siblings (although there are also longitudinal data on adult siblings of children with autism; Orsmond & Seltzer, 2007). Wolf and colleagues (1998) and Fisman et al., (2000), examined siblings of children with Pervasive Developmental Disorder (PDD), Down syndrome and a TD comparison group on measures of behavioural adjustment. Longitudinal data were collected three years later on siblings. Results revealed that

siblings of children with PDD had more internalizing and externalizing adjustment problems and these problems increased over three years.

In the present study, we compared siblings of children with ID with and without an additional diagnosis of autism on a standardized measure of behavioural and emotional adjustment. We also compared the siblings of children with autism to a nationally representative normative sample. Additionally, we gathered data on the stability of psychological problems in siblings of children with autism over an 18-month period. Finally, we explored a limited number of correlates of emotional and behavioral adjustment for the siblings of children with autism. In previous research, although findings are inconsistent, a number of potential correlates of adjustment in siblings of children with autism have been found including static and intra-familial variables, such as gender and age of the child with autism or the TD sibling (Gold, 1993; Hastings, 2003; Verte et al., 2003), and the nature and severity of impairment of the child with autism (Hastings, 2007a; Pilowsky et al., 2004; Rivers & Stoneman, 2003). Family and individual dynamic variables have also been found to be associated with sibling adjustment including: parental distress, marital satisfaction, self concept and social competence of the TD sibling, parental and sibling social support, and differential parental preference (Ferrari, 1984; Fisman, 1996, 2000; Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003; Rodrigue et al., 1993; Verte et al., 2003; Wolf et al., 1998).

Method

Participants

Forty-nine mothers who were the primary caregivers of their children with ID with or without autism rated the emotional and behavioral adjustment of the sibling

closest in age to the child with ID. The mothers were between 29 and 52 years of age, with a mean age of 40.75 years (SD = 5.05). Twenty-four (49%) of mothers had a college or university degree, 23 (46.9%) had high-school leaving qualifications, and two (4.1%) had no formal education qualifications. Thirty-eight (78%) of the mothers were married, eight (16%) were living with a partner, and three (6%) were divorced. All families resided in the South East of England and were recruited through special schools catering for children with intellectual disabilities. The number of children in the families ranged from two to six (mean[SD]= 2.62[0.90]). Median annual family income was approximately £30,000 (roughly equivalent to \$55,000 US dollars).

The children with ID were 35 boys and 14 girls. Their ages ranged between five and 19 years with a mean age of 10.75 years (SD = 3.66). Twenty-five children had a diagnosis of autism in addition to their ID, 10 children presented with ID alone, seven children had Down syndrome and ID, and seven children had Cerebral Palsy and ID. According to mothers' ratings of the child with a disability, as measured by the Vineland Adaptive Behaviour Scales (VABS, Sparrow et al., 1984), 31 children had profound to severe developmental delay, whilst 18 had moderate/mild developmental delay.

The research sample were 49 siblings of children with ID. These children and mothers were a subsample from a larger study, selected on the basis of there being a TD sibling in the family (see Procedure for details). According to the mothers' reports, these siblings did not have a disability or psychiatric diagnosis. At Time 1, data were available on 12 brothers and 13 sisters of siblings of children with autism. Their ages ranged from five to 17 years (mean age [SD] = 10.36 [3.38]). Six siblings were younger than the child with autism, 18 were older, and one was a twin. Thirteen siblings were the same gender as their sibling with autism and 12 were of different

gender. Data were available on 15 brothers and nine sisters of children with ID only, and their ages ranged from four to 17 years (mean age [SD]= 11.00 [3.63]). Fifteen siblings were younger than the child with ID, whilst nine were older; 12 siblings were same gender pairs, and 12 were different. At 18 month follow up, data were available for 15 siblings of children with autism, nine brothers and six sisters, whose ages ranged from seven to 19 years (mean age [SD] = 12.68 [4.62]). Eight of these siblings were the same gender as their sibling with autism, and seven were of different gender.

Measures

A demographic questionnaire was used to collect basic background information that has been described in the Participants section about the mothers, the child with ID, and the TD sibling closest in age to the child with ID. An overall measure of family deprivation circumstances was constructed because siblings from families with fewer resources may be exposed to increased stress in their home environment (Giallo & Gavidia-Payne, 2006; Williams et al., 2002). In previous research, Lloyd and Hastings (2008) used the Index of Multiple Deprivation (Noble *et al.*, 2004) to assess neighbourhood deprivation. The index combines national data on 37 separate indicators across seven domains: income; employment; health and disability; education, skills, and training; barriers to housing and services; living environment; and crime. National data are available for neighbourhood regions with an average population of 1,500 people, based on the 2001 national census. We used three variables: maternal education, annual family income, and a neighbourhood deprivation index score derived from the postal (zip) code. These three variables were converted to z scores and summed together to provide an overall index of family deprivation. A lower score on this family deprivation index indicates more severe deprivation.

Mothers completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) as a measure of siblings' behavioural and emotional adjustment. This questionnaire is a 25 item behavioural screening measure that takes about five minutes to complete. The SDQ measures four problem domains, assessing Emotional problems, Conduct problems, Hyperactivity, and Peer relationship problems. In addition, the SDQ measures Prosocial behaviour. Dimensional scores on each of the SDQ domains can be obtained by summing ratings on the constituent items. A total difficulties score can be derived by summing the scores of the four problem domains. Cut-off scores that suggest clinical levels of symptoms on the five sub-scales and the total problems scale are available. The SDQ is a well validated instrument and has been shown to be equally effective as both the Child Behavior Checklist (Achenbach, 1991) and the Rutter Scales (Elander & Rutter, 1996) in the identification of clinically meaningful levels of behavioural problems in children (Goodman, 1997). Use of the SDQ in previous research with siblings of children with developmental disabilities suggests that good levels of reliability are maintained (Hastings, 2003; Hastings, 2007a). Cronbach's alpha coefficients for the current total sample of siblings of children with ID with and without autism on the SDQ subscales were as follows: .78 for emotional symptoms, .83 for prosocial behaviour, .89 for hyperactivity, .67 for conduct problems, .62 for peer problems and .89 for total difficulties.

Procedure

Letters of invitation were sent to 17 special schools and nine chose to take part in the research. Of 130 mothers who responded initially to the advertisement, 91 (70% of those who expressed interest) returned a complete questionnaire pack and were subsequently interviewed over the telephone about their child with a disability using the VABS. If questionnaires were not returned within two weeks of being sent out, a

personally addressed reminder letter was mailed to the home. For the present study, data were analysed for a subsample that provided data on the TD sibling of their child with ID with or without autism. Mothers were asked to complete the SDQ for the child closest in age to the child with ID and who also met two initial inclusion criteria: 1. Between 4 and 17 years of age, and 2. With no known disabilities or diagnosed psychiatric disorder. Forty-nine mothers reported on siblings who met these criteria.

Results

To assess whether the siblings of children with or without autism differed on demographic variables, a series of t-tests and chi-square tests were performed. On average, children with autism and ID were younger ($M = 112.12$ months, $SD = 36.79$ months) than children with ID without autism ($M = 146.64$, $SD = 44.58$), ($t(47) = 2.96$, $p = .005$). In addition, siblings of children with autism and ID were more likely to be older than their brother or sister with ID, and more of the children with autism and ID were male. No other demographic differences were apparent between the two groups.

Four phases of statistical analysis were conducted. First, mean scores on all of the SDQ subscales including total difficulties were compared for the siblings of children with ID with and without autism using independent samples t-tests. We also used ANCOVA to control for the relative age of the TD siblings, and the age and gender of the child with ID as covariates, as these were shown to differ between the two groups. Mean SDQ scores of the siblings of children with autism and ID were also compared to normative data using one-sample t-tests. Second, group comparisons were conducted for the proportion of siblings reaching clinical cut-off scores on the

SDQ scales. The normative data were drawn from a nationally representative sample of 10,298 British school children aged 4 to 16 years (Meltzer et al., 2000). Third, associations between family and sibling demographic variables and sibling emotional and behavioral adjustment outcomes were explored within the sample of siblings of children with autism and ID. Finally, we examined the stability of emotional and behavioral adjustment for all of the SDQ domains over 18 months for the siblings of children with autism and ID.

The mean SDQ scores of the siblings of children with autism and ID, siblings of children with ID only, and the normative sample are summarized in Table 1. Siblings of children with autism and ID had higher scores on the emotional problems domain of the SDQ than siblings of children with ID and no diagnosis of autism, although this was only marginally statistically significant ($t(47) = 1.97, p = .054$). No other differences approached significance at $p < .05$. Siblings of children with autism and ID also had higher scores on the emotional problems domain of the SDQ when compared to the normative sample although this difference was also only marginally significant ($t(24) = 2.02, p = .054$). Again all other differences were non-significant and not approaching statistical significance. Effect sizes for the group comparisons are also displayed in Table 2.1. Effect sizes were calculated using the pooled standard deviation, and these reveal a moderate effect size (Cohen, 1988, 1992) for emotional problems but only small effect sizes for all other SDQ dimensions. When the relative ages of the siblings, and the age and gender of the child with ID were controlled using an ANCOVA design, the relationship between group membership and sibling's emotional problems was statistically significant, $F(1, 45) = 5.57, p = .023$.

Table 2.1 - SDQ Scores for Siblings of Children with Autism Compared to Siblings of Children with ID and Normative Data

SDQ Score	Autism & ID		ID only		Effect size	Normative Sample		Effect size
	Mean	SD	Mean	SD		Mean	SD	
Emotional Problems	2.88	2.42	1.58	2.17	.56	1.90	2.00	.49
Conduct Problems	1.20	1.38	1.39	1.76	.12	1.60	1.70	.24
Hyperactivity	2.68	2.85	2.83	3.42	.05	3.50	2.60	.32
Peer Problems	1.64	1.75	1.38	1.91	.10	1.50	1.70	.08
Prosocial Behavior	8.27	2.49	8.88	1.19	.31	8.60	1.60	.21
Total Problems	8.40	6.75	7.18	7.32	.17	8.40	5.80	.00

The proportion of siblings of children with autism and ID who scored within the "abnormal" range on each of the SDQ domains was compared using binomial tests to the proportion of siblings of children with ID only who scored within the abnormal range, and also to the proportion of children from the normative sample who scored within the abnormal range. These data are summarized in Table 2.2. The proportion of siblings of children with autism and ID scoring in the abnormal range was significantly higher than that of siblings of children with ID only on the emotional problems ($p < .001$) and prosocial behaviour domain ($p < .001$) of the SDQ. All other differences were non-significant. The proportion of siblings of children with autism and ID scoring in the abnormal range was also significantly higher than the proportion of children in the normative sample that scored within the abnormal range for the emotional problems ($p < .001$) and prosocial domain ($p = .019$) of the SDQ. Again, none of the other differences reached significance at $p < .05$.

Table 2.2. Percentages of Siblings Scoring Within the Abnormal Range on SDQ Scales.

SDQ Score	Autism & ID	ID only	Normative Sample
Emotional Problems	28.0%	12.5%	11.4%
Conduct Problems	12.0%	16.7%	12.7%
Hyperactivity	12.0%	16.7%	14.7%
Peer Problems	12.0%	12.5%	11.7%
Pro-social Behavior	12.0%	0.0%	2.3%
Total Problems	12.0%	12.5%	9.8%

We next addressed all of the demographic variables described in the participants section to test for associations with siblings' emotional and behavioral adjustment in the sub-sample of siblings with a brother or sister with autism and ID. Correlation analyses revealed a positive association between the age of the child with autism and ID and siblings' emotional problems ($r(25) = .47, p = .016$), and total difficulties ($r(25) = .43, p = .029$) on the SDQ. Using Mann-Whitney tests, it was found that siblings with a brother with autism and ID had higher emotional problem scores than those with a sister with autism and ID ($z = -2.20, p = .027$). Siblings younger than the child with autism and ID had higher emotional problem scores ($z = -2.60, p = .007$) than those who were older than the child with autism and ID. Lower scores on the family deprivation index, indicating more socio-economic deprivation, were associated with higher sibling SDQ scores on the hyperactivity scale ($r(23) = -.45, p = .027$) as well as total difficulties ($r(23) = -.50, p = .015$). There were no other significant associations between demographic variables and SDQ scores for the siblings of children with autism and ID.

Finally, bivariate correlations were performed to test for stability of the SDQ scores over 18 months for the siblings of children with autism and ID. Table 2.3 summarizes these data. With the exception of hyperactivity, all of the correlations indicated moderate to high stability over time.

Table 2.3. Stability of SDQ Scores over 18 months for Siblings of Children with ID and Autism.

SDQ Domain	<i>r</i>	<i>p</i>
Emotional Problems	.66	.004
Conduct Problems	.92	.000
Hyperactivity	.47	.056
Peer Problems	.76	.000
Pro-social Behavior	.73	.001
Total Problems	.73	.001

Table 2.4 presents means and standard deviations of SDQ subscales at Time 1 and 18 months later at Time 2 for siblings of children with autism and ID.

Table 2.4. Means of SDQ Scores at Time 1 and Time 2, for Siblings of Children with ID and Autism.

SDQ subscale Time 1	Mean Time1	SD Time1
Emotional Problems	2.88	2.42
Conduct Problems	1.20	1.39
Hyperactivity	2.68	2.86
Peer Problems	1.64	1.76
Prosocial Behavior	8.27	2.49
Total Problems	8.40	6.75
SDQ Subscale Time 2	Mean T2	SD T2
Emotional Problems	2.52	2.25
Conduct Problems	0.8	1.26
Hyperactivity	1.07	1.83
Peer Problems	0.9	1.58
Prosocial Behavior	8.18	2.40
Total Problems	5.32	5.98

Discussion

Siblings of children with autism and ID were reported by their mothers as having more emotional problems than siblings of children with ID only and when compared with a normative sample. This effect was statistically significant after demographic differences were controlled in ANCOVA. Siblings of children with autism and ID were also more likely to score within the abnormal range for emotional problems and prosocial behaviour problems when compared with siblings of children with ID only and with a normative sample. The variables that had independent relationships with increased emotional and/or behaviour problems in the siblings of children with autism and ID, included, the increasing age of the child with autism, having a brother rather than a sister with autism, being younger than the child with autism, and living in more social deprivation. Behaviour problems scores for the siblings of children with autism and ID were relatively stable over 18 months, with the exception of hyperactivity.

Thus, our central finding is that siblings of children with autism and ID may be at increased risk for emotional problems and these problems persist over time. This putative increased risk for siblings is not accounted for by the presence of ID in the child with the disability. Our results are consistent with previous findings indicating increased internalizing difficulties in siblings of children with autism (Bagenholm & Gillberg, 1991; Gold, 1993; Ross & Cuskelly, 2006; Smalley, McCracken, & Tanguay, 1995). More importantly, where effect sizes could be calculated by the present authors from other published data, the magnitude of the observed effect was similar to that found in the present study. For example, the group difference effect size was .60 in Gold's (1993) study for depression symptoms as measured by the CDI-Short form (Kovacs & Beck, 1977). We also explored effect sizes from two

previous studies where the adjustment of siblings of children with autism was compared to that of siblings of children with Down syndrome and where no statistically significant differences between groups were found. In these examples, the effect sizes for internalizing difficulties actually represented medium effects (ES = .42: Kaminsky & Dewey, 2002; ES = .56: Rodrigue et al., 1993).

A number of potential correlates of sibling emotional and behavioral adjustment were noted, reflecting the results of previous research where internalizing difficulties for female siblings with a brother with autism were found to be positively correlated with increased age of the child with autism and also being younger than the child with autism (Gold, 1993). Hastings (2003) also found that siblings who were younger than the child with autism had more total difficulties, as measured by the SDQ, compared to normative data. In addition, Giallo and Gavidia-Payne (2006) and Macks and Reeve (2007) have found lower socioeconomic status (SES) to be associated with increased emotional and behavioral adjustment problems in siblings of children with developmental disabilities.

These relationships between demographic factors and emotional and behavioral adjustment outcomes in the TD siblings render further investigation with respect to the underlying mechanisms. Siblings who were born before the child with autism have different experiences to those that were born after and this may in turn have a differential effect on their emotional and behavioral adjustment. Furthermore, it is possible that siblings whose emotional and behavioral adjustment is already being compromised by having to cope with a brother or sister with autism can be additionally affected where family financial resources are low. With respect to the gender of the child with autism, boys with autism might present with higher levels of challenging behaviour than female children. Previous research has shown that

challenging behaviours, especially attacking others, are more common amongst adolescent or young adult males (Emerson et al., 2001). It would be interesting to explore in further research whether child gender plays a moderator role in increased genetic loading of the autism phenotype in siblings of children with autism.

While the present design supports a conclusion that autism and not associated ID somehow places siblings at risk for emotional problems, it is still not clear what it is about autism that constitutes the risk. Research has shown that the incidence of autistic features is markedly increased among first-degree relatives (Piven et al., 1990). Therefore, a potential avenue for future research is extending the focus to the genetic liability for the broader autism phenotype in siblings (Bailey et al., 1995; Baily et al., 1998; Hughes, Plumet, & Leboyer, 1999). Parents of children with autism also appear to be at risk for emotional problems such as depression (Singer, 2006). It is possible that similar genetic mechanisms that may explain the risk for autism phenotype symptoms may also account to some extent for the emotional difficulties apparently experienced by parents and siblings of children with autism. Future research is needed to tease apart the potential contributions of the child with autism (and their behaviour or care needs/demands) and the broader autism phenotype to parent and sibling well-being.

The present study has a number of limitations that need to be considered when interpreting the results. First, the sample is small. However, presentation of effect size statistics clarifies the practical salience of the group analyses. Second, only siblings of children with ID were included in the study (by design) and so it is not clear whether other siblings of children with autism (e.g., siblings of children with Asperger syndrome) are at risk for emotional problems. Third, our data were based on maternal report and the sample was comprised of volunteers, which may be biased in several

ways (e.g., by their own current psychological health, disagreement with sibling self-reports, attracting participants who were already concerned about the TD child).

Multi-informant research is needed in future.

Chapter 3. “I like that he always shows who he is”: The Perceptions and Experiences of Siblings with a Brother with Autism Spectrum Disorder*.

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Abstract

Semi-structured interviews were used to explore the perceptions and experiences of eight typically developing siblings in middle-childhood who had a brother with ASD. The interviews were analysed using Interpretative Phenomenological Analysis (IPA). The analysis yielded five main themes: (i) siblings' perceptions of the impact of their brother's condition on their lives, (ii) siblings' perceptions of the attitudes of others, (iii) siblings' tolerance and acceptance towards their brothers (iv) positive attitudes and experiences, and (v) siblings' views on support for themselves and their brothers. These exploratory findings can be used to inform future larger scale and quantitative research. Initial implications for practice are focused on issues to consider in the development of support packages for siblings of children with ASD.

Parents of children with autism often report increased stress compared to parents of children with another disability or typically developing (TD) children (Abbeduto et al., 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Hastings, Daley, Burns, & Beck 2006; Herring et al., 2006; Koegel et al., 1992; Rodrigue, Morgan, & Geffken, 1990; Weiss, 2002). Hence, there has been interest in whether some siblings in a family environment that includes a child with autism, and possibly a parent under considerable stress, might also be at risk for adjustment difficulties.

In terms of how siblings adjust to living and growing up with a brother or sister with autism, there are mixed findings. Some researchers report that children with a brother or sister with autism are at a higher risk for internalizing and externalizing behavior problems (Fisman, 1996; 2000; Gold, 1993, Hastings, 2003a; Rodrigue, Geffken, & Morgan, 1993; Ross & Cuskelly, 2006; Verte, Royers, & Buysse, 2003; Wolf, Fisman, Ellison, & Freeman, 1998), and for impoverished sibling and peer relationships (Bägenholm & Gillberg, 1991, Hastings 2003a, Kaminsky & Dewey, 2001) compared to siblings of children with another disability or TD children. Other researchers suggest that siblings of children with autism may not be at increased risk for such difficulties (Hastings 2007, Kaminsky & Dewey, 2002; Mates, 1990; Pilowsky, 2004). Furthermore, in a number of studies positive outcomes have been reported, such as better sibling emotional and behavioral adjustment (Hastings, 2003b), more positive perceptions of sibling relationships with their brothers and sisters with autism (Royers & Mycke, 1995), and higher social competence (Ferrari, 1984) and self concept (Macks & Reeve, 2007), when compared to siblings of children with another disability or with normative data.

Research focusing on siblings has generally started with research questions that explicitly or implicitly assume that growing up with a brother or sister with

autism is necessarily a stressful experience that can lead to emotional and behavioral difficulties. Not only is the evidence contradictory, but respondents in research are typically parents reporting on siblings' adjustment rather than the siblings themselves. Siblings' personal accounts of their circumstances might reflect aspects of their appraisal process that form an integral component of their coping efforts (Lazarus & Folkman, 1984). McHale, Sloan, and Simeonson (1986), interviewed 30 siblings of children with autism, 30 siblings of children with an intellectual disability (ID), and 30 siblings of TD children aged between six and 15 years, about their sibling relationships and their perceptions of their siblings. Overall, reports from all three groups were positive. Individual data, however, revealed that while some children expressed positive views of their siblings with a disability, others described their relationships in very negative terms. In the groups of siblings of children with autism and with ID, negative sibling relationships were associated with worries about the future of the child with a disability, perceived parental favoritism and feelings of rejection toward the child with a disability. On the other hand, siblings' greater understanding of their brother's/sister's disability, and perceived positive reactions from parents and peers towards the child with a disability, were related to more positive sibling relationships.

In a replication of the McHale et al., study, Bågenholm and Gillberg (1991) interviewed 20 siblings of children with autism, 20 siblings of children with ID, and 20 siblings of TD children between the ages of five and 20 years, using the same semi-structured interview format with the added domain of siblings' self-perceptions. All three groups of siblings expressed fairly positive views, but siblings of children with autism were relatively more negative in their accounts of their relationships, reported more problems with their siblings' Behavior, and expressed greater concerns

for their siblings' future. These children also reported feeling more lonely than siblings of children with ID and TD children.

These studies using sibling self-reports derived quantitative data from semi-structured interviews. It was not their aim to provide the detail and wealth of information that can be found in verbatim interview data (Smith, Harre, & Langenhove, 1995). Qualitative research methods allow the researcher to focus on issues that are meaningful to the participants, without the constraints of predetermined categories, therefore allowing for the emergence of different perspectives (Barbour, 2000). Given the diversity of perceptions and adjustment of siblings of children with ASD, these aspects of the siblings' experience lend themselves to exploration via qualitative methods. In one of the few recent qualitative studies on the experiences of siblings of children with autism, Benderix and Sivberg (2007) conducted face-to-face interviews with 14 siblings aged between five and 29 years from five families. The interview transcripts were analysed via content analysis (Burnard, 1991) and yielded seven categories of siblings' experiences: (i) having a sense of responsibility, (ii) feeling sorry for their sibling with autism, (iii) dealing with abnormal Behavior, (iv) feeling empathy for their sibling with autism, (v) expressing hope and anticipating relief through respite, (vi) experiencing violent Behavior, and (vii) a negative impact on siblings' peer relationships. Also using content analysis, Mascha and Boucher (2006) interviewed 14 siblings between the ages of 11 and 18 years using a semi-structured format. In general, siblings' reports were positive. Where there were negative reactions, these related to the Behavior problems of the child with autism and feelings of embarrassment in the TD siblings.

In an earlier qualitative investigation, Dellve and colleagues (2000) interviewed 15 sisters between the ages of 12 and 18 years who had a brother with deficits in

attention motor control and perception (DAMP) and/or Asperger syndrome. The analysis of the data was performed via a constant comparative method for grounded theory (Glaser & Strauss, 1991). These authors found that where siblings possessed increased knowledge and understanding of their brother's disability this was associated with less embarrassment in relation to the child with a disability and greater acceptance of their circumstances. Some siblings described a marked sense of responsibility and striving for a close relationship with their brothers, while others were attempting to distance themselves from the family and gain independence.

There is a dearth of qualitative data from siblings' accounts of their experiences in families where there is a child with ASD. Existing samples either span the childhood and adolescent years in toto, or focus on adolescent siblings exclusively. Minimal research attention has been paid to the experiences of siblings of children with autism in middle childhood and preadolescence. In a home observational study, child siblings of children with an ASD spent on average 40 minutes out of every hour in mutual interaction (Knott, Lewis, & Williams, 1995). At this stage, siblings are an important part of each other's emotional support network (Harris & Glasberg, 2003), and sibling conflict may increase (McHale, Osgood, & Crouter, 2006). This is also the time when sibling relationships become more egalitarian (Buhrmester & Furman, 1990; Dunn, 1992), and have been shown to predict stability of relationship quality longitudinally within the sibling relationship (McHale, Kim, & Whiteman, 2006) as well as with peers (Updegraff, McHale, & Crouter, 2002). Therefore, the aim of the present study was to investigate, using qualitative methods, the perceptions and experiences of TD siblings, in middle childhood, who were growing up with a brother with ASD.

Method

Methodological Approach

Interpretative Phenomenological Analysis (IPA: Smith, Jarman, & Osborn, 1999) was the chosen method of analysis in this investigation. IPA deliberately seeks to capture the richness and diversity of participants' accounts by uncovering the central themes that emerge from the participant's talk (Jarett, Payne, Turner, & Hillier, 1999). In this respect, the participant is seen as an expert on his or her personal experience. Herein, IPA is used to capture the experience of siblinghood where there is a child with ASD as it is understood by the TD sibling.

In addition to the meaning offered by the participants' accounts, IPA recognises the dual aspect of analysis as the investigator also engages in an interpretative relationship with the interview data. Direct access to the personal meaning offered by the participant is not achievable without acknowledging the influence of the researcher's personal conceptions; this interpretative activity is therefore a necessary component in IPA (Smith et al., 1999).

IPA methodology typically involves small (N typically 6-8) somewhat homogenous samples, which allows for in depth examination of participants' accounts, although samples have varied from single case studies to 30 participants (Brocki & Wearden, 2006). Additional researchers are often involved in credibility checks to ensure that the emerging themes are internally coherent and grounded in the transcripts (Elliott, Fisher, & Rennie, 1999). Furthermore, treatments such as seeking consultation from the participants on the accuracy of the findings, discussion within the research team, peer review, and the use of reflective practice via a reflexive journal can also be utilised to aid verification and consistency, and ensure the quality of the findings (Carradice, Shankland, & Beail, 2002). The data interpretation in this

study was facilitated by discussions within the research team and an audit of themes conducted by each author.

Participants

The participant recruitment process was facilitated by a local parent group, a local ASD school, a local branch of a national disability charity, and also through advertisement in a local newspaper and the UK National Autistic Society (NAS) website (see Appendix F,G). The inclusion criteria for the study were that there was a child in the family with a formal diagnosis of ASD between five and seventeen years of age and a TD sibling between the ages of eight and 17 years, and families resided in or around the area local to the University. Families were asked to volunteer to participate (see Appendix I). Demographic information was collected via a demographic questionnaire completed by the primary caregiver (see Appendix H). Twenty-two siblings with a brother with ASD who met the inclusion criteria for the study were interviewed. The present study reports on a sub-sample of eight biological siblings with a brother with ASD, who were selected based on the children's age (middle childhood age 9-12 years; $M = 11.19$ years, $SD = 1.32$). There were three brothers and five sisters of males with ASD. Three siblings were younger, four were older and one was a twin of the child with ASD. Two children, one male, one female, were biological siblings, from the same household, with a brother with Asperger syndrome. The number of children in the participants' homes ranged from two to five ($M = 2.87$; $SD = .83$; mode = 3). The ages of the boys with ASD ranged from eight to 17 years ($M = 11.99$ years, $SD = 2.83$). Three boys had a diagnosis of autism and had an intellectual disability, and five boys had a diagnosis of Asperger's syndrome. Apart from one child with ASD who had an additional diagnosis of ADHD, the rest of

children did not have any comorbid neurological or psychiatric diagnosis. Seven boys with ASD lived in the family home, while one child with ASD was living away from home.

Procedure

The semi-structured interview (see Appendix A) was developed through multiple discussions with the research team and was first piloted with one sibling whose interview is not included in this analysis. The pilot interview resulted in some minor changes to the interview format. The interview schedule included a number of initial warm-up questions aiming to put the participant at ease before moving on to the substantive areas, as well as subsidiary questions and prompts should a sibling have difficulty discussing a particular area. The interview schedule covered two main areas: (1) siblings' knowledge and perception of their brother's ASD, and (2) siblings' perceptions and experiences of their relationships with their brothers with ASD. Information on the aims of the research and the potential topics that would be discussed during the interview was provided via an information sheet (see Appendix B,C,D,E) which the participating families received a number of days prior to the interview.

During the interview, the participant was allowed to lead the discussion and at the end of the process participants were given the opportunity to provide feedback and raise any additional topics. Interviews were conducted face-to-face and lasted 21 minutes on average (range 14.13 - 42.51 mins). Participants were given the choice of being interviewed in their home (n = 7), or at the researcher's base (n = 1). All participants reported positively on the interview experience, and none requested that the interview be terminated prematurely.

Data Analysis

Interviews were recorded and subsequently fully transcribed. Initially, the first author listened to and read through the transcript a number of times to become familiar with the interview content. Following this, the transcripts were read line-by-line noting comments (preliminary interpretations, summaries of meaning, etc.) on the transcript. This process continued until saturation and was repeated for each transcript. An initial list of themes relating to the siblings' experiences was drawn up, and a list of relevant verbatim quotes corresponding to these themes was created. A master list of themes was developed as emerging sub-themes were grouped together. The audit and validation process involved a co-author reading through each transcript, the list of themes and quotes, and the list of master themes, to ensure that the emerging themes were grounded in the data and none had been omitted. Discussion between the authors resulted in minor changes to the presentation and description of themes. A final list of five themes emerged through this process. The themes are discussed below and illustrated with verbatim quotes from the interviews. For purposes of confidentiality, all names have been changed. When providing extracts from the interviews, (...) is used to indicate words omitted to shorten a quote. The research team consisted of two doctoral students, two expert researchers in the field of developmental disabilities, and a clinical psychologist. Discussion of the data within this diverse research group led to contributions from different respective interpretative positions.

Results

Five main themes were extracted. The first theme represents siblings' perceptions of the impact of their brother's condition on their lives. The second theme describes siblings' perceptions of others' attitudes and the influence these attitudes have on the siblings. In the third theme the focus is on siblings' tolerance towards their brothers with ASD, while the fourth theme presents positive attitudes and experiences in the sibling participants' lives with their brothers. The final theme refers to various sources of support that the participants identified as helpful, or supports they would like to receive. All of the siblings interviewed in the research were explicitly aware of their brother's diagnosis.

Theme 1. Living with a brother with ASD: Siblings' accounts of the impact on themselves and their families.

Growing up with a brother who has ASD is an experience unique to each sibling, ASD in itself is a particularly complex disorder, given its multi-factorial nature, and it may differ from one affected individual to the next. Accounts of the perceived impact of their brothers' disability varied greatly across the TD siblings, as did their responses to the challenges they faced. The children spoke about the typically negative impact of having a brother with ASD on themselves, their families, as well as on their brother with ASD. Children spoke about the disruption in their daily lives caused by their brothers' peculiar or aggressive Behavior, the concessions they made, and the atypical roles some have had to assume. Lizzy reflected on her caretaking responsibilities for her brother with ASD despite being the younger sister

Lizzy - "I never feel like the youngest, even when I was small (...) I suppose I learnt how to take care of people just like if I had a younger brother."

Elliott has resigned himself to interacting little with others and has forsaken attention within and outside the home because of what he perceives as his brother's needs.

Elliott spends time in his room with his brother, reducing the contact he has with others.

Elliott - Well I keep on looking out for him, which I don't really mind but he doesn't interact much so I've pretty much taken to staying in my room most of the time. He wants a lot of attention. I just try and keep my distance from most people.

Interviewer - How come?

Elliott - I don't know, Oscar deserves most of the attention because he can't understand what it's like to have no attention and I don't mind staying in my room.

Maddie struggles with her brother's idiosyncratic and eccentric habits that often mean not being able to get to sleep until late. Maddie then describes how she has to cope with her brother's disruptive Behavior by taking a problem-focused approach.

Maddie - He's loud and very awkward, and when it's night time and he's got like a book, even when the lights are out and he makes these funny little noises, so I can't get to sleep until nine or ten. (...) Jake's loud and he won't stop running into my bedroom when we're talking; and then he just wants to play with us all the time. I get very irritated and I can't get him out. That's why I have a lock on my bedroom door now.

Four siblings spoke about having to face physically and verbally aggressive Behavior from their brother with ASD in the home. This was often reported as unprovoked.

Leah - when like you play with something, Jack he comes along because he wants to put it in a little order; and he absolutely takes it off you. And say you just walk off and just go and sit in the sitting room and go and watch TV, he just comes in and starts chucking things at you, (...) he just chucks things at you, shouts at you, screams at you.

Kevin described how his brother's tantrums and aggression have been difficult for him in the past and continue to have a considerable negative impact on his life. Despite this, Kevin makes an effort to understand the reasons that might lie behind his brother's challenging Behavior.

Kevin - Say if he is in a bad mood, and he takes it out on me, like he hits me, or throws something at me, or calls me names, you know, it can affect me. When I was in primary, he did take it out on me quite a lot and at school I felt, I wouldn't be in a good mood because of what happened that morning. It's mainly in the mornings that he will start a tantrum, because he doesn't like how, he thinks we all rush to get to school, and he doesn't like how we rush about, and he gets frustrated about that.

Kevin went on to give an account of the disruption that his brother's Behavior often causes to family life with reference to his parents, and the emotions he experiences as a result.

Kevin - I feel quite angry, because he has spoiled a day, which we were all enjoying to that point. I feel quite sad because my Mum and Dad spend that money on us, and then he has to go and spoil it by having a tantrum.

Having a family member with ASD also impacted on family recreational activities and spending time together was a luxury seldom enjoyed by many of the children.

This in turn resulted in perceived restricted opportunities for the siblings. Eddie spoke about the disruption and constant pace that the family experienced during outings

Eddie - "We can't go to many places, and when we go to town, we can't stop and look at something, we always have to go."

Eddie also talked about how certain situations can prompt difficult Behavior from his older brother with ASD.

Interviewer - (...)would you have any advice to give any other younger brothers, like yourself, who have an older brother like Isaac?

Eddie - Don't wind him up, or he'll hurt you, and don't take him to a lot of shops (...) Because when he sees something he wants, and he can't have it, he won't go out of the shop.

Theme 2. Others' reactions: Implications for siblings. Having a sibling with ASD comes with more than just the immediate demands of the condition. Siblings often reported prejudice and misunderstanding in addition to having to answer

questions and combat the ignorance of others. They were experiencing a range of emotions as a result of a lack of understanding and negative attitudes on the part of strangers and friends. Participants described feeling angry, embarrassed, and anxious. This resulted in explanations on the part of some, and silence and withdrawal for others.

Some siblings spoke about other children's attitudes toward their brothers, and the difficulties associated with reactions from peers.

Leah - "It's quite annoying because they don't see Jack for who he really is; they just see a big person that's got Asperger's and is really annoying."

Lizzy - "Most of my friends are fine but it's quite hard when people act different around him because he's autistic. I like when people just see him as a person."

To some, social awkwardness and embarrassment were regular occurrences.

Maddie - It can be quite embarrassing because they just want to go to my room and lock themselves in, because none of my other friends have got autistic brothers and sisters, so they just get freaked out by Jake sometimes.

Others, like Leah, experienced rejection as a result of negative peer reactions to their brother with ASD.

Interviewer - "What's it like for you, Leah, when your friends meet Jack?"

Leah - "It's like they don't really like me any more, because they see Jack as someone they don't really want to know."

Often, feelings of embarrassment turned to frustration and anger in the context of what Kevin regarded as stigmatizing and discriminating Behavior of an unsympathetic public. Kevin perceived onlookers as lacking the necessary

understanding and etiquette when a child with ASD acts in a way that is out-of-the-ordinary or out of control.

Kevin- (...) people look at us in funny ways, so if another family has a tantrum, but there's nothing wrong about them, nobody would look at them in a funny way, must be like sort of not getting treated with respect as everybody else should, just because it's a family with autism. (...)so if he starts swearing or starts kicking, you know, it's quite embarrassing because people might think, oh, you know, their mother or father taught him to do that, so it's quite embarrassing to me to think that people sort of disrespecting my family and me and my brother.

The children spoke about the curiosity that their brothers' condition provoked in peers, and facing the issue of providing an explanation to others.

Lizzy - Just sometimes they sort of – well, when you make new friends they ask what's wrong with him and I have to explain it. And they get used to it when they get to know him. You tell them more about it, and you tell them stories and stuff.

In addition, the attitudes of others led some children to remain silent and guarded about their siblings, which in Elliott's case followed a negative experience:

Interviewer - "How come you've decided to not talk with other people about Oscar?"

Elliott - "Because I tried it once in primary and they started to make fun of my brother so I didn't want that to happen again."

Kevin expressed his unwillingness to talk about personal issues, and his anxiety about his friends not understanding the reality of having a brother with ASD.

Kevin- I don't really speak about what has happened in the house with him. (...) I don't know how my friends would take it [talking about having a brother with ASD], you know, if they would understand, or if they would think that, the house doesn't really sound at all nice, sounds a bit like a madhouse.

Theme 3. Acceptance, and wanting change.

Particularly evident in this research were siblings' views that conveyed a sense of acceptance toward their brothers with ASD. Many children acknowledged their siblings for who they were, and perceived the disability as an inseparable part of the person with ASD, clearly stating their positive acceptance. Dylan's circumstances did

not deviate from what he perceived to be normal and acceptance emerged in the form of normalizing his experience.

Dylan - Jack's just like an average person, that he's just got this Asperger's; but he's just like a normal kid. He's just got Aspergers. (...) He's just like my normal brother; I never even think about it. I just recognise him as just another human.

Despite all of the children having in some way come to terms with their life circumstances and the reality of their brother's condition, tension between accepting their brother while still wanting certain things to be different was apparent in some siblings. Elliott initially stated that he wouldn't want to take away his brother's ASD but then expressed a desire to alleviate his brother's ASD, which he viewed as responsible for the depleted interaction between his brother and other family members.

Interviewer - Okay, do you think that autism is something that you can get rid of?'

Elliott - 'I think possibly, but I wouldn't like to do it because I like Oscar how he is.

Interviewer - If you could wave a magic wand, is there anything that you would change about Oscar?'

Elliott - His autism so we could spend more time. Apart from that there isn't much. (...) Just so that he could talk and interact a bit more and spend more time with his family.

Tension was also evident in Kevin's account, where despite blatant dissatisfaction with his brother's Behavior, Kevin appeared forgiving of such Behavior, and justified it by acknowledging that his brother is not fully in control of his actions.

Kevin - I suppose, like on weekends, if he was less aggressive towards the family and friends. I don't like hitters or biters. I don't think he's really thinking about what he's doing at the time, but I suppose that could make him more aggressive and violent.

As the interview with Kevin progressed, regret over the little time spent interacting with his brother and letting his brother know of his feelings of appreciation toward

him gradually surfaced. Kevin wistfully described how he would like to be able to communicate this fervent appreciation to his brother.

I'd like to take him to the little park, with my friends, and he'd make new friends by doing that. I'd like to tell him how much I appreciate him, because I don't really do that enough. He's often said to me, you're the worst brother in the world, you know, I don't like you, and I could show my appreciation more towards him than I do now. Yes, I could show my appreciation more towards him.

The tension that was evident in the siblings' accounts offered a sense of the dynamic nature of the children's attitudes. It is less clear whether the children actively held these tensions between acceptance and change, or whether these often contradicting views were evidence of ongoing processing and appraisal perhaps elicited by the interactions in the interviews.

In contrast, five siblings clearly expressed a yearning for something different, such as change in some of the Behavior of the sibling with ASD.

Leah - Well, I would, I think I'd change that he would be more, say like I wanted to play on the computer and Jack's had his turn, I would like him to be like, if you can have your turn, then Dylan can have a turn then I'll go back on, rather than just saying, five more minutes; and then ten minutes later, no, five minutes more.

Maddie demonstrated a clear desire for change as she expressed her wish for her brother to be normal on the grounds of a healthier and richer sibling interaction.

Maddie - I'd make him a normal person.

Interviewer - Can you tell me more about that? How would he be normal?

Maddie - He'd just be like me. It would be nice to have a nice, normal brother because I could do more with him, so that would be better.

For Lizzy, unlike others, the change she longed for came in the form of wanting to know more and gaining more information on her brother's disability.

Lizzy - I'd just like to, to know how, to know more about Tyler, and the area around Tyler, and that sort of thing really.

Interviewer - Do you mean autism?

Lizzy - Yes. Autism, and handicapped people, I'd like to learn more about that.

Throughout the interviews it was apparent that the experience of living and growing up with a sibling with ASD had a profound influence on the children's views and perspectives. Lizzy welcomed having a brother with ASD and acknowledged the value and uniqueness of the individual through an unconditional acceptance.

Lizzy - (...) I like him the way he is. He's my brother. I'd never make him normal because I knew him like this. And I can't imagine a brother any other way. Well, not like Tyler any other way. I can't imagine him any other way, I wouldn't change anything.

Theme 4. Positive views and experiences.

Most siblings, though they acknowledged the challenges associated with having a brother with ASD, spoke about various positive aspects of the experience. The siblings reported having fun with, feeling proud of, and even marvelling at the achievements of their brother with ASD. All of the interviewees recognized positive qualities and traits in their siblings. Within the siblings' accounts there was evidence of moments when children enjoyed interacting and engaging in recreational activities with their brothers with ASD. Children described how they happily engaged in imaginative play and shared humour, intimacy, and a special bond.

Leah - Oh, like last night when Jack and Dylan, they were doing a little show where Dylan was saying that in school they were saying that girls were saying how boys walked, and boys were saying how girls walked; and Jack kept on doing this little walk, and then we really laughed at the way he looked.

Kelsey - He's really nice sometimes; he's really fun. (...) At nights, we'd always go into one of our rooms and play like paper games and stuff. Yes. Noughts and Crosses, and Hangman and things like that which really is fun (...) and watch TV in his room, watching South Park because I wasn't allowed to, so he always used to let me because it was after my bedtime.

Other siblings spoke with pride about the distinctive and idiosyncratic skills that set their brothers apart, including exceptional memories. Achievements, however big or

small, were regarded highly. The participants acknowledged the magnitude of these attainments in the context of having an ASD.

Dylan - Well, what I like about Jack, he like knows absolutely loads more than me, and he's got this Asperger's thing; I reckon some of that Asperger's is to do with Jack's learning, stuff like that. (...) Well, really, it's like if you have learning difficulties, it's a lot harder to learn but I reckon Asperger's is like an extra brain that you have.

Eddie - He's good at remembering things, like if he puts something up on his textbook, he'll remember it there, he'll remember it easier than anyone else.

Kevin - last year, I'm not quite sure, he won a computer by doing horse riding. He didn't win, but he got it for doing so well, which I was really pleased by him for doing that. Not just for winning the computer, but because he'd done so well. And, how he speaks to people, how he has a social life here in school, how he's pretty popular in school, you know, cause when it comes to Christmas cards, (...) he ends with seventy-five cards, you know, and all the teachers have said about how well behaved he is. (...) I do enjoy how he talks to strangers and how he copes with day-to-day life.

Lizzy appreciated her brother's sincere and genuine nature.

Lizzy - I like that he always shows who he is. He always shows that he does have a personality and he is someone. And also just so he can't talk doesn't mean he doesn't have anything to say. He can sort of speak to you in a way.

For some siblings, the experience of growing up with a brother with ASD was highly valued. These children expressed a sense of gratitude and felt they had gained positively and learnt from their siblings.

Interviewer - So can you tell me how you think it's affected you?

Lizzy - I think it's actually in a good way. I've learnt about caring well for people. (...) We get to understand more about other people. Because if I didn't have Tyler then I wouldn't know what autism means or understand all of that. But I have more knowledge in that area, and about autism.

Theme 5. Support.

Most of the siblings discussed different facilitators and sources of support, or indeed the lack of support that they had. Siblings commented on both formal and informal support networks. Sometimes the support was tangible such as a respite

service or a support group. At other times, children spoke of the importance of being able to reach out to family and friends. Although siblings reported utilizing different sources of support, being able to draw on other people's help, whether peers, parents, or professionals facilitated the process of meeting some of the demands of growing up with a brother with ASD.

The presence of other TD children may provide additional support not available in families where there is only one TD child, with TD siblings acting as a source of support for each other.

Leah - We just talk, it's called our huddle. I talk to Dylan and Dylan talks to me about how things are, and how we can get really frustrated with Jack. (...) We talk about how we can get so annoyed when Jack gets mad, and how frustrated me and Dylan can be when we talk about things about Jack, and how we'd like things to be different.

Effective communication between parents and the TD siblings appeared to facilitate the adjustment process. Participants spoke about turning to a parent for help in acquiring a greater understanding of their brother's disorder, as well as seeking parental support when they felt upset. An open channel of communication was important in facilitating children's understanding of emotionally sensitive topics.

Interviewer - What about with Carol, your mom. Do you talk with mom about Tyler?

Lizzy - I speak to her more about how things were about when he was born, how he became and how they found out. And what it is.

Interviewer - And what about at home with Mom and Dad, do you ever talk about Max?

Kevin - (...) I speak to her, 'bout, now and then when it's actually affecting me, about what happens in the house, like if I've got upset, and you can speak to them about why I've got upset, you know, and about what happened in the house that day.

Lizzy spoke about the helpfulness of a respite service: allowing the family to spend time together enjoying a day out, while at the same time providing her brother with the opportunity to enjoy leisure himself.

Lizzy - (...) He had someone called Lana who took him out on days out which was fun for him, and gave us as a family some time to go to places that maybe he wouldn't like to go. Like just as a family, without him, so that he would go where he liked to go, and us where we liked to go. Like just daytrips.

Siblings felt alone and lacking in support at times.

Leah - "I feel quite annoyed, because there's no one really to talk to about when I feel angry with Jack, and when he always gets his own way, and stuff about that."

Participants spoke about the valued experience of attending support groups and being able to share their experience

Interviewer - Kelsey, I'm wondering if there are any other questions that you think I should ask other sisters who have a brother like Ryan.

Kelsey - Would you like to meet more people in the same situation as you?

Interviewer - Okay. Why do you think that's a good question?

Kelsey - Because once Mum went to a meeting for people who had children like Ryan and once she had to take me, and I met two other girls there, who had brothers who were autistic which is cool because you can still have a laugh with them and that, but they understand it better.

For Kevin, realizing the extent to which others shared his experiences and being with people he could confide in and that understood how he felt was a valuable source of support.

Kevin - I go out with a staff member called Gemma who once a month takes me out to places of my choice. If there's anything that I want to say that I'm not too confident to do, you know I tell her, and I can speak to her about it. I can speak to her about what's happened at home, and also, once a fortnight there's a group in [location name] that I go to which go swimming or wall climbing or different activities, where we just, it's a youth club, but for children with similar problems in the home. Yes, I quite, like felt that, I don't feel alone, like there's nobody else like me, that's got a sibling that's disabled. I mean, before I went, about three or four years ago, and before I went there I didn't know anyone that's got brothers or

sisters that are disabled, but when I went there, I found out there's a whole range of children with problems worse, or not as bad as me. I felt more reassured on how you know, I'm not alone, there is people to speak to you know and there is other children with the same issues in the family as me.

Discussion

The siblings' accounts highlighted a number of salient dimensions of experience with regard to having a brother with ASD. Siblings differed in their attitudes and interpretations of their experiences and all siblings, albeit to varying extents, identified positive aspects of having a brother with ASD. Siblings in the present study described being affected in different ways by having a brother with ASD including becoming socially isolated, dealing with their brother's strange habits and aggressive Behavior, and reduced family leisure and recreational time. These results are in line with findings from previous research reporting on siblings of children with autism facing problems with difficulties with their brother's/sister's aggressive Behavior and tantrums (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; Ross & Cuskelly, 2006), strange and upset Behavior (Benderix & Sivberg 2007; Royers & Mycke, 1995), and also expressing feelings of loneliness, and impoverished social interactions (Bägenholm & Gillberg, 1991).

In addition to the direct demands placed on them by their brothers with ASD, the siblings also described having to cope with the attitudes and, often unhelpful, reactions of others. Peers' and others' reactions, and having to explain their brother's condition to peers often led to feelings of embarrassment, frustration, and anger. In previous research Royers and Mycke (1995) also found siblings of children with autism to be more embarrassed in the presence of other children and peers compared to other groups of siblings. In a qualitative investigation, Opperman and Alant (2003)

reported that the majority of their adolescent participants felt that others did not accept their sibling with a disability without prejudice and often did not know how to act in the presence of a person with a disability.

The current research highlighted siblings' divergent attitudes toward their brothers with ASD. Some expressed a positive acceptance of their circumstances, while others clearly wanted change. Siblings' experiences and perceptions did not appear to differ as a function of their gender, however, Leah and Dylan, who were biological siblings, growing up in the same household with their brother Jack, who has Asperger syndrome, differed greatly in their accounts. Leah recounted negative experiences and was less accepting of her older brother's condition, while Dylan described positive experiences and acceptance toward his twin brother. Siblings' experiences may differ as a function of their relative age. Earlier studies have found a relationship between being younger than the child with autism and increased emotional difficulties in the TD siblings (Gold, 1993, Hastings, 2003a). More research is needed to corroborate these findings and explore the potential relationships between TD siblings' relative age, their experiences, and the impact these might have on their adjustment. A sense of ambivalence and tension was also evident in some of the sibling's accounts. Opperman and Alant (2003) also noted high rates of ambivalent feelings in the adolescent siblings of children with a severe disability. They postulated this reaction to be an attempt to regulate the stressful event and negative emotions associated with having a sibling with a disability; a mode of coping that adolescents use to work through their emotions surrounding their sibling with a disability.

Alongside siblings' attitudes and accounts of their experiences, positive perceptions of their brothers with an ASD were present in every interview. These

included positive interactions between siblings, feelings of pride and profound appreciation toward their brother with ASD, and a sense of having gained from their sibling relationships. Similarly, Mascha and Boucher (2006) found that siblings of children with ASD referred to playing and having fun with their brother or sister when asked what the best part of having a sibling with ASD was. Parents of children with disabilities also recognize the positive impact on siblings including learning about diversity (Taunt & Hastings, 2002).

The final theme described in this study makes reference to sources of support that siblings identified as being useful or that they would like more of. Siblings drew support from various resources including other TD siblings in multi-child families, parents, and professionals. Siblings identified being able to openly communicate thoughts and feelings and sharing their experiences with others in similar circumstances as helpful practices. Some siblings however also commented that support was not always readily available. Bågenholm and Gillberg (1991) also found that some siblings could only talk with someone outside the home about their brother or sister with a disability.

Regrettably, research with siblings of children with ASD has yet to fully recognize the importance of siblings' personal accounts and subjective meanings. These accounts might reflect important aspects of siblings' appraisal processes that shape their responses to living in a family environment that includes a child with ASD. Lazarus and Folkman (1984) have suggested that individuals' emotional responses are specified by the appraised meanings they assign to given situations and that one's coping response is also cognitively mediated through one's appraisal, a process which is dynamic in nature. It is not clear from this research whether the tension observed in some of the siblings' accounts reflects the ongoing dynamic

appraisal process that may enable some children to reframe events and experiences in adaptive ways or whether these children indeed hold multiple, and at times conflicting, views of their circumstances.

There is little research systematically exploring childrens' coping strategies in the context of having a sibling with ASD. Ross and Cuskelly (2006) identified emotional regulation and wishful thinking as the most common coping strategies employed by siblings of children with ASD. Royers and Mycke (1995) found that siblings of children with autism used other directed cognitions (blaming others) as a coping strategy more often than other sibling groups. The role of siblings' perceptions in their coping responses and adjustment outcomes may be informative. Elliott's perceptions of the impact of ASD on his brother may mediate his response of adopting a passive withdrawal coping strategy. Future research needs to consider the factors that mediate the adjustment and coping of siblings of children with ASD throughout the trajectory of siblings' development. The chronic nature of ASD means that some siblings may have long-term and ever-changing needs.

Positive perceptions in particular may serve a functional role for siblings' adaptation to having a brother or sister with autism (Hastings & Taunt, 2002). Recent findings from a longitudinal study investigating the effects of positive sibling relationships on child adjustment suggest that affectionate relationships between siblings moderate the relationship between stressful life events and subsequent child adjustment (Gas, Jenkins, & Dunn, 2007). There is evidence from previous studies that siblings' perceptions of their siblings with ASD are associated with sibling adjustment and relationship outcomes. Gold (1993) reported that for male siblings of boys with autism the response that 'there is nothing good about having a brother with autism' was associated with higher scores on the Child Depression Inventory (CDI;

Kovacs & Beck, 1977). McHale, Sloan, and Simeonson (1986) found that worries about the future of the child with a disability, perceptions of parental favoritism toward the child with a disability, and feelings of rejection toward the child with a disability were associated with more negative sibling relationships. Conversely, when siblings perceived their parents and peers as reacting positively to the child with a disability and possessing a better understanding of the nature of their siblings' disability, siblings reported more positive relationships with their brother or sister with disability. Future research should explore the potential function of positive perceptions as a process variable affecting the adjustment and relationships of siblings of children with ASD.

Acceptance of the child with ASD was a prevalent theme in our research and one that has not featured to date in any of the literature investigating the adjustment of siblings of children with ASD. Positive acceptance in particular might be a plausible mechanism by which siblings may come to accept and tolerate difficult experiences.

The results from this study evidence siblings' perceptions of the importance of support from different sources. A lack of support may have a more adverse affect on some siblings than others. Gold (1993) noted that siblings with a brother with autism who had no one to talk to about having an autistic brother scored significantly higher on the CDI than those who did. Sibling support groups may validate and normalize siblings' experiences. Support groups might additionally be helpful by offering siblings a type of respite. Wolf, Fisman, Ellison, and Freeman (1998) suggested that securing a supportive relationship for the TD sibling outside of a stressful family system may be an important component of intervention to benefit siblings of children with PDD.

The interpretative facet of this research was inevitably influenced by the authors' perspectives. The first and last authors are doctoral students who have worked with children with ASD within a care capacity, the second and third authors are researchers in the field of families with children with a developmental disability, and the fourth author is a clinical psychologist within autism services. The interpretation of the data in this study is a product of the authors' diverse and convergent characteristics. In this sense, the analysis and discussion of the results represents an integrated care, research, and clinical perspective with an emphasis on family systems principles. The recognition of the author's interpretative roles, from the onset of the research, led to concerted efforts to ensure that interpretation was firmly grounded in the data.

The findings from the present study point to a number of practical implications such as areas that might be targeted through intervention, pedagogical support, and training and information for parents, siblings and professionals who come into contact with families where there is a TD child and a child with ASD. Raising awareness in families and professionals of the potential issues faced by siblings of children with ASD may facilitate increased dialogue within families, and also between families and professionals to improve the lives of siblings.

Interaction training for siblings of children with ASD may prove valuable in enhancing the social Behavior and communication and reducing conflict between siblings. In addition, booster programming may ensure that the training siblings receive is kept abreast with the demands siblings face at different time-points. For a number of siblings in this study parent-child communication played an important role in their understanding of their brother's condition and coping with problematic situations. Parents may act as both trainers and agents for the effective support of

siblings. In addition to equipping parents with the skills and knowledge to educate their TD children, parent training may additionally be useful for parents to learn how to appropriately reinforce and maintain siblings' efforts to positively interact with their brother or sister with ASD and also to sensitize siblings to how their skills may impact upon the child with ASD. Lobato and Kao (2002), reported on an integrated sibling-parent group intervention for 54 TD siblings with a brother or sister with a chronic illness or developmental disability, and their parents. Results showed improvements in sibling connectedness, knowledge of the child's disorder, and Behavior problems, which were maintained at three-month follow-up.

In the present study, Kevin spoke about being able to share activities with other children who dealt with issues similar to his. If sibling support groups are developed there is a need to tailor their product taking into consideration the developmental level of the children they are targeting for support or intervention. Evans, Jones, and Mansell (2001) for example noted that discussion groups were not received as well as activity groups, in a small (N=10) sibling-group with children in middle childhood (aged eight to 12 years) who had a sibling with intellectual disabilities and challenging behavior. More importantly, increasing siblings' access to support, which offers developmentally appropriate information and promotes positive perceptions and experiences, early in their development may have lasting effects on their adjustment and relationships. Middle childhood is an ideal period in which to focus supports for a number of reasons; siblings achieve a more mature understanding of illness (Glasberg, 2000), and have high access to each other (Knott et al., 1995) during those years.

Casting aside assumptions and actually allowing siblings to describe their experiences and express their thoughts about life with their brother with ASD is an

important contribution to the literature in this area, which is overrun with anecdotal evidence and retrospective accounts. There is much more that we need to understand about siblings' perceptions and experiences; qualitative research is needed to provide a solid theoretical framework as the basis for future quantitative analysis. Moreover, this exploratory study identifies potential areas that may be targeted via support services whose aim is to improve the psychological well-being of siblings of children with ASD.

Chapter 4. The Perceptions and Experiences of Adolescent Siblings with a Brother
with Autism Spectrum Disorder

Abstract

Semi-structured interviews were used to elicit the perceptions and experiences of 12 typically developing adolescent siblings who had a brother with autism. Interpretative Phenomenological Analysis was used and yielded six themes: 1) Siblings expressed the difficulties and negative impact of their brother's condition, 2) Siblings reflected on how others' reactions negatively affected them, 3) They offered accounts of their histories with their brothers, and described how their past contextualized their present circumstances, 4) They expressed acceptance and tolerance towards their brothers, as well as wishes for certain things to be different, 5) Siblings described positive perceptions and experiences with their brothers, and 6) Siblings conveyed thoughts and worries about the future. The main implications are focused on supporting adolescent siblings by helping them to develop skills in managing others' reactions and openly discussing concerns about their brother or sister's future.

Early research with siblings of children with autism suggested that the complex and unpredictable nature of the behavior of children with autism might place siblings at greater risk for adjustment difficulties compared to siblings of children with other disabilities (Morgan, 1988). Subsequent research with siblings of children with autism has provided evidence for their compromised well-being compared to siblings of children with another disability or typically developing (TD) children (Fisman, Wolf, Ellison, & Freeman 2000; Gold, 1993, Hastings, 2003a). However, other research has seen siblings of children with autism emerge as well adjusted (Hastings 2007, Kaminsky & Dewey, 2002) and even potentially thriving through their experiences with outcomes including better emotional and behavioral adjustment (Hastings, 2003b), increased social competence (Ferrari, 1984), and more positive self concept (Macks & Reeve, 2007) compared to siblings of children with another disability or who are TD.

Given the mixed findings and lack of clarity in the research literature, it is important to identify the possible mechanisms and processes responsible for differential adjustment outcomes in siblings of children with autism. A priority for this research effort is siblings' personal accounts of their circumstances, which might help us to understand aspects of their appraisal processes that in turn influence their coping strategies (Lazarus & Folkman, 1984) and subsequent adjustment. There are some quantitative research studies that contribute to such an understanding. Gold (1993) found that for male siblings with a brother with autism, reports of “nothing good about having a brother with autism” were related to increased symptoms of depression. Roeyers and Mycke (1995) showed that siblings' appraisals of stressful events with their brother or sister with autism or intellectual disability, and in

particular the intensity of their affective reactions to those stressful events, correlated significantly with the quality of the sibling relationship.

Although quantitative research can help us to understand sibling adjustment, we currently know little about how siblings make sense of their circumstances and experiences when they have a brother or sister with autism. Qualitative research studies have an important role to play when we seek to understand siblings' perspectives, but there are few such studies focusing on siblings of children with autism. In our previous qualitative research, we explored the perceptions and experiences of eight siblings in middle childhood with a brother with autism spectrum disorder (ASD) (Petalas, Hastings, Nash, Dowey, & Reilly, 2008). Analysis of interviews with siblings identified a number of themes: Siblings expressed their perceptions of the impact of their brother's condition on their lives; how other people's attitudes affected them; their feelings of tolerance and acceptance towards their brothers with ASD, with some expressing a wish for their brother to change; most of the young siblings expressed positive attitudes and experiences with their brothers; and finally, siblings described various sources of support that they identified as helpful, or that they would like to receive.

These data and those of a small number of other qualitative studies (Dellve, Cernerud, & Hallberg, 2000; Mascha & Boucher, 2006; Opperman & Alant, 2003) reflect both negative and positive perceptions and experiences that might go some way to explain the mixed findings from quantitative research studies. Few qualitative research studies have focused on the perspectives of adolescent siblings, despite the potential significance of lifespan development and transitions. The transition from middle childhood to adolescence is a period marked by changes within both the family system as well as the sibling subsystem (Bongers, Koot, van der Ende, &

Verhulst, 2003). Adolescence is a time when siblings are likely to share more equal status and relative power, and may therefore hold common views, mutual respect, and understanding for each other (Moser, Paternite, & Dixon, 1996). At the same time, adolescence is characterized by decreased levels of sibling interaction, companionship, intimacy, and affection (Buhrmester, 1992). As adolescents begin to increasingly explore relationships outside of the family, the significance of friends grows relative to family members (Furman & Buhrmester, 1992; Larson et al., 1996). Data focusing specifically on siblings with pervasive developmental disorder (PDD) suggest that siblings may externalize their distress at a younger age, while developing internalizing symptoms with their transition into adolescence (Wolf et al., 1998).

Therefore, the aim of the present research was to gather data on the perspectives of adolescent siblings of children with ASD using interview methods and a qualitative analysis approach suited to presenting and interpreting these perspectives.

Method

Methodological Approach

Data were gathered using semi-structured interviews (see below) and the interview transcripts were examined using Interpretative Phenomenological Analysis (IPA: Smith, Jarman, & Osborn, 1999). IPA focuses on an in-depth examination of participants' accounts by elucidating the central themes that emerge from the participant's talk (Jarett, Payne, Turner, & Hillier, 1999). IPA views the participant as an expert on his or her personal experience, at the same time however, IPA recognizes the influence of the researchers' own preconceptions in the interpretative process; this interpretative activity is therefore a necessary component in IPA (Smith

et al., 1999). In the present study, IPA was used to capture the experience of having a brother with ASD from the perspective of the TD sibling.

IPA methodology generally involves small (N typically 6-8) somewhat homogenous groups, which allows for a comprehensive examination of participants' accounts, although samples in previous research have varied from single case studies to 30 participants (Brocki & Wearden, 2006). Additional researchers may be involved in credibility checks to establish the internal coherence and grounding of the emerging themes in the transcripts (Elliott, Fisher, & Rennie, 1999). Further treatments, including seeking further consultation from the participants on the accuracy of the findings, discussions within the research group, peer review, and reflective practice using a reflexive journal, may also be employed to verify and promote the consistency of the findings (Carradice, Shankland, & Beail, 2002). In the present research, the interpretation of the data was facilitated by discussions within the research team as well as an audit of themes conducted by each author.

Participants

The participant recruitment process was facilitated by a local parent group, a local ASD school, a local branch of a national disability charity, and also through advertisement in a local newspaper and the UK National Autistic Society (NAS) website (see Appendix F,G). The inclusion criteria for the study stipulated that there was a child in the family with a formal diagnosis of ASD between four and 17 years of age and a TD sibling between eight and 17 years of age, and that families resided in or around the area local to the University. Twenty-two siblings with a brother with ASD, who met the inclusion criteria for the study, were interviewed. The present study reports on a sub-sample of 12 biological siblings with a brother with ASD, who were selected based on the siblings' age (range 14-17 years; $M = 15.71$ years, $SD =$

1.55). There were six brothers and six sisters of males with ASD. Three siblings were younger and nine were older than the child with ASD. Eight siblings came from two-child families and four came from multi-child families. The number of children in the participants' homes ranged from two to five ($M = 3.25$; $SD = .75$; mode = 3). The ages of the boys with ASD ranged from four to 18 years ($M = 13.02$ years, $SD = 4.43$). Nine boys had a diagnosis of autism and also had an intellectual disability, and three boys had a diagnosis of Asperger's syndrome. Ten boys with ASD lived in the family home, while two boys with ASD were living away from home. One was placed in foster-care and the other lived in a full-time residential care service.

Procedure

A semi-structured interview protocol (see Appendix A) was developed from multiple discussions within the research team and was initially piloted with one sibling whose interview is not included in this analysis. The pilot interview led to some minor changes of the interview format. The interview protocol began with some warm-up questions designed to put the participants at ease and aid in the establishment of a rapport prior to addressing the more substantive areas. The interview schedule covered two main areas: (1) siblings' knowledge and perception of their brother's ASD, and (2) siblings' perceptions and experiences of their relationships with their brothers with ASD. A number of subsidiary questions and prompts were also included to help in circumstances where a sibling had difficulty discussing a particular area. Information on the aims of the research and the potential topic areas that may be discussed during the interview was provided via an information sheet (see Appendix B,C,D,E) sent to the participating families a number of days prior to the interview. Families were asked to volunteer their participation

(see Appendix I). Families interested in participating were asked to read the information leaflet before signing and returning the consent forms. Written consent was sought from both the parents and the sibling participants. Verbal consent was additionally sought from the sibling participants before the interview.

During the interview, the participant was allowed to lead the discussion and at the end of the process participants were given the opportunity to provide feedback and raise any additional topics. Interviews were conducted face-to-face and lasted 26 minutes on average (range 10.18 - 50.00 mins). Participants were given the choice of being interviewed in their home, or at the researcher's base, and all chose to be interviewed at their homes. All participants reported positively on the interview experience, and none requested that the interview be terminated prematurely. A copy of the interview protocol is available from the corresponding author.

Data Analysis

Interviews were recorded and transcribed verbatim. To begin with, the first author listened to and made several close readings of the transcript to become familiar with the interview content, identifying points of interest and significance throughout the document. Following this, the transcript was read line-by-line noting comments (preliminary interpretations, summaries of meaning, etc.) on the left and right margins of the transcript. This process continued until saturation, and was repeated for each transcript. An initial list of the emerging themes was drawn up, and a list of verbatim quotes corresponding to these themes was created. A master list of themes was developed as elicited sub-themes were grouped together. The audit and validation process was carried out by a co-author who read through each interview transcript, the list of themes and quotes, and the list of master themes, to ensure that

the emerging themes were firmly grounded in the data and none had been omitted. Further discussions between the authors resulted in minor changes to the presentation and description of the themes. A final list of six themes emerged through this process. The themes are discussed below and quoted material appears verbatim to ensure the accuracy and transparency of siblings' views and feelings. We have changed the names of the interviewees to protect their identity. When providing extracts from the interviews, '...' is used to indicate words omitted to shorten a quote. The research team comprised two doctoral students with experience in care service provision of children with ASD, two expert researchers in the field of developmental disabilities, and a clinical psychologist.

Results

The analysis elicited six themes. First, siblings expressed the difficulties and negative impact that their brother's condition has on them. The second theme describes siblings' perceptions of the influence of others on their circumstances. The third theme revolves around siblings' accounts of their histories with their brothers and how the past serves as a context for their present circumstances. The fourth theme refers to siblings' acceptance and tolerance towards their brothers with ASD, and siblings' wishes for some things to be different. The fifth theme focuses on siblings' reports of positive perceptions and experiences with their brothers. Finally, the sixth theme presents siblings' thoughts and worries about the future.

Theme 1. Difficulties/Negative impact

Being the sibling of a child with autism can be a daunting task and at times the challenges may seem overwhelming. Yet profound feelings of empathy and compassion are also present. Undoubtedly, some circumstances are perceived as

more challenging than others. The following accounts describe siblings' thoughts, feelings, and experiences when faced with aggressive, destructive, unpredictable, and unusual behaviors.

Four of the 12 siblings interviewed in his study mentioned their brother's aggressive behavior as having a negative and stressful impact on their daily lives. Natalie describes how she has been affected by her brother's aggressive outbursts that eventually led to him being removed from the home and placed in foster care.

Natalie - It was quite difficult when he became very angry and aggressive. That was quite hard to handle and cope with In the end he started to physically damage objects. At the very end he threw the Hoover against the living room door. And he's damaged our car, a couple of times he threw his bike against the car. ...That incident with the knife was what tipped it over the edge. That's when they decided that he couldn't stay at home. ... at the end the police were being called almost every night. ...it has been quite hard. I haven't seen him since he went into foster care, which was about four months ago.

The emotional and practical challenges varied from one sibling to the next. For Evan, his brother's aggression is the source of disappointment as his efforts to interact with his brother go unrewarded. Elizabeth appears to be more affected by her brother's erratic and unpredictable behavior.

Evan - He's more violent now. ...Say if I do something wrong, and I put a piece of Lego in the wrong place he'll start shouting and going mad, and he didn't want me to put it in the wrong place but he won't be able to tell me that, so then he'll go mad, he'll smash it again and again and again until I get it perfect so that's let us down a bit.

Elizabeth - just like changes in behavior like that is difficult because you don't know how to react to it, and you don't know when it's going to stop. The things he does all the time you don't find difficult because you're so used to it.

Although all the siblings reported being affected in different ways, there were common threads throughout the interviews that tied siblings' experiences together. Emily, and William spoke about the frustration that their brothers' peculiar and at times difficult behavioral repertoires often caused them. Their reports however are all characterized by a tension between their apparent irritation and feelings of empathy

and understanding toward their brothers. The siblings recognized the emotional conflict within them.

Emily - But then, like with the habits ... Lewis started up some weird ones. ...If I've told him, like five times, I'll say, Lewis, come on, I've just told you not to do that, and he'll kind of get angry then, and I'll say, you don't have to be angry. But if he's angry with himself for doing it, like he can't stop it and he knows he shouldn't be doing it, and that's why he's angry and he gets upset sometimes, wild and stuff. And that's the hard thing to see because you know that they're trying but that it just doesn't work, something in there is making them do it.

William - Usually when he walks around playing with his hands, it's supposed to be a way he relaxes; his way of escaping all the aggro, whatever, and it makes him more relaxed. That for me gets quite annoying. I know I shouldn't get annoyed at him it's just his own little way but it does get quite annoying because if I'm trying to do homework, or I'm talking to my friends it gets a little bit annoying, so I usually say, can you please do that in the other room, but he's usually, when he's stressed out he's in a world of his own, so he won't really pay much attention.

William also commented on the stresses placed on the whole family as he recalled his parents having to go through the protracted and strenuous journey of accessing supports for his brother; a process he wishes could be made easier.

William - He had his carer before.... But that wasn't necessarily part of the system; it was sort of battled for by mum and dad, which caused a lot of stress and a lot of things. Things like making phone calls and a lot of things to do with that. It wasn't at all easy to approach, to get to the stage he's at now. So I would change that. Make it easier, the system in which to get all the support.

Another issue the adolescents reported on was the embarrassment and the predicaments presented by social situations, during a time in the adolescents' lives when the opinions of peers and others may seem to override any sense of loyalty to family members.

Anthony - If we go to a shop or something he'll just go up to people and start tapping them and pushing them out of the way, and then he walks out of the shop without paying for stuff. ...It can be embarrassing because everyone's watching.

Ethan does not want to take the chance of being mocked and ridiculed because of his brother not fitting in. He describes the emotional discord he

experiences between his efforts not to become an outcast within his peer group and his own perceptions of what is right and fair for his brother.

Ethan - I find it really difficult to walk through a town with Joseph because I feel that people are going to point and laugh because people always take the mickey out of disabled people, which is just really stupid. I just think, It's really stupid that I do, but I think, oh if I get seen with Joseph they're going to poke fun at me. ... say I was in [Town name] and say some kids who are like the cool people at school with loads of girls and they walk past and they see me with Joseph, they might think, who's that person he's with, he looks weird. And then I would just think, well sod them, but deep down I feel, oh no, I don't want them to see me.

Apart from the everyday difficulties, the adolescent siblings described stressful instances caused by what could be perceived as major incidents, which although less frequent in their occurrence than the daily problems, were of high intensity. Seeing her brother hospitalized and having to undergo comprehensive medical examinations, including blood tests, a lumbar puncture, and MRI scans after an unusually sustained episode of severe self-injurious behavior and weight-loss was a painful experience for Sophie. *Sophie - "When I had to see him in the hospital when he had his op [operation/surgery]. ...That was bad because I couldn't stay in there [hospital] because it was upsetting me too much."*

Natalie speaks about her brother's relationship with their grandmother:

Natalie - ... I remember her and the way she was with Gavin, and the effect it's had on Gavin. ...He was quite close to her. She just had this real patience ...and he used to enjoy going to talk with her. ...He would listen and try and talk things through with her.... He has some nice memories, and I do as well. ...The rest of the family, we understand that she had cancer. She died of cancer. We understood that she wasn't well and that she'd never recover from it. And when she died, we realised she's died and it was easier for us to accept than for Gavin. It was a lot harder for Gavin to accept. ... He finds it quite difficult to communicate his feelings across in a way that we would understand. I think that frustrates him that we don't know how he properly felt. ... I think that he feels as though she's just gone and she's left him; left him alone in the world, and he can't understand why [becomes emotional].

Theme 2. The impact of other people's reactions and social comparisons

The reactions of others to their brother with ASD were often unhelpful for the siblings and raised emotions of anger, frustration, and disappointment. Rhiannon finds some of her friends' behavior toward her younger brother with autism infuriating as she feels they demonstrate a lack of understanding despite having been provided with an explanation. On the other hand, she praises the conduct of a particular friend who seems to consider and appreciate John's needs.

Rhiannon - ... They sort of go, hello John, speak John, and I've explained to them loads of times that he doesn't and then it just gets me really angry then, that they don't understand. What I do like, is when one of my friends comes round and he's dead understanding with him, if he doesn't speak to him he doesn't speak to him, if he doesn't say hello, he doesn't want to, fair enough.

Siblings' unhappiness with peers' reactions toward their brother with ASD is shown further by Evan who has some strong emotional responses.

Evan - ...people I'm not sure about, people I don't really like, I don't tell them anything about my brother. Like one person called him a really nasty name. ...Called him a retarded mong cause Ryan's disabled, so I tried to grab him and I was going to hurt him ...I nearly cried, I was so upset, annoyed, I nearly cried.

Elizabeth felt that the invisible nature of her brother's condition coupled with people's ignorance led them to draw inaccurate and unfair conclusions about the cause of his challenging behavior, often attributing blame to her parents. Elizabeth feels unable to do anything else but passively resign herself to the situation.

Elizabeth - I know it sounds nasty to say about people, because it doesn't look like there is anything wrong with him, but just the way he is, when people see him walking down the street they just all look funny, it's like, why is he like that? ... If he's angry or agitated, some people will pass and say, oh, mum can't look after him. It's like parents can't look after him because he's acting like that. It's quite horrible...

In a way you just want to go up to the person and shout at them and explain, but also you feel upset because it's not nice for him... You just go along and you pretend no one's looking. That's all you can do because you can't just go up to people and shout at them, you can't do that. You just have to get on with things. That's how it's got to be.

Having to provide explanations to others was another thing siblings highlighted as difficult to deal with. Rhiannon refrains from telling her friends about her brother, as she believes that she will be misconstrued or pitied.

Rhiannon - I don't want to explain because I don't want them to feel sorry for me but they just ask silly questions and most of the time they just don't understand what you're talking about unless they do absolutely meet John.

Catrin accounts for her reticence in talking about her brother through her fear of being bullied.

Catrin - "I haven't told anybody at school, just my mates, because I know they'd take the mickey out of him, because they do that in the school anyway. ... I'd get bullied more, and things."

Ethan also finds it difficult to explain about his brother but mainly because others may not understand.

Ethan - They said to me, what's Joseph like? ... And I'm like, I don't know how to act like Joseph because I'm not Joseph and I said, the only way you will ever be able to understand what Joseph is like is if you meet him and you understand what it's actually like to be autistic. I just find it really hard to talk to people about Joseph having autism because it's so completely different to how they would live life because they probably have a completely different lifestyle to me.

Siblings often employed social comparisons, judging their personal circumstances against those of others. Rhiannon for example, longs for the sibling interaction that she believes takes place within typically developing sibling dyads, and her sense of longing increases when other siblings mention their interactions with their brother or sister.

Rhiannon - ... I was looking forward to doing all these things with him and now it seems he's just missed out on all those things, or all that's going to happen in years to come, and he's going to be older then and it's just hard. When other people are going on about their brothers and sisters, it's like, Oh.

In a similar way, Sophie finds it difficult to watch other siblings with a TD brother/sister interact, and recognizes the atypical relationship she shares with her brother Noah.

Sophie - It's very hard sometimes, because you see other brothers and sisters all just acting like brothers and sisters, if you know what I mean, having good times together. But like it's different with me and Noah, we have like play-fights and that kind of thing but it's not the same as other people, if you know what I mean.

Not all social comparisons found the adolescent siblings missing out.

Emily - ...siblings don't seem to get on when they're both in their teens, do they? They're, like, trying and keep away from each other. So, in a way, I'm grateful, because we do spend a lot of time together, or as much as we can, and we do enjoy being with each other. So I think I'd be doing less, if anything.

Theme 3. Change. Then and now: Looking back

Adolescent siblings were able to appraise their present circumstances in the context of their past. There was a sense of history, a pool of data, from which the adolescents were able to draw upon when considering their current situations. Some perceived change in a positive direction with hindsight offering the benefit of appreciation of their relationships with their brothers. Emily recalled her brother's aggressive behavior and intense tantrums, which disappeared when he entered middle childhood and Daniel has also noticed his brother's development.

Emily - ... When he was, like, three, and five and six, then he would just scream and the tantrums would be, and she'd be out with the first aid kit and towel and stuff then. He was quite violent then, as well, like he'd bite me, and hit and stuff like that. But it was just when they were younger and he hadn't been disciplined and they hadn't gotten him to himself and stuff, but then, as soon as he hit, eightish, I guess, he was fine then.

Daniel - He's more patient than he used to be. He can sit through things. ... I suppose another thing that has improved is going out for meals... now he eats more things than he used to. Overall he's just more mature. Even though mentally he's not necessarily much older he can speak in part now. If he wants something he can ask for something.

However, others like Natalie reminisced about times of closeness and connectedness that were no longer there.

Natalie - Even though he's had this awfully aggressive side, there's been another side to him where he's been absolutely lovely. There was a really loving side to him. ...When we were younger there was that lovingness, in a brother and sisterly way, although we would argue. ...There were times when he was in a

good mood when he'd want to give me hugs, and Mum often as well. That side of him was just lovely.

Ethan looked back over happy memories and enjoyment with his brother when he was not preoccupied with what others might think, although things are different now.

Ethan - When we went on holiday to Majorca we had a lot of fun in the pool because no one was around I knew, and no one could see us so I could have loads of fun. That's probably the best thing that's happened with me and Joseph for a long time since I didn't know what it was like to tell the people, I was young enough so we were basically like twins because I liked the same things he liked and we got on really well but as I grew up I became more apart.

Theme 4. Acceptance, tolerance, and wishful thinking

Having a brother with autism was something that siblings accepted to varying degrees. Whether their reports reflected strategies they used to cope with the problems they experienced, or simply a cognitive approach to evaluating and making sense of their circumstances, it appeared that siblings were expressing views on a continuum of acceptance ranging from positive acceptance, to wishing change. Five siblings openly reported wishing their brother did not have autism or the autism associated characteristics.

Rhiannon - If I had a magic wand, I'd take away the autism straightaway; and he'd go to a normal school and have friends round and things like that. That's what I'd do, straightaway.

Natalie - ...obviously I wouldn't want him to have Asperger's Syndrome. Although it's something that's happened to him, it's something he's born with. Well, I'm not sure if he was born with it, but it's something that he has and that can't be changed.

Ethan - I can cope but sometimes I really wish that I did know what it's like to live a life without a brother with autism.

Ethan went on to imagine how things might have been easier if his brother had been the younger sibling.

Ethan - Say he could start again from when he was a child so he could go back to being my little brother instead of being my older brother and I could watch him grow up and help him... If you have an older brother your older brother has to be your big brother who's bigger than you, stronger than you, better than you.

For other siblings wishing for change was related to gaining insight and an increased understanding of their brother's and their needs. The siblings' compassionate nature often drove their desire to know what it's like to be in their brother's situation and their emotional bond with their brothers drove their wishes for more intimate sibling relationships and reciprocal involvement in activities.

Natalie - I would love to read his mind. If I could read anybody's mind, I'd read his. ...But I would love to be able to know his thoughts and feelings, what he really thought about things; to be able to understand what he thought. Then we'd be able to try and properly sort things out in his head, and make him on the whole a happier person. He's very tormented; I just want him to be happy.

Elizabeth - I'd love him to be able to speak. It's upsetting that he can't, because he tries so hard to. ... I would give just his speech. That would be everything if he could just speak to me. ...For one day of my life I would like to be Oliver. I would like to know what it's like to be him, and for him to be like me, as well.

William - I wish I could go to a band with him and take him with my friends and he wouldn't be all annoying. ... I wish I could leave him to do what he wants, he's not as independent; he usually likes to tag along with me and do what I'm doing but I wish he would do what he wants by himself.

For two siblings, their brother's autism, which set him apart from others, was regarded as something positive.

Catrin - Well, he is like a normal brother to me, but it's like... I don't know. It's kind of cool that he's different, but it's like, I don't know. It's like with a normal brother, but he's got, well, he's different.

William - I really like him because I know he's got all these special needs but he's still my brother. So I still love him. ...It's quite nice knowing that your brother's special. I don't know. He's cool in his own little way.

At other times, there was evidence that siblings expressed a tension between wishing for change and what might be best for their brother.

Emily - I wouldn't want him to change, and I like him the way he is, and I wouldn't want him normal. But then, that's just the totally selfish option, isn't it, and not thinking about him, and would his life be better? Would it be better for him in this day and age if he was normal and stuff? And weighing up the pros and cons, there, like, does he really want to be that in this world right now, because, is it really that good of a place to be? And when is he happier, just in himself, and around his family, and with his Maltesers and his Coke and that kina thing, but I honestly don't know.

Albeit to varying extents, all of the adolescent siblings interviewed expressed positive views of their brothers. These included positive descriptions of their brothers' idiosyncratic behavior and personality traits, positive impact on the siblings' own characteristics, as well as accounts of positive experiences and time spent together.

Daniel - ...he's a very happy person. He's always like just generally being happy and I always think to sort of learn from that, and take after him. ... I obviously feel comfortable around other handicapped people. I know how to react because of being with Reese.

Sophie - I like it when he laughs, because he makes everybody laugh when he smiles. ...I'm glad that I've got Noah because it makes me appreciate stuff, like you shouldn't judge people on what they are and what conditions they have, or anything like that.

Ethan - He's a really nice person. He's never hurt anyone, he wouldn't bully; if he tells someone to shut up he doesn't mean it like we mean it, he means it as in he thinks that he's saying I want to watch this program, leave me alone but when he says shut up, he probably means, can you be quiet please? Sometimes he gets the giggles and he laughs for about ten minutes non-stop, really laughing, it's so funny. He says some quite funny things; he says the punch line joke to the strangest things.

Rhiannon - I like the way he plays on the computer; he's brilliant on that. He'll just press all over the screen; he's really quite remarkable. I love it when he does things like that, or when he does something new.

Emily - We went on a few holidays in the summer and they were fun because, like in Greece, we had to share a room and stuff, so we had a lot of time to ourselves and we could sit and watch these videos, and get sweets in and stuff. ...That was fun because we spent all our time in the sea together. ... Yes, the holiday was good.

Evan - He's energetic, You can go do anything with him and he won't get out of breath; he'll keep on doing it say if you go on a bike ride, go on the track or something, yeah, he won't stop, he'll keep riding and riding and riding and riding, he won't stop, so that's fun.

Theme 6. Thoughts and worries about the future: Looking ahead

Four siblings expressed concerns about what the future holds, and what their role will be in their brothers' future. While some siblings were more optimistic for their brothers' prospects than others, it was clear that for a number of siblings future concerns lay at the forefront of their minds.

William - So the first thing I've got to worry about is when he gets to high school he might get bullied and I'm hoping to go to sixth form so I'll be able to stick with him through his first year until I get a job. I'd like to see how he does in high school because if he gets bullied then I'll get, I'll kill them, no I won't I'll just hit them really bad. He shouldn't get bullied he's just different.

Rhiannon - I hope by him going to school now and getting all the help that he needs that when he is older, he is going to be able to have a job and have family and kids and be able to drive and things like that. But it won't make me sad if he couldn't like, because my mum's obviously quite old; well, she's not that old, don't tell her I said that, but when she's really old, am I going to have to look after him, which I wouldn't mind doing, but is he going to be able to look after himself? That's what worries me about it.

Emily - I know like one day I'm not going to be here, and I'm the one who's most on top of him all the time about them. And one day, I won't be. I'll be off, wherever I am, and I'm afraid they're going to get so bad and I don't want him to get all the attention when he goes out. I want him to be able to be comfortable going out into the street and being able to do things like he should be able to do and he wants to do. And I'm just afraid if he keeps on with the habits, they'll get worse and worse and worse as they progress, and then he's just not going to be able to have – well, not a normal life; he'll never have a normal life – but, kind of, just to be able to do what he wants to do without getting this attention all the time. I just want it to be okay for him.

In one instance, future care plans had been discussed in some detail within the family but there was a tension again between what the family might like and what might be best for the brother with ASD.

Emily - The plan was always he would live with mom, and then I would take care of him; and then he could come and live with me and my family. But now, as he's gotten older, we've found out about places you can go, like [name of community residential service] and all these different places where they can go and work, and they can stay in little flats with their friends, so that would give them a lot of independence, and although it scares all of us because we just want to keep him with us, and we want him to live with us and that, it's not quite the fair thing to do all the time.

Natalie expressed her fears for her brother who is placed in foster care and what the future might hold for him.

Natalie - His foster parents told him that if he was to damage anything there he wouldn't be able to stay in that place anymore, which would mean that he would have to be sectioned [detained under mental health legislation]. And I think I heard Mum talk to somebody else about that, and that really shocked me. That was quite shocking because being sectioned sounds awful. ... it just makes you think that the situation has become so severe that they've had to resort to doing that. That's quite hard to handle.

Discussion

The findings in this study offer insight into the perceptions and experiences of having a brother with ASD from the perspective of TD siblings in adolescence. In discussing the results of this research, we focus on three issues: similarities with sibling experiences reported in previous ASD research, potentially different experiences that may emerge during adolescence, and the implications of the findings both for our understanding of siblings' adjustment to children with ASD and ways of supporting siblings as they develop through childhood and adolescence.

Before discussing these issues, there are a number of methodological points worth reviewing. The influence of researchers' preconceptions on the interpretation of the data is an inevitable part of qualitative research. Group discussion within the research team led to contributions from different interpretative angles, namely, care-service, clinical psychology, and developmental psychopathology. Furthermore, although this study does not involve secondary analysis of data, it is nevertheless an attempt to analyze data after having conducted similar research with siblings in middle-childhood with a brother with ASD. We acknowledge the possible constraints this situation presents for the process of extracting original meaning from data. However, we also recognize this as a positive characteristic that allowed the researchers to enter the interpretative process with an enhanced theoretical framework.

The generalizability of these findings for siblings of children with autism more broadly needs to be considered in the context of the number of siblings participating in the study, as well as the participant demographics: all participants had a male biological sibling with an ASD, and they came from families living in the same geographic region. In addition, the majority of the siblings were older than their

brother with ASD. Previous research suggests siblings younger than the child with autism may be at increased risk for adjustment difficulties (Hastings, 2003a). Finally, gender differences did not emerge clearly as a theme in the present research or within themes. Putative gender effects could be more systematically studied in future research.

Similarities and differences with extant research

Similar findings to those reported here have been identified in previous research with siblings of children with ASD, especially reports of difficulties with their brother's/sister's aggression (Mascha & Boucher, 2006; Ross & Cuskelly, 2006), strange behavior, and feelings of embarrassment (Roeyers & Mycke, 1995). Findings from studies with siblings of children with various disabilities also identified worries about the future of their brother or sister (Damiani, 1999). Burke (2004) interviewed 22 siblings of children with a learning or physical disability and noted that the majority of the siblings expressed positive feelings about their brother and sister with a disability, and all of the siblings reported thinking about the future prospects of their brother or sister. The tension that was at times observed in the present siblings' accounts, their perception of others' negative reactions toward their brother with ASD as well as themselves, as "siblings of a child with ASD", and the value siblings placed on extended family such as grandparents, are also issues that have been identified previously in research with siblings of children with a disability (e.g., Opperman & Alant, 2003).

Our previous qualitative investigation with siblings in middle-childhood with a brother with ASD (Petalas et al., 2008) also identified some similar themes: difficulties and negative impact experienced as a result of their brother's condition;

embarrassment and others' reactions; varying degrees of acceptance and tolerance of their brothers; and positive perceptions and experiences. However, a number of qualitative differences exist within themes, as well as between themes across the two studies. For example, the adolescents' reports also demonstrate a sense of empathy when recounting the difficult nature of their brothers' difficult behaviors. This increased introspection may not be intuitively accessed in young siblings, and may have implications for the support and promotion of siblings' positive emotional wellbeing. Unlike the younger children, the adolescents compared their present and past experiences with their brothers with ASD. The influence of perceived improvement or deterioration over time in terms of siblings' thoughts and attitudes towards the future remains to be explored. In contrast to younger siblings, adolescent siblings also compared their personal circumstances against peers and other families, and expressed worries about the future of their brother with ASD and often acknowledged or assumed responsibility for this.

Implications for Practice

The few intervention studies focused on siblings of children with ASD that have been reported thus far in the literature have a strong focus on educating siblings about ASD (Howlin & Yates, 1990; Lobato & Kao, 2002; Smith & Perry, 2005). Although siblings in middle-childhood reported wishing for increased knowledge about their brother's disability (Petalas et al., 2008), within the present adolescent siblings' accounts knowledge needs did not emerge as a theme, suggesting that this may be much less relevant to adolescent siblings. This reinforces that fact that parents and professionals need to be aware of the issues siblings face at different

developmental stages and recognize that adolescent siblings will have different needs.

Two points in particular may be important for intervention designed to support adolescent siblings. First, dealing with others' reactions came through strongly in the adolescents' reports. Thus, adolescent siblings of children with ASD may benefit from support in negotiating friendships, informing others and providing explanations, as well as dealing with their own reactions (e.g., anger) that might result from such situations where others' reactions are perceived negatively. Second, future care worries also stood out within the adolescents' accounts. Parents and professionals need to acknowledge siblings' roles in their brother's or sister's future, and be able to support siblings in dealing with their concerns. Support may come in the form of encouraging open discussion in the family.

More generally, supporting siblings of individuals with ASD during adolescence is important at various practical levels. Positive relationships among siblings in middle childhood and early adolescence predict positive relationships in later adolescence (Dunn, Slomkowski, & Beardshall, 1994). Closeness of sibling relationships earlier in life may also be related to support for adults with disabilities later in life (Greenberg, Seltzer, Orsmond & Krauss, 1999). Finally, siblings in the present study referred to their shared histories with their brothers. Linking the past and present under a supportive therapeutic climate may be beneficial for siblings (Bank, 1992). Thus, practitioners working with young siblings who are experiencing difficulties in their relationships need to recognize the importance of early intervention designed to improve and facilitate harmonious sibling relationships and to ensure good outcomes longer term for individuals with ASD and their siblings.

Chapter 5. Psychological Adjustment and Sibling Relationships in Siblings of
Children With Autism Spectrum Disorders: The effects of environmental stressors
and the broad autism phenotype*

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Abstract

Research focused on siblings of children with Autism Spectrum Disorders (ASD) suggests that they may be at increased risk for behavioral and emotional problems and relatively poor sibling relationships. Bauminger and Yirmiya (2001) suggested a diathesis-stress model to guide future research on sibling adjustment in which biological-genetic vulnerability (especially the presence of Broad Autism Phenotype (BAP) features) might interact with family-environmental risk variables to explain sibling outcomes. In the present research, mothers provided data on 168 siblings between five and 17 years of age, their child with ASD, and their own psychological well-being. Sibling behavioral adjustment was found to be associated with the extent of behavior problems in the child with ASD and with the extent of the sibling's BAP. Sibling relationships were more negative when the child with ASD had more behavior problems and when there was evidence of a negative family environment (critical expressed emotion). Consistent with the diathesis-stress model, BAP interacted with family-environmental risk variables to predict sibling adjustment. Specifically, siblings with more extensive BAP characteristics who had siblings with the highest levels of behavior problems had more behavior problems themselves. Siblings with more extensive BAP characteristics who also had parents with mental health problems had more conflict in their sibling relationships.

Some siblings growing up with a brother or sister with autism may experience difficulties affecting their emotional and behavioral well-being (Hastings, 2003a; Rodrigue & Gefken, 1993; Verte, Roeyers, & Buysse, 2003), as well as their relationships (Kaminsky & Dewey, 2001) with their brother or sister with an autism spectrum disorder (ASD). However, some siblings avoid adverse adjustment outcomes, enjoying warm relationships with their brother or sister with autism (Fisman et al., 1996) and potentially deriving benefit through their unique circumstances and experiences (Hastings, 2003b; Macks & Reeve, 2007).

The variability observed in sibling adjustment, has led to a shift away from a unidirectional model focusing on the adverse impact of the child with ASD on the typically developing (TD) sibling. Researchers have increasingly adopted ecological and family systems perspectives (Fisman, et al., 1996, 2000). The role of factors such as parental and marital satisfaction (Rodrigue, Geffken, & Morgan, 1993), siblings' perception of parental partiality (Wolf et al., 1998), and family climate (Benson & Karlof, in press) has been examined. Although research conducted from a family-systems perspective improves on the simplistic model of focusing solely on the child with autism, there has been neglect of the putative impact of the genetic component that is characteristic of ASD (Folstein & Rutter, 1988). Studies comparing relatives of individuals with ASD to TD controls have described the presence of subtle features that closely resemble autistic characteristics, referred to as the Broad Autism Phenotype (BAP) (Fombonne et al., 1997; Hughes, Plumet, & Leboyer, 1999). In siblings, the BAP has been described in terms of difficulties in language, socialization, and emotional experience (Bolton, Pickles, Murphy, & Rutter, 1998; Smalley, 1995).

Bauminger and Yirmiya (2001) urged researchers to pursue a more integrated

biological-genetic and environmental-family approach to study sibling adjustment. They proposed a diathesis-stress model, highlighting the interplay between genetic liability (e.g., BAP-related impairments in problem-solving ability or social-emotional functioning), and various environmental stressors (e.g., parental availability for the TD sibling). Orsmond and Seltzer (2006), applied this diathesis-stress model to research with adolescent siblings of children with autism. They found that adolescents with a family history of ASD reported more symptoms of depression, and BAP characteristics in siblings were associated with increased anxiety and depressive symptoms in the siblings. Exposure to stressful life events also predicted sibling adjustment. Orsmond and Seltzer also reported significant interactions between sibling BAP characteristics and environmental factors. The extent of sibling depression symptoms was most pronounced when they had more autism characteristics themselves and had experienced a higher number of life events in the past year. Sibling anxiety was highest when they had more autism characteristics themselves and a mother with high levels of depression symptoms.

In the present study, our main aim was to explore the interactions between genetic liability (i.e., the BAP) and environmental stressors in predicting the adjustment of siblings of individuals with ASD and their sibling relationships. We used a psychometrically robust measure of the BAP (Autism Quotient (AQ); Baron-Cohen et al., 2006; Baron-Cohen & Auyeung, 2007), and selected environmental stressors based on previous research findings. Previous research has shown sibling adjustment to be negatively related to the behavior problems of their brother or sister with ASD (Hastings, 2007), parental psychological distress (Fisman et al., 1996, Lecavalier, Leone, & Wiltz, 2006), lower socioeconomic status (Petalas et al., in press), and negative family climate (Benson & Karlof, in press). We explored the

main and interacting effects of the BAP and environmental stressor variables and hypothesized that siblings with a more pronounced BAP alongside higher levels of environmental stress would be those with the most psychological problems themselves and less positive sibling relationships.

Method

Participants

One hundred and sixty eight families participated in the research. The parental primary caregivers were between 26 and 64 years of age, with a mean age of 42.28 years ($SD = 5.18$). Four were male, 164 were female; there were 162 mothers, four fathers, one foster parent, and one adoptive parent. In terms of their ethnicity, all stated White British, or White Irish, and one stated White and Black Caribbean. Eighty seven (51.8%) of the parents had a postgraduate or university undergraduate degree, and eighty-one (48.2%) did not have a university degree. One hundred and forty three (85.1%) parents were married and living with a spouse/partner, and 25 (14.9%) were divorced, separated, single or widowed and not living with a partner. The number of children currently living in the family home ranged from two to six (mode = 2; mean = 2.47, $SD = .69$). Eighty four (50%) parents reported a family income of above £35,000 (approximately 60-65,000 US dollars) and 82 (48.8%) reported an income below this level two parents (1.2%) did not provide any income information. Overall, 60% of parental primary caregivers also worked outside of the home. Of these, 26 worked full-time and 80 worked part-time.

The children with ASD were 138 boys and 30 girls. Their ages ranged between five and 17 years with a mean age of 10.51 years ($SD = 2.74$). Based on

parental report, 100 children had a diagnosis of autism and comorbid intellectual disability, 67 children had an Asperger syndrome diagnosis, and one child had a diagnosis of Pervasive Developmental Disorder, Not Otherwise Specified. Fifty two children were diagnosed by a clinical psychologist, 63 were diagnosed by a paediatrician, 30 children received their diagnosis through a multidisciplinary team, 13 children were diagnosed by a psychiatrist, and for 10 cases information on who provided the diagnosis was not provided. Twenty five children attended mainstream school, 87 attended mainstream school with support, 34 children attended a special school, 12 children attended a specialist autism unit in mainstream school, and 10 children attended other educational services.

The main study sample was 168 TD siblings of children with ASD. According to parental report, these siblings did not have a disability or psychiatric diagnosis. There were 85 brothers and 83 sisters of siblings of children with autism. Their ages ranged from five to 17 years (mean age = 10.54, SD = 3.41). Eighty four siblings were younger than the child with ASD, 74 were older, and eight were twins (missing data N=2). Eighty seven siblings were the same gender as the child with autism, 81 were different. There were 149 biological siblings of children with ASD, two non-biological siblings, and three half biological siblings (missing data N = 14). Sixty eight siblings attended the same school as their brother or sister with ASD, while 100 siblings attended a different school.

Measures

Five measures were used in addition to a demographics questionnaire (see Appendix J, T), which was used to collect basic background information (see Participants) about the parents, the child with ASD, and the TD sibling closest in age

to the child with ASD. As part of the demographics questionnaire, parents were asked to provide information on the total family income as a measure of socio-economic circumstances.

Behavioral and emotional adjustment. Parents completed the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997, see Appendix K,L) as a measure of emotional and behavioral adjustment for the child with ASD and the TD sibling. The SDQ is a 25 item behavioral screening measure with four problem domains, assessing Emotional problems (e.g., “often unhappy, downhearted or tearful”), Conduct problems (e.g., “often has temper tantrums”), Hyperactivity (e.g., “easily distracted”), and Peer relationship problems (e.g., “has at least one good friend”), as well as a positive behavior domain (Prosocial behavior, e.g., “Considerate of other people’s feelings”). A total difficulties score is derived by summing the total ratings of the four problem domains. The SDQ is a psychometrically robust measure and has been shown to be as effective as both the Child Behavior Checklist (Achenbach, 1991) and the Rutter Scales (Elander & Rutter, 1996) in the identification of clinically meaningful levels of behavior problems in children (Goodman, 1997). Previous research with siblings of children with developmental disabilities and children with autism and intellectual disability, using the SDQ, suggests that good levels of reliability are maintained in these populations (Hastings, 2003a; Hastings, 2007). Cronbach’s alpha coefficients for the current total sample of siblings of children with ASD and TD siblings respectively on the SDQ subscales were as follows: Children with ASD .77 for prosocial behavior, and .78 for total difficulties; TD siblings .80 for prosocial behavior, and .88 for total difficulties.

Broad Autism Phenotype in siblings. The Autism Spectrum Quotient (AQ) is a self-report measure that was originally developed to quantify autistic traits in adults

(Baron-Cohen et al., 2001). The AQ was subsequently adapted into parent/carer-report versions for adolescents aged 12+ years (Baron-Cohen et al., 2006, see Appendix M) and children aged 4 - 11 years (AQ-Child; Auyeung et al., 2007 see Appendix N), which were the versions used in this study. The adolescent version is a 50-item questionnaire, comprised of five domains: social skills (e.g., "S/he prefers to do things with others rather than on her/his own."), attention to switching (e.g., "S/he prefers to do things the same way over and over again"), attention to detail (e.g., "S/he often notices small sounds when others do not"), communication (e.g., "S/he enjoys social chit-chat"), and imagination (e.g., "If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind"), each assessed through 10 questions. The adolescent AQ has moderate to good levels of internal consistency (Cronbach's α coefficients for all five domains range from .60 to .90, and for the AQ total score .79) and high test-retest reliability ($r = .92$) (Baron-Cohen et al., 2006). Cronbach's alpha coefficients for the current sample of siblings of children with ASD for the total adolescent AQ score was .82.

The AQ-Child is also a 50-item questionnaire, comprised of the same five domains as the adolescent version, each assessed through 10 questions. The AQ-Child has good levels of internal consistency (Cronbach's α coefficients for all five domains range from .80 to .90, and for the AQ-Child total score .97) and high test-retest reliability ($r = .85$) (Auyeung et al., 2007). Cronbach's alpha coefficients for the current sample of siblings of children with ASD for the AQ-Child total score was .78.

Sibling relationship. The Sibling Relationship Questionnaire - revised (SRQ brief version, Buhrmester & Furman, 1990, see Appendix O), is a 39 item questionnaire, measuring 16 dimensions of sibling relationship contributing to four scales: Warmth/Closeness (e.g., "How much do _____ and this sibling go places and

do things together?”), Relative Status/Power (e.g., “How much does _____ tell this sibling what to do?”), Conflict (e.g., “How much do _____ and this sibling disagree and quarrel with each other?”), and Rivalry (e.g., “Who usually gets treated better by mother, _____ or this sibling?”). On the parent-report version of the SRQ, which was used in this study, the parent/carer is asked to rate how well a particular characteristic describes the relationship between two siblings on a five-point likert scale ranging from *hardly ever true* to *extremely much*. We were granted permission by the SRQ authors to adapt the wording of the questionnaire for use with a British-English speaking population, and some minor wording alterations have been made (a copy of the version used in this study is available from the first author upon request).

The SRQ brief version has been used previously in research with siblings of children with ASD (Fisman et al., 1996; Kaminsky & Dewey, 2001).

Warmth/closeness, relative status/power, and conflict are scored by summing rated items within these domains. The rivalry score is derived by averaging items for maternal partiality and paternal partiality. For participants with one parent only, the missing values were replaced with a case-wise weighted mean for completed items. Internal consistency coefficients, Cronbach’s α , for the SRQ range from .71 to .81 for children aged 8, 11, 14, and 17 years, and reported test-retest reliability is .71 (Buhrmester & Furman, 1990). Cronbach’s alpha coefficients for the current sample of sibling dyads were: Warmth/Closeness = .91, Relative Status/Power = .63; Conflict = .87, and Rivalry = .90. Given the poor reliability of the relative status/power scale, this was excluded from the statistical analyses.

Parental emotional expression (criticism). The Five Minute Speech Sample (FMSS; Magana et al., 1986) was used as a measure of the parents’ critical expressed emotion (EE) towards the child with autism and the TD sibling (i.e., emotional

climate within the family). Speech samples were collected during telephone interviews with the parent. The interviewer instructed the parent to talk uninterrupted for five minutes about their thoughts, feelings and relationship with the target child focusing on the preceding six months. Speech samples were recorded and subsequently coded using the FMSS scoring manual (Magana et al., 1986).

Categorical scores for critical climate were created by coding parents as high or borderline versus low for criticism. Negative family climate was categorized as present when parents expressed high or borderline criticism towards one or both children. A rating of high criticism applied if the parent met one or more of the following criteria: they made a negative initial statement about the target child, they described having a negative relationship with the target child or made one or more critical comments about the target child. A borderline coding applied if a parent made a comment about the target child that implied dissatisfaction but was not strong enough to be considered a criticism. Low criticism was scored where parents did not meet high or borderline ratings.

Previous research has demonstrated good agreement between EE coded from telephone interviews and face-to-face interviews (Beck et al., 2004). The FMSS possesses a good degree of correspondence with the Camberwell Family Interview (the 'gold standard' of EE measurement) and good concurrent validity and inter-rater reliability across measures (Moore & Kuipers, 1999). Good inter-rater reliability has also been found in studies of EE with mothers of individuals with autism (Percentage Agreement Index = 83.3%, kappa = .67) (Greenberg et al., 2006). In the present research, code-recode reliability (25 speech samples coded and recoded by the same person 4 weeks apart) for criticism was high (Percentage Agreement Index = 92%, Cohen's kappa = .84), as was inter-rater reliability (20 speech samples coded by

different raters) for criticism (Percentage Agreement Index = 95%, Cohen's kappa = .90).

Parental mental health. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983, see Appendix P) was used as a measure of parental mental health. The HADS is a 14-item questionnaire that can be divided into two subscales, one assessing for depression and one for anxiety, each consisting seven items. Scores from 8 to 10 on each scale represent a mild clinical disorder, scores from 11 to 21 indicate moderate clinical disorder, and scores of 16 and above are indicative of a severe clinical disorder (Zigmond & Snaith, 1983). In this study a cut-off score of 11 was employed. A dichotomous variable "parent mental health problems" was created based on whether or not the parent scored 11+ on either the anxiety or the depression subscale. Use of the HADS in previous research with mothers of children with autism has shown good internal consistency for the anxiety sub-scale ($\alpha = .90$) and the depression sub-scale ($\alpha = .82$) (Hastings, 2003c). Cronbach's alpha coefficients were also high in the present sample with .84 for the anxiety subscale and .79 for the depression subscale.

Procedure

Following receipt of ethical approval for the research, 1000 invitations (see Appendix Q, S) were given to a national autism charity to distribute amongst families who had previously attended one of their introductory support programmes. Three hundred and five families, who met the inclusion criteria (presence of a child with autism between the ages of five to 17 years, and a primary caregiver present in the home), expressed an interest in the research by returning the invitation with their personal contact details. Questionnaire packs were sent out to the families, and a

member of the research team telephoned the families for an interview with the primary caregiver. Of the 350 families who were mailed questionnaires, responses were received from 215. If questionnaires were not returned within two weeks of being sent out, a personally addressed reminder letter (see Appendix R) was mailed to the home. The present research focuses on 168 families where there was also a TD sibling between the ages of 5 and 17 years, with no known disabilities or diagnosed psychiatric disorder.

Results

All of the demographic variables described in the participants section were tested for associations with siblings' total difficulties and prosocial behavior on the SDQ, and warmth/closeness, conflict, and rivalry on the SRQ. The SDQ total difficulties score was used for the analyses, rather than any of the individual subdomains, as it demonstrated the strongest and most consistent relationships. Correlation analyses revealed a negative association between the length of time since diagnosis of the child with ASD and conflict ($r(164) = -.38, p < .001$), and rivalry scores ($r(159) = -.18, p = .023$) on the SRQ. Siblings whose parents had university level education had lower scores on SDQ total difficulties ($t(166) = 3.02, p = .003$), and also had a lower conflict score on the SRQ ($t(165) = 2.79, p = .006$). Finally, siblings older than the child with ASD had lower conflict scores on the SRQ than those who were younger ($t(155) = 2.95, p = .004$). No other relationships with demographic variables were statistically significant.

The main analyses focused on regression models. In each model, control variables were introduced (i.e., demographic variables with significant relationships with sibling dependent variables) but otherwise predictor variables were identical: sibling AQ score, child with autism SDQ total difficulties, whether the parent scored

at a clinically significant level for anxiety or depression symptoms, critical family climate, and total family income. Four interaction terms were then generated by multiplying the sibling AQ z-score with the z-scores of each of the four environmental stressors. These interaction terms were included in all regression models to test the diathesis-stress predictions.

The results of the regression analyses are summarized in Tables 5.1. and 5.2.

A number of main effect relationships were observed. Total difficulties on the SDQ of the child with ASD was a significant independent positive predictor of sibling SDQ total difficulties and conflict and rivalry in the sibling relationship, and also a negative predictor of warmth in the sibling relationship. Sibling AQ score was a positive predictor of sibling SDQ total difficulties and a negative predictor of sibling prosocial behavior.

Table 5.1. Regression analysis of Sibling total difficulties and Sibling prosocial behavior

Predictor	Sibling total difficulties ¹		Sibling prosocial behavior ²	
	β	p	β	p
Parent level of education	-.143	.099	-	-
Sibling AQ	.390	<.001	-.365	<.001
Child with ASD total difficulties	.212	.010	-.029	.740
Critical family environment	.040	.605	-.008	.921
Parent mental health problem	-.087	.274	.025	.764
Total family income	-.011	.892	.083	.323
Sibling AQ x Child with ASD total difficulties	.173	.042	-.135	.144
Sibling AQ x Critical family environment	.061	.421	.036	.656
Sibling AQ x Parent mental health problem	.049	.574	-.004	.965
Sibling AQ x Total family income	-.070	.362	.140	.093

¹ Model R = .57, R² = .33, F (10,128) = 6.17, p < .001

² Model R = .45, R² = .20, F (10,129) = 3.56, p < .001

Finally, total family income was a marginal negative predictor of conflict in the sibling relationship, and a critical family environment was also a negative predictor of conflict. Relative age of the siblings and length of time since diagnosis of the ASD child also emerged as significant independent predictors of conflict in the sibling relationship. Specifically, siblings older than the child with ASD and whose brother or sister had been longer diagnosed had less parent-reported conflict in the sibling relationship.

Table 5.2. Regression analysis of Sibling relationship factors (Warmth/Closeness, Conflict, Rivalry).

Predictor	Warmth/ Closeness ³		Conflict ⁴		Rivalry ⁵	
	β	p	β	p	β	p
Sibling relative age	-	-	-.197	.007	-	-
Child with ASD time since diagnosis	-	-	-.294	<.001	-.118	.152
Parent level of education	-	-	.018	.833	-.100	.299
Sibling AQ	.013	.832	.118	.122	.089	.311
Child with ASD total difficulties	-.192	.004	.279	.001	.204	.024
Critical family environment	-.043	.470	.242	.001	.082	.339
Parent mental health problem	.005	.930	.003	.968	-.221	.012
Total family income	-.023	.703	-.151	.062	.136	.143
Sibling AQ x Child with ASD total difficulties	-.005	.933	.012	.885	-.025	.788
Sibling AQ x Critical family environment	.027	.645	-.021	.770	-.042	.613
Sibling AQ x Parent mental health problem	.042	.550	.180	.034	-.091	.345
Sibling AQ x Total family income	.004	.942	-.039	.597	.056	.505

Two interaction terms also emerged as statistically significant predictors in the regression models: the interaction between the child with ASD's SDQ total

³ Model R = .31, R² = .10, F (9,128) = 1.49, p = .157

⁴ Model R = .64, R² = .41, F (12,123) = 7.15, p < .001

⁵ Model R = .45, R² = .20, F (11,125) = 2.86, p = .002

difficulties and sibling AQ score for sibling SDQ total difficulties, and between parent mental health problems and sibling AQ for conflict in the sibling relationship. To explore the nature of these interaction effects, the procedures outlined by Aiken and West (1991) were followed. For sibling SDQ total difficulties, values were entered into the regression equation for SDQ total difficulties of the child with ASD at high (1 SD above the mean) and low (1 SD below the mean) levels crossed with three levels of sibling AQ scores (high, low, and medium - at the mean value). The results of this analysis are displayed in Figure 5.1. Sibling SDQ total difficulties were highest when they had more autism characteristics themselves and when environmental stress was high (i.e., their sibling with ASD had a higher SDQ total difficulties score). An identical procedure was used to explore the parent mental health--sibling AQ interaction, and the results of this analysis are displayed in Figure 5.2. Parents reported more conflict in the sibling relationship when both the BAP risk (sibling AQ score) and environmental stressor (presence of parental mental health problem) were high/present.

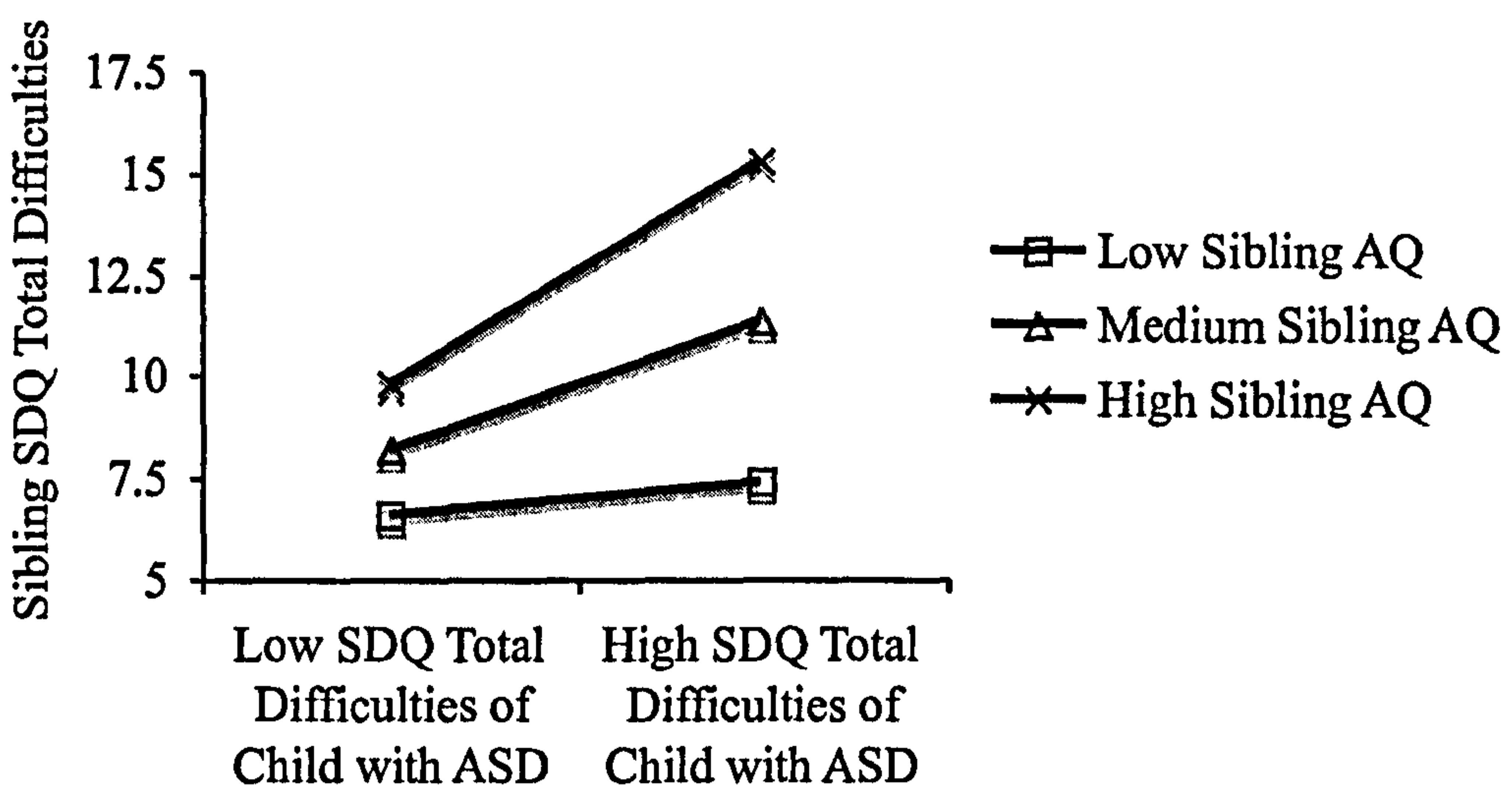


Figure 5.1 - Interpretation of the interaction between child with ASD total difficulties and sibling AQ in predicting sibling total difficulties

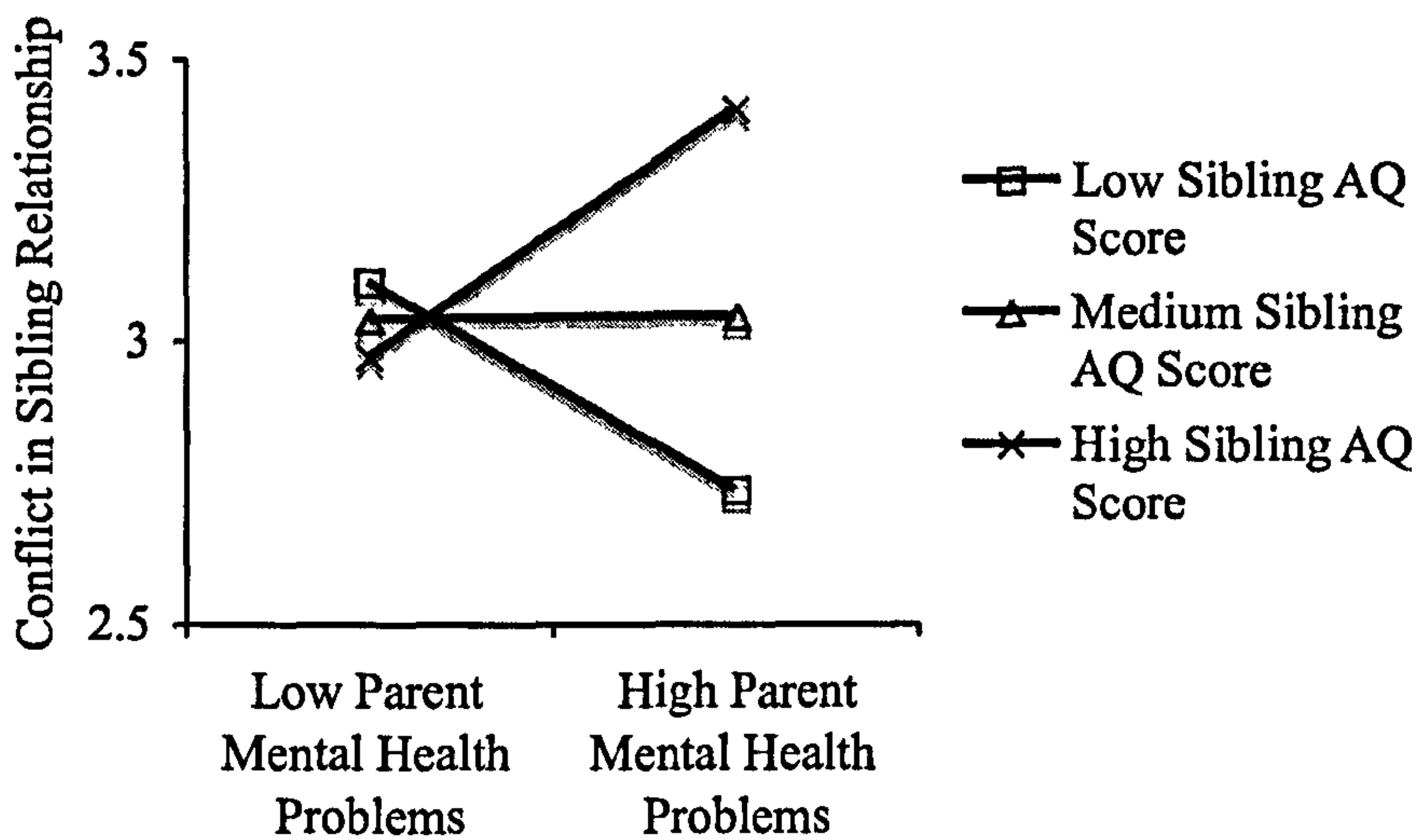


Figure 5.2 - Interpretation of the interaction between parent mental health problem and sibling AQ in predicting conflict in the sibling relationship.

Means and standard deviations on all of the sibling measures are presented in Table 5.3 below.

Table 5.3 Mean Scores and Standard Deviations of Sibling Measures.

Sibling Measures	Mean	SD
Sibling total difficulties	9.70	7.19
Sibling prosocial behavior	8.06	2.10
Sibling AQ	37.44	19.01
Warmth/ Closeness	2.27	.66
Conflict	2.99	1.06
Rivalry	0.42	0.41

Discussion

The results of the present research both replicate and extend previous research findings. First, the behavior problems of the child with ASD were a predictor of increased behavior problems in siblings (cf. Hastings, 2007), and also predicted less reported warmth and more conflict and rivalry in the sibling relationship. Second, demographic factors were predictive of sibling conflict. Specifically, the longer the time since the child with ASD had received a diagnosis the less sibling conflict was reported (cf. Ferrari, 1984), and when siblings were younger than the child with ASD more conflict was reported between siblings.

Original findings resulted from our exploration of critical family environments (as assessed with the Five Minute Speech Sample), and sibling BAP. When mothers were rated as critical towards either their child with ASD, their sibling, or toward both children, more conflict was reported between the siblings. The BAP had both main and interacting effects. Thus, those siblings with a more pronounced BAP also had increased behavior problems and reduced prosocial behavior scores, although sibling BAP was not predictive of sibling relationship quality in any domain. The main effect in the prediction of sibling behavior problems was moderated by the extent of the behavior problems of the child with ASD such that siblings with higher BAP scores and a brother or sister with more behavior problems were most at risk of behavior problems themselves. There was also an interaction between sibling BAP and the presence of parental health problems such that siblings with higher BAP scores and parents with likely mental health problems were reported to have more conflict in their relationships with their siblings.

The interaction effects between BAP and environmental risk variables (behavior problems of the child with ASD, and parent mental health) were consistent

with the predictions from a diathesis-stress model (Bauminger & Yirmiya, 2001). Thus, this model is worthy of more attention in research on sibling adjustment and sibling relationships in families of children with ASD. In the present research, the exact processes by which risk variables contribute to negative sibling adjustment, decreased prosocial behavior, and difficulties in the sibling relationship are not clear. To establish causal links between risk factors and adjustment outcomes future research needs to explore how changes in a given risk variable temporally precede changes in the outcome variable using longitudinal designs (Hastings, 2007). A further limitation of the current study is that parents provided data on their own mental health as well as reporting on the child with ASD and their sibling. Thus, source variance is likely to be a problem and multiple sources of data including potentially secondary caregiver/fathers' reports and siblings' self-reports need to be explored in future research.

Implications for practice

The findings from the present research suggest that siblings of children with autism who have features characteristic of autism themselves may find it especially difficult to cope with environmental stressors in the home. When their siblings have significant behavior problems and their parents have mental health difficulties siblings with a significant BAP may struggle to cope, and this is reflected in their own behavioral adjustment and their relationship with their sibling. A negative family environment, in the form of significant levels of parental criticism may also place siblings at risk for poorer sibling relationships. The implications of these results are twofold: for the identification of siblings at risk, and the design of sibling support interventions.

In terms of identifying siblings of children with ASD who may be at risk of problems themselves, practitioners might consider systematic measurement of sibling BAP using a reliable tool. Similarly, when a critical family environment, parent mental health problems, or ASD child problem behaviors are present in the family, practitioners should consider the potential risks to siblings. In terms of support, developing resilience in the form of social skills and stress coping skills may be an important intervention target for siblings. It is also possible that psychoeducational support would be of assistance. Specifically, increased understanding of autism and associated difficulties (e.g., behavior problems) and the potential impact on their own parents' health may help siblings to cope more effectively when members of their family are suffering significantly.

Our results further stress the importance of family-centered approaches to clinical intervention because of the inter-relationships between the well-being of different family members (also see Hastings et al., 2005). Clinical assessment and intervention should focus on the family system rather than individual members, taking into account the interconnectedness of family subsystems. The present results suggest that siblings are likely to benefit from interventions not necessarily aimed directly and solely at them. Thus, improving behavior problems in the child with ASD, treating parental mental health problems such as anxiety or depression, and promoting positive parent-child interactions, might all have benefits for sibling well-being and positive sibling relationships.

* Chapter 6. General Discussion.

Growing up with a brother or sister with ASD, like any other sibling experience, vacillates between highs and lows. Their lives are closely linked and interrelated; they share genes and environment, and inevitably influence each other throughout their development. This thesis has attempted to expand upon the existing knowledge base on sibling adjustment and relationships, where one child has ASD. In the introduction (Chapter 1), a review of extant literature was conducted, and methodological considerations were noted. Four empirical investigations followed (Chapters 2, 3, 4, 5,) addressing issues previously unexplored, or adding to the evidence where that is still thin on the ground. This discussion will provide a summary of the findings, and outline the implications of this thesis as a whole, for future research and practice within the field.

The literature review presented in Chapter 1 showed that existing research on the adjustment and relationships of siblings of children with ASD lacks consensus, and interpretation of the outcomes is convoluted by researchers often applying standards of experimental designs where such do not apply. In this context, the usefulness of correlational designs was also discussed, before findings from research on intervention and support for siblings of children with ASD were summarised. The chapter concluded by outlining methodological issues that merit consideration in future research with siblings of children with ASD, some of which we addressed in the following chapters.

In Chapter 2, a group comparison analysis of the emotional and behavioural adjustment between siblings of children with autism and intellectual disability, and siblings of children with ID only, was performed in an effort to establish whether the difficulties observed in some siblings of children with autism are attributed to the

autistic characteristics per se or to the associated ID in the child with autism and ID.

According to this analysis, siblings of children with autism and ID had increased emotional difficulties compared with the comparison group (ID only) as well as

normative data that were available from typically developing children in the UK.

Furthermore, in common with previous research, correlation analyses revealed that certain variables, namely: having a brother with autism, being younger than the child with autism, the increasing age of the child with autism (as the child with autism grew older), and socioeconomically deprived familial circumstances, were associated with increased adjustment difficulties in siblings of children with ASD. In acknowledging methodological limitations of this research, the role of the broader autism phenotype (BAP) was considered.

The qualitative interview studies described in Chapters 3 and 4, present two exploratory, empirical investigations into the subjective accounts of siblings growing up with a brother with ASD. Using a semi-structured interview format, siblings were asked about their relationships and experiences with their brother with ASD. In Chapter 3, our analysis of siblings' accounts, in middle childhood, identified five main themes: 1) the impact of their brother's condition on their lives, 2) the attitudes of others, 3) their own feelings of tolerance and acceptance towards their brothers 4) positive attitudes and experiences, and 5) useful support for themselves and their brothers.

In Chapter 4, our analysis of the adolescent siblings' accounts identified six main themes: 1) the difficulties and negative impact of their brother's condition, 2) others' reactions that negatively affected them, 3) their shared histories with their brothers 4) their own feelings of acceptance towards their brothers, as well as wishes for certain things to be different, 5) positive perceptions and experiences with their

brothers, and 6) thoughts and worries about the future. Taken together the findings from these two studies add a developmental dimension to the research area, which is indicative of qualitative differences in the perceptions and experiences of having a brother with ASD between siblings in middle childhood and adolescence. These issues are discussed in more detail in the following section, which outlines theoretical implications.

The purpose of the study presented in Chapter 5 was to examine a diathesis-stress model of sibling emotional and behavioural adjustment and relationships. The conceptual model tested the main effect contribution of environmental factors, and a genetic factor (the BAP), as well as their interaction on sibling adjustment and relationship outcomes. The results showed that increased autistic characteristics in the siblings predicted reduced levels of sibling prosocial behaviour, and increased emotional and behavioural problems in the siblings. Higher emotional and behavioural problems of the children with ASD significantly predicted more emotional and behavioural problems in the siblings and reduced warmth/closeness in the sibling relationship, as well as increased conflict and rivalry in the sibling relationship. Furthermore, there was evidence that autistic characteristics in the siblings moderated the relationship between emotional and behavioural problems in the children with ASD and emotional and behavioural problems in the siblings, as well as the relationship between parent mental health problems and emotional and behavioural problems in the siblings. A number of environmental variables were shown to be significant predictors of sibling relationship outcomes, namely, being younger than the child with ASD predicted increased conflict in the sibling relationship. Both the recency of the diagnosis of the child with ASD, and a critical family environment also predicted increased conflict in the sibling relationship, and

more parental mental health problems predicted increased levels of rivalry in the sibling relationship.

Theoretical implications

Taken together the findings from chapters 2 through 5 point to the need for a more elaborate multi-component conceptual model of sibling adjustment, which incorporates systemic influences (e.g. parent-child relationship, sibling relationship, peer relationship), environmental factors (e.g. socioeconomic status, parent mental health) and genetic predisposition (e.g. BAP). Sociodemographic factors such as sibling relative age, or family socioeconomic status were highlighted as important components of such a model. For example, if a younger sibling, growing up with an older brother or sister with ASD, is denied his or her status as the youngest or is deprived of parental time and attention, this may lead to adjustment difficulties. Low socioeconomic circumstances might place further strain on a family that is already dealing with stressful circumstances with a child with ASD. Additional help might not be affordable, and siblings and other family members might take on increased responsibilities that weigh down on them both physically and emotionally.

In Chapters 3 and 4 siblings expressed some of the demands and difficulties associated with having a brother with ASD. While these accounts reflect personal perspectives and subjective experiences, it is not unlikely that such negative experiences might at times lead to transitory feelings of anger, hostility, or resentment. Siblings facing difficulties in dealing with their brother's or sister's behaviour that lack the necessary support and guidance to effectively deal with these problems, run the risk of turning to short term coping strategies that may not be the most beneficial in the longer term. For example, siblings may adopt passive coping

mechanisms such as not communicating their distress and isolating themselves from family and friends. Despite the difficulties reported by siblings, and in line with some existing research literature, siblings expressed positive acceptance, remarkable tolerance and maturity, and a sense of responsibility and pride for their brothers with ASD. These findings may possibly account for some of the variation encountered in the literature on sibling adjustment outcomes. Even seemingly positive attributes in the TD siblings, such as increased maturity may not necessarily buffer against difficulties of growing up with a brother or sister with ASD; some siblings might choose to stay insulated from peers and ordinary adolescent affairs if they feel their interests are not on a par with those of their peers.

As siblings enter adolescence a different set of dynamics emerges. Normal teenage concerns surface in the context of having a brother or sister with ASD. If adolescents feel embarrassed about having a brother or sister with a disability they may feel rejected by their peers. At a time when peer relationships play an important role in the adolescent's development, TD siblings of children with ASD may perceive their brother or sister with ASD as a burden; this, in turn, may raise feelings of guilt. Peer relationships may also be negatively affected through learned maladaptive behaviour patterns that a sibling may acquire via his/her interaction with the child with ASD. Younger siblings especially are ideally placed to imitate the behaviour of their older brother/sister with ASD. On the other hand, Knott et al., (2007) reported TD siblings of children with autism to stage-manage their interactions with their brother or sister with ASD more often than TD siblings or siblings of children with Down syndrome. Such behaviours, if generalized outside the home environment, may undermine relationships of a more egalitarian standing and cause difficulties with peers.

The notion that siblings may themselves be at the far end of the continuum of the autism phenotype, implies that they, too, may be affected by some of the problems that are more evident in the child with ASD. There is a paucity of empirical research exploring whether or not the difficulties observed in some siblings are related to genetic or environmental factors; the research presented in Chapter 5 highlighted the potentially negative contribution of autistic characteristics that may be present in some siblings who might be described as being on the higher end of the BAP. Adjustment difficulties in TD siblings who are already genetically predisposed to difficulties in social communication and social interactions, may be exacerbated in a family environment with a brother or sister with significant behaviour problems, and a parent who also has difficulties. Once again these problems may interfere with the development of peer relations at various stages in life. On the counter side, a healthy familial environment, may buffer against psychological difficulties for siblings already at risk because of their genetic predisposition.

Mental health problems in a parent may compromise their capacity to offer a secure attachment relationship. Previous research with siblings of children with disabilities has shown how maternal negativity has been associated with increased internalizing difficulties in the TD sibling and conflict in the sibling relationship (McHale & Gamble, 1989). Parental criticism might reflect the primary parental caregiver's attempts to cope with behaviour of the child with ASD or the TD sibling. A critical parent may be inadvertently modelling and reinforcing beliefs and behaviours that negatively affect siblings' coping and adjustment and their relationship with their brother/sister with ASD. The theoretical framework presented in figure 6.1. below, offers an outline of a proposed theoretical model of sibling adjustment that may be used to guide future research with siblings of children with

ASD. The model incorporates socioeconomic, cultural, family systemic, individual and genetic factors that might impact on sibling adjustment and the sibling relationship. As a conceptual framework, this model is not meant to be a comprehensive, exhaustive account of the factors contributing to sibling adjustment. Rather, it serves as a useful paradigm to guide future research with siblings. The model points to the importance of studying the interrelationship of constellation, genetic, and psychological factors. Central to this model is the premise that cognitive appraisal is a common final pathway through which the relationship between different variables, and sibling adjustment outcomes might be mediated. Methodological complexities notwithstanding, this model places high priority on future research investigating the role of cognitive appraisal in sibling adjustment. One way to achieve this would be through the integration of quantitative and qualitative research, which may help explicate the mechanisms underlying adjustment outcomes.

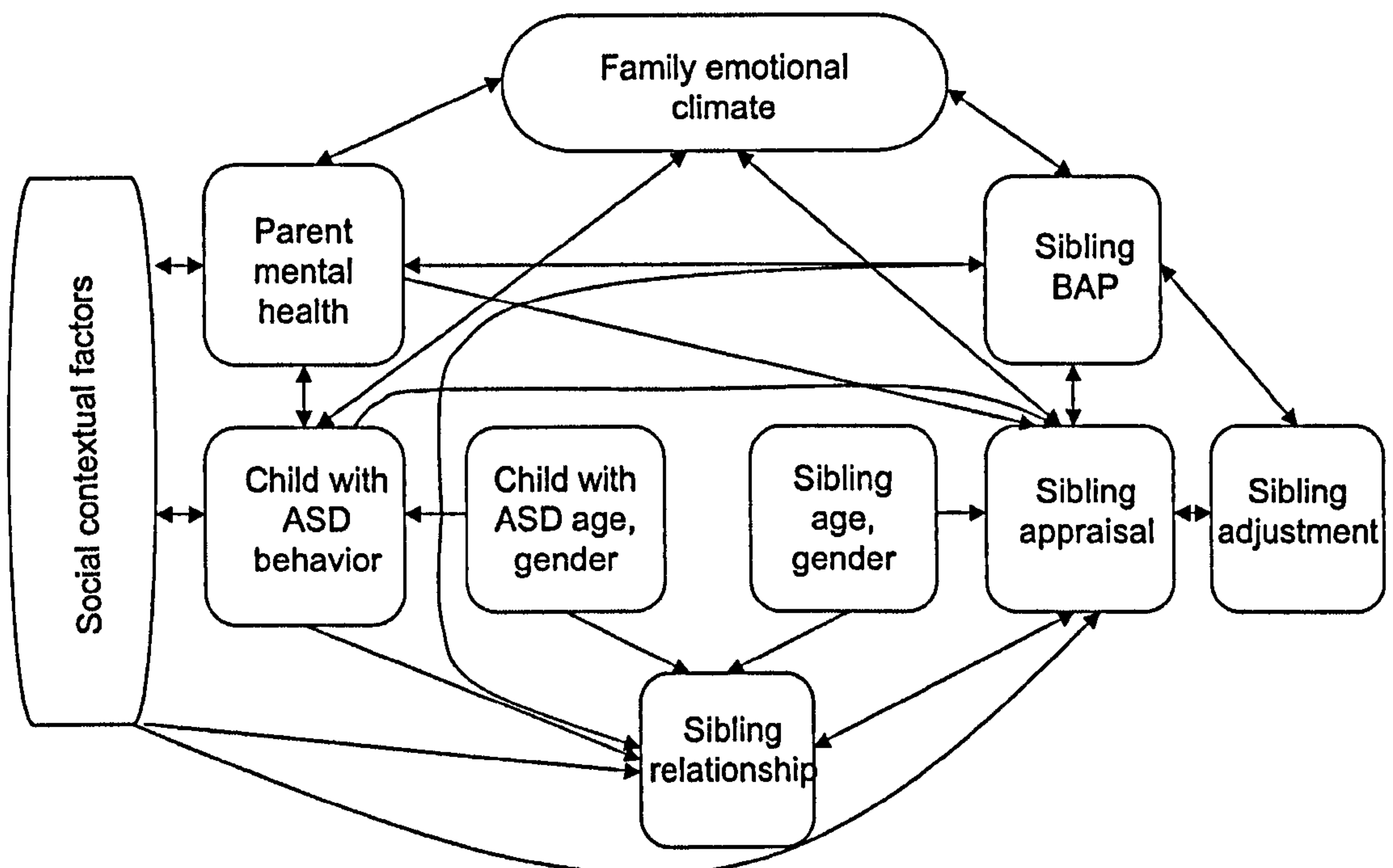


Figure 6.1. Proposed theoretical model for the adjustment of siblings of children with ASD.

Implications for research

The interests of researchers focusing on sibling well-being in the childhood years typically encompass two areas, that is, to establish how the TD siblings is adjusting to having a brother or sister with ASD, and secondly to determine how the sibling relationship is affected. Methodological issues have been raised in the introduction (Chapter 1) and throughout this thesis including the need to focus on single diagnostic groups; consider developmental trends and longitudinal research designs; include multiple sources of information and methods of data collection; and use reliable and valid measuring instruments. We also discussed the potential pitfalls of the experimental design paradigm, which uses control or comparison groups to reduce the number of alternative explanations for a given effect, in research with siblings of children with ASD. On these grounds we questioned the rationale and implications of group comparison studies comparing siblings of children with ASD to other sibling groups on different outcomes of adjustment. This is not to suggest that group comparison designs are not important tools, in fact a comparison design is employed in Chapter 2 of this thesis to address a very important question; however, researchers should be aware of their limitations in the context of sibling adjustment research. There are good reasons why researchers should be cautious when concluding that sibling adjustment is compromised in families with a child with ASD: Despite numerous papers showing negative adjustment outcomes for siblings, there appears to be little in the way of longitudinal research, which could provide better evidence for causality. There is therefore a grave risk of inadvertently conveying the message that the child with autism is the root cause for siblings' adjustment difficulties. Moreover, it is often unclear whether the difficulties in siblings are directly related to the child

with ASD, especially since plausible alternative mechanisms such as the BAP remain under-researched.

Future research investigating the adjustment of siblings of children with ASD has much ground still to cover. As next steps researchers may want to explore what factors are associated with positive adjustment outcomes; In addition, rather than asking whether siblings of children with ASD differ from other sibling groups and TD children, more salient questions include, which specific autistic characteristics of the child with ASD are associated with sibling adjustment, and what particular effects these have on which siblings in the family? Systems outside the family including, friends, the neighbourhood, school, and support services, should be explored as potential buffers or risk factors for sibling adjustment. The family climate may act to either enhance or compromise sibling adjustment and this needs further exploration.

The question of whether some siblings are more primed through their genetic predisposition to encounter difficulties needs to be addressed further . While the findings from this study go some way toward answering this question, future replication is required. Furthermore, one cannot be certain that a questionnaire measuring autistic traits in the siblings (such as the one employed in chapter 5) unequivocally reflects a genetic predisposition; other alternatives are plausible, for example, in younger siblings of children with autism, autistic characteristics might to some extent represent learned behaviour if the sibling is imitating their older brother or sister with ASD. Further to corroborating this evidence base, researchers need to make use of alternative robust methodologies for establishing genetic susceptibility. If siblings who score higher on the BAP run an increased risk for adjustment difficulties, what are the processes through which siblings are affected by this genetic liability? If indeed genetic liability is implicated in sibling adjustment, are analogous

processes at play with parents (some of whom might also score on the higher end of the BAP continuum)? And, what is the role of a positive or negative sibling relationship on siblings' adjustment? Most importantly, when attempting to address any of these pertinent questions, they should be considered over the course of time, longitudinally, possibly even beyond childhood and adolescence.

Finally, what is conspicuously absent from this thesis is the voice of the child with ASD. To date much has been written about sibling relationships and adjustment where one child has an ASD. Interestingly, while the child with ASD is clearly a major stakeholder in the dyadic relationship, there are no studies on sibling adjustment that incorporate the perspective of the child with ASD, along with the views expressed by the TD siblings. Future research should endeavour to address this lack of first-hand information.

Implications for practice

There are currently a number of services operating (though not systematically) sibling support groups in the UK. These take different forms and are usually dependant on limited funding that prevents their long-term continuity. Given the lack of funding and available literature, sibling supports are at present being carried out by well-meaning but often inexperienced staff who are ill-educated about siblings' needs. Regrettably, there is little published research evaluating the effectiveness of sibling support services. In most cases if there is an evaluation process, this often involves obtaining descriptive reports from the siblings or parents, without the use of psychometrically robust outcome measures. This self-perpetuating situation is likely to continue because of the lack of research output to draw attention to the benefits of specific support services. In a classic catch-22 situation, funding to set up and

evaluate sibling supports is in short supply, partly due to the dearth of empirical evidence that can be used to convince commissioning bodies.

The combined practical implications derived from the empirical papers described in Chapters 2 through 5, point to a number of practical implications. Clinicians need to support siblings in attaining a realistic and accurate understanding of their brother or sister with ASD, while also recognizing that siblings may have needs of their own beyond those imposed by a child with ASD in the family. Parents and professionals should be aware of siblings' feelings of love and anger, embarrassment, guilt and protection, worries and concerns about their brother's or sister's and their own future, to be able to reassure siblings that such responses are both common and natural. Equally important is to support siblings with their own thoughts and feelings, which will constantly change and at times be filled with tension and ambivalence. Providing siblings with simple, age appropriate information from early-childhood and allowing them to talk openly about their fears and confusion could resolve many difficulties and promote positive appraisals. Such practices also help with dealing with the curiosity of their peers. As the sibling develops into adolescence and grows capable of more abstract thought and comprehension of complex issues, more expanded information should be made available.

If the child with ASD poses major management problems this may be stressful for parents, who might be negatively reinforced to socially restrict or isolate themselves and as a result the other children in the family. There is therefore a need to continue to educate the wider public about autism and to challenge misperceptions. Clinicians may also benefit siblings through family oriented intervention, such as communication and problem solving training; teaching family members to effectively negotiate with one another about plans for family activities.

Some parents may benefit from learning to use behavioural techniques to promote positive relationships between the child with ASD and the TD sibling, and to recognise and subsequently alter antecedents and maintaining consequences of problem behaviours. With the right guidance and support, siblings too may acquire the skills to apply behaviour management techniques for the child with autism. This may help both reduce problem behaviour in the child with autism as well as increase a sense of mastery and self-efficacy and positive sibling interaction. Such interventions however should be undertaken only after a careful assessment of the impact that any additional pressure may place on the sibling.

Some siblings might benefit from social-problem solving skills if they themselves have difficulties in social interactions with peers, or in order to manage peers' reactions to their brother or sister with ASD more effectively. Some siblings might be genetically predisposed to having serious difficulties and would encounter problems with or without the presence of the child with ASD. Professionals working with families with a child with ASD should approach sibling adjustment with an open mind, avoiding readily attributing difficulties in the siblings to the child with ASD. Internalizing difficulties, such as depression and anxiety as well as more specific emotions such as guilt, that may interfere with siblings' well-being, lend themselves well to cognitive behavioural or counselling intervention. Clinicians may examine irrational thoughts and negative appraisals that siblings might have surrounding their sense of self and others, the implications of their brother's/sister's disability, and what lies ahead in the future. The combined findings from the four chapters in this thesis strongly suggest that sibling supports do not focus narrowly on producing positive change in isolated areas of concern, rather, a thorough assessment of broader family dynamics is undertaken prior to any support or service provision. Intervention or

supports offered to siblings and their families therefore need to address as much the individual's as the family's needs, stretching as far as the social environment; clinicians should be cognisant of the interrelatedness of various domains, which may encompass factors such as, the school environment, parent mental health, and the sibling relationship. Figure 6.2. gives a graphic representation of this multi-component model for service provision. Importantly, the need for evaluation of any such support-provision for siblings of children with ASD cannot be overemphasized. There are currently too few studies on interventions designed to enhance positive outcomes for siblings and families where there is a child with ASD.

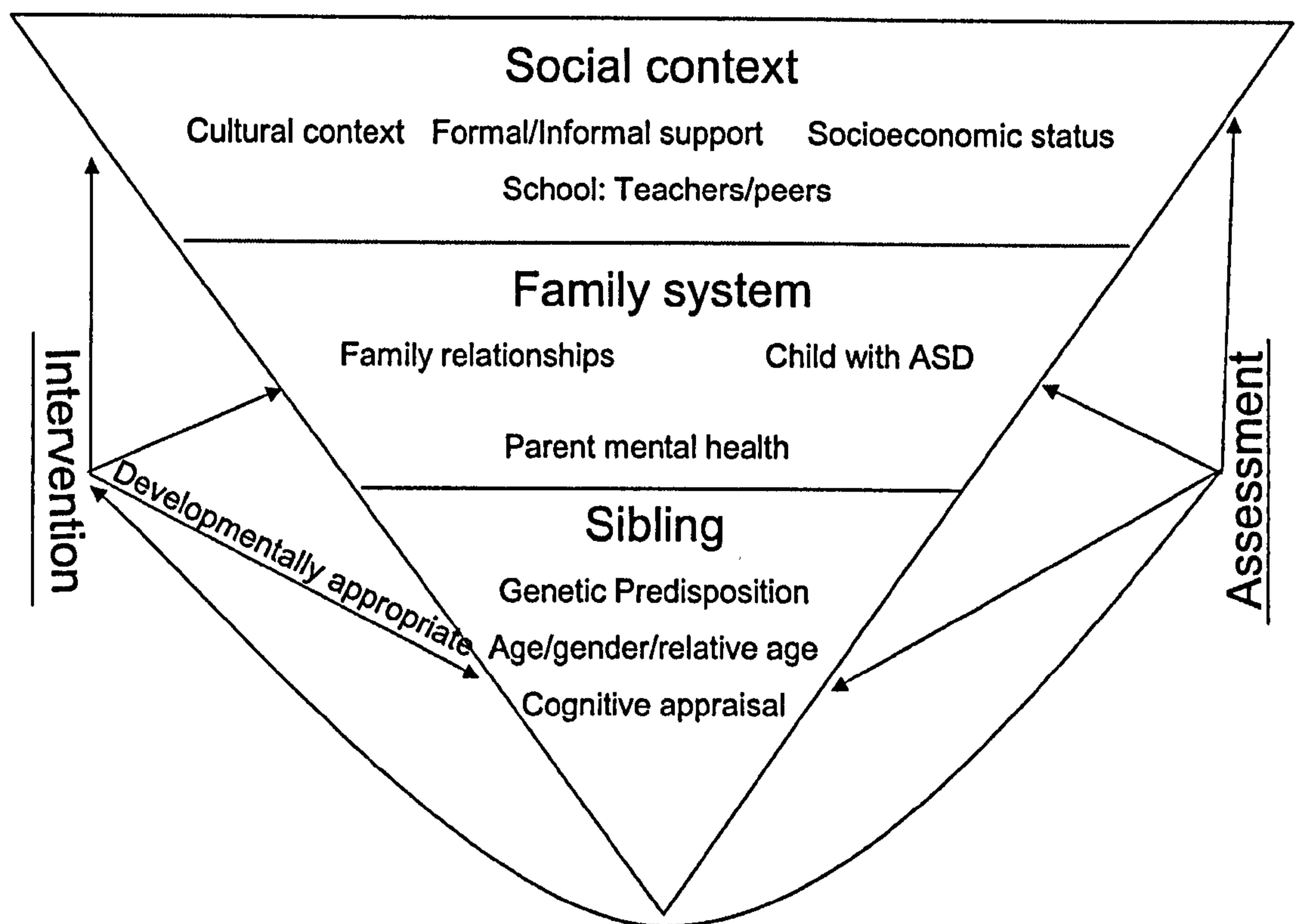


Figure 6.2. A model of multi-component assessment and intervention for siblings of children with ASD.

One of the strengths of this thesis is that it allows siblings of children with ASD to

offer their valuable insights. Part of our research focuses on the experiences and appraisals of child siblings, however, the chronic prognosis of ASDs extends well beyond the childhood years; the transcript below presents the content of an e-mail sent to us by an adult sibling (names have been changed to protect anonymity). What is remarkable is how close the themes from this research resonate to many of the observations Michelle makes, such as: strong positive feelings about her brother with ASD, also the tension with difficult aspects of the relationship (especially relating to behavioural challenges), and her disappointment and anger at other people's responses, as well as an increased awareness and acceptance of disability and difference.

Dear Prof. Hastings,

My mother pointed out your research into how siblings of ASD are affected in 'Communication' magazine and I thought an email may help your research in some small way. I realize I am out of your stated age bracket at 22 years old but I thought you may still be interested.

I am the youngest of three children and the only daughter. My eldest brother, Jake, is roughly 5 years older than me (now aged 28) and my other elder brother, Nick, is roughly 3 years older than me (now aged 25). Nick has severe ASD - he has little or no language, major behavioural difficulties with some violent tendencies and requires 24-hour care (preferably two to one).

I have always considered my relationship with my brother complicated. I love him, and find many of his eccentricities a small and innocent joy. However, being ever smaller than him I was always the easiest target for when he was frustrated or angry, and I inevitably bore the brunt of some of his physical frustrations. As a little

girl this naturally scared me and even now I find that I purposefully avoid him or be unnecessarily tense when Jane is upset.

My parents also naturally had to put Nick first in many situations, even if it was just to calm him down or make sure he was happy. Being the youngest, it did used to grate on me that he got everything first, but as I grew older I fully understood why and became less selfish.

Due to these reactions I have never really had a very close relationship with Nick - my eldest brother Jake dotes upon him and my parents are his carers, but I always feel a certain distance between us. However, I believe that being a sibling of a person with ASD has made me a better person. Without him I do not believe that I would've known about ASD or the disgusting challenges that the disabled and family of the disabled have to overcome to gain the basic rights they deserve. I believe that discrimination of the disabled (and particularly mental disabilities) is sadly the last great discrimination left unheeded, and it absolutely horrifies me.

I am terrifically loyal to my brother - whenever I see anybody roll their eyes at him as he gently pushes them out of his way, or snigger at the noises he makes, or even if they dare to point or make gestures, I am pulling at the leash to show them just exactly why this behaviour will not be tolerated by me. My brother may be different and he may be mentally disabled, but he will never hurt anybody intentionally and that already means he is a better person than they could ever be.

My parents are both wonderful people - my mother became Nick's full-time carer as soon as it became apparent he would never be able to care for himself, and my father's decent enough wage allowed him to retire a few years ago to help my mother every day. They have taught me the value in everyone and how never to make assumptions about people. They are the most selfless and loving parents I could ever

imagine, and their efforts to ensure their son is cared for when they are gone are heart-wrenchingly ignored by ignorant and coin-counting councils (at least, our council is!). I hope this brief email scratches the surface for you in your attempt to better research the affect ASD has upon the entire family. I am happy to help you more if you so wish it.

Best of luck!

Kind Regards,

Miss Michelle Brown

In the chapters that precede this discussion a number of questions were raised, some were answered, and some remain. Our findings add to the current state of the research literature examining sibling adjustment where one child has an ASD. Up to this point the field has lacked a clear specification model for the adjustment siblings of children with ASD. The empirical findings presented in this thesis provide a substantial basis for proceeding towards a model of sibling adjustment, by purporting the importance of individual-constellation, environmental and systemic, developmental and genetic influences on indices of behavioural adjustment and relationships in siblings of children with ASD. Such a model has both research as well as clinical utility.

This research employs a mixed methods design with qualitative research, using semi-structured interviews with siblings of children with ASD, alongside quantitative statistical analysis. The advantages of mixed methods research include the reduction of methods-induced bias, methodological complementarity, corroboration of evidence, and expansion of ideas (Greene et al., 1989). Paradigmatic differences aside, the methodological pluralism employed here offered effective

answers to the research questions. The interpretative phenomenological analysis (IPA) used in Chapters 3 and 4 granted us access to the siblings' personal categories of meaning. We were able to gain detailed insight into complex, dynamic phenomena, such as the sibling relationship, and siblings' experiences with their brothers in the context of ASD. The results offered a number of potential hypotheses as to how and why outcomes of adjustment may vary across siblings, which may be explored in future research.

On the other hand, the statistical analyses used in Chapters 2 and 5 produced findings that we were able to generalize and use to make predictions across the sibling population who have a brother or sister with ASD. We were able to test theories (i.e. whether the difficulties in siblings are accounted for by autism or the associated intellectual disability (ID) in the child with autism and ID - Chapter 2) and models (diathesis-stress model - Chapter 5), and our results were free from our own interpretations and biases.

The experiential element added through the face-to-face interviews with the siblings in Chapters 3 and 4, and the telephone interviews with the primary parental caregivers in Chapter 5, gave meaning to the numbers; it offered the author of this thesis insights and understanding that extend well beyond a necessary conceptual framework required to carry out research in this specialized area.

Nietzsche (1891, as cited in Yalom, 2008) put forward the idea that a tree, by weathering storms, sinks its roots deep into the earth, growing stronger and taller. The concept serves as a powerful reminder that adverse experience may leave one stronger and more resilient to adversity. While there is still much work left to be done in terms of gaining an understanding of the factors and processes affecting sibling adjustment, some siblings will be positively shaped and toughened by their experiences; they will

learn how to cope with difficulties, develop a broader understanding of the human condition, and attain resourceful coping strategies that will serve them well throughout life.

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*, 237-254.
- Abrams, J., & Kaslow, F. W. (1976). Learning disability and family dynamics: A mutual interaction. *Journal of Clinical Child Psychology, 5*, 35-39.
- Achenbach, T. M. (1991). *Manual for the Child Behaviour Checklist*. Burlington: University of Vermont, Department of Psychiatry.
- Achenbach, T. M., & Edelbrock, C. S. (1983). *Manual of the Child Behaviour Checklist and Revised Child Behaviour Profile*. Burlington: University of Vermont.
- Achenbach, T. M., & Edelbrock, C. S. (1979). The child behaviour profile-II. Boys aged 12-16 and girls aged 6-11. *Journal of Consultant and Clinical Psychology, 47*, 223-233.
- Achenbach, T. M., & Resclora, L. A. (2001). *Manual for ASEBA school-age forms and profiles*. Burlington, VT: University of Vermont, Research Centre for Children, Youth, and Families.
- Adams, M. E. (1969). Siblings of the retarded: their problems and treatment. In W. Wolfensburger & R. Kurtz (Eds.), *Management of the family of the retarded* (pp. 444-452). Chicago: Follett Educational Corporation.
- Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park, CA: Sage.
- American Psychiatric Association. (1980). *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision). Washington, DC: American Psychiatric Association.
- August, G., Stewart, M. A., & Tsai, L. (1981). The incidence of cognitive disabilities in siblings of autistic children. *British Journal of Psychiatry, 138*, 416-422.
- Auyeung, B., Baron-Cohen, S., Wheelwright, S., Allison, C. (2007). The Autism Spectrum Quotient: Children's version (AQ-child). *Journal of Autism and Developmental Disorders, 38*, 1230 - 1240.
- Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population based study. *Journal of Mental Deficiency Research, 35*, 291-307.
- Bägenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population based study. *Journal of Mental Deficiency research, 35*, 291-307.
- Bailey, A., Palferman, S., Heavey, L., & Le Couteur, A. (1998). Autism: The phenotype in relatives. *Journal of Autism and Developmental Disabilities, 28*, 369-392.

- Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: Towards an Investigation of clinical, genetic neuropsychological and neurobiological perspectives. *Journal of Child Psychology and Psychiatry*, 37, 89-126.
- Bailey, T., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., & Rutter, M. (1995). Autism as a strongly genetic disorder: Evidence from a British twin study. *Psychological Medicine*, 25, 63-77.
- Baird, T. D., & August, G. J. (1985). Familial heterogeneity in infantile autism. *Journal of Autism and Developmental Disorders*, 15, 315-321.
- Bank, S. (1992). Remembering and reinterpreting sibling bonds. In F. Boer and J. Dunn. (Eds.), *Children's Sibling Relationships: Developmental and Clinical Issues* (pp. 139-151). Erlbaum, Hillsdale, NJ.
- Barbour, R. S. (2000). The role of qualitative research in broadening the 'evidence base' for clinical practice. *Journal of Evaluation in Clinical Practice*, 6, 155-163.
- Baron-Cohen, S., Hoekstra, R. A., Knickmeyer, R., & Wheelwright, S. (2006). The autism-spectrum quotient (AQ) - Adolescent version. *Journal of Autism and Developmental Disorders*, 3, 343-350.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism Spectrum Quotient (AQ): Evidence from Asperger syndrome/high functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 33, 5-17.
- Bauminger, N. & Yirmiya, N. (2001). The functioning and well-being of siblings of children with autism: behavioral-genetic and familial contributions. In J. A. Burack, T. Charman, N. Yirmiya & P. Zelazo (Eds.), *The Development of Autism: Perspectives from Theory and Research*. (pp. 61-80). Lawrence Erlbaum. Mahwah: NJ
- Beck, A., Daley, D., Hastings, R. P. & Stevenson, J. (2004). Mothers' expressed emotion towards children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 48, 628-638.
- Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. *Journal of Pediatric Nursing*, 22, 410-418.
- Benson, P. R., & Karlof, K. L. (in press). Child, parent and family predictors of latter adjustment in siblings of children with autism. *Research in Autism Spectrum Disorders*.
- Bishop, D. V. M., Maybery, M., Wong, D., Maley, A., & Hallmayer, J. (2006). Characteristics of the broader phenotype in autism: A study of siblings using the children's communication checklist. *American Journal of Medical Genetics Part B (Neuropsychiatric Genetics)*, 141B, 117-122.
- Blackledge, J.T., Hayes, S. C. (2006). Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child and Family Behavior Therapy*, 28, 1-18.
- Bolton, P. F., Pickles, A., Murphy, A., & Rutter, M. (1998). Autism, affective and psychiatric disorders: Patterns of familial aggregation. *Psychological Medicine*, 28, 385-395.

- Bongers, I. L., Koot, H. M., van der Ende, J., & Verhulst, F. C. (2003). The normative development of child and adolescent problem behavior. *Journal of Abnormal Psychology, 112*, 179-192.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness in family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*, 722-730.
- Brady, A., Hoffman, C. D., & Sweeney, D. P. (2005). *Level of autism and sibling adjustment: parent and sibling reports*. Poster presented at the meeting of the Western Psychological Association, Portland, OR.
- Breslau, N. (1982). Siblings of disabled children: Birth order and age spacing effects. *Journal of Abnormal Child Psychology, 10*, 85-96.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*, 87-108.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Buhrmester, D. (1992). The developmental course of sibling and peer relationships. In F. Boer and J. Dunn. (Eds.), *Children's Sibling Relationships: Developmental and Clinical issues* (pp. 19-40). Erlbaum, Hillsdale, NJ.
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development, 61*, 1387-1398.
- Burke, P. (2004). *Brothers and Sisters of Disabled Children*. London: Jessica Kingsley Publishers.
- Burke, P., & Elliott, M. (1999). Depression in pediatric chronic illness: A diathesis-stress model. *Psychosomatics, 40*, 5-17.
- Burke, P., & Montgomery, S. (2000). Siblings of children with disabilities: A pilot study. *Journal of Learning Disabilities, 4*, 227-236.
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today, 11*, 461-466.
- Carradice, A., Shankland, M. C., & Beail, N. (2002). A qualitative study of the theoretical models used by UK mental health nurses to guide their assessments with family caregivers of people with dementia. *International Journal of Nursing Studies, 39*, 17-26.
- Celiberti, D. A., & Harris, S. L. (1993). Behavioural intervention for siblings of children with autism: A focus on skills to enhance play. *Behaviour Therapy, 24*, 573-599.
- Cherry, D. B. (1989). Stress and coping in families with disabled children: Application to a model in pediatric therapy. *Physical and Occupational Therapy in Pediatrics, 9*, 11-32.
- Clark, L. M., Cunningham, J. L., & Cunningham, C. E. (1989). Improving the social behaviour of siblings of autistic children using a group problem solving approach. *Child and Family Behaviour Therapy, 11*, 19-33.
- Cohen, J. (1988). *Statistical Power Analysis for the Behavioural Sciences* (2nd edition). New York: Academic Press.
- Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*, 155-159.

- Colletti, G., & Harris, S. L. (1977). Behaviour modification in the home: Siblings as behaviour modifiers, parents as observers. *Journal of Abnormal Child Psychology*, 5, 21-20.
- Constantino, J. N., Lajonchere, C., Lutz, M., Gray, T., Abbachi, A., McKenna, K., Singh, D., & Todd, R. D. (2006). Autistic social impairment in the siblings of children with pervasive developmental disorders. *American Journal of Psychiatry*, 163, 294-296.
- Cox, A. H., Marshall, E. S., Mandlco, B., & Olsen, S. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, 9, 397-413.
- Creak, M., & Ini, S. (1960). Families of psychotic children. *Journal of Child Psychology and Psychiatry*, 1, 156-175.
- Crnic, K. A., Freidrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency*, 88, 125-138.
- Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological Issues. *International Journal for the Advancement of Counselling*, 21, 111-124.
- Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers and siblings. *American Journal of Mental Retardation*, 108, 234-244.
- Damiani, V. B. (1999). Responsibilities and adjustment in siblings of children with disabilities: Update and review. *Families in Society: Journal of Contemporary Human Services*, 80, 34-40.
- D'arcy, F., Flynn, J., McCarthy, Y., O'conner, C., & Tierney, E. (2005). Sibshops: An evaluation of an interagency model. *Journal of Intellectual Disabilities*, 4, 227-236.
- Dellve, L., Cernerud, L., & Hallberg, L. R.-M. (2000). Harmonizing dilemmas: Siblings of children with DAMP and Asperger syndrome's experiences of coping with their life situations. *Scandinavian Journal of Caring Sciences*, 14, 172-178.
- Donovan, A. M. (1988). Family stress and ways of coping with adolescents who have handicaps: maternal perceptions. *American Journal of Mental Retardation*, 92, 502-509.
- Dorris L., Espie, C. A. E., Knott, F., & Salt, J. (2004). Mind reading difficulties in the siblings of people with Asperger's syndrome: Evidence for a genetic influence in the abnormal development of a specific cognitive domain. *Journal of Child Psychology and Psychiatry*, 45, 412-418.
- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9, 416-427.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2, 97-110.

- Dunn, J. (1992). Sisters and brothers: Current issues in developmental research. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 1-40). Hillsdale, NJ: Erlbaum Associates.
- Dunn, J., & Plomin, R. (1990). *Separate Lives: Why Siblings Are So Different*. New York: Basic.
- Dunn, J., Slomkowski, C., & Beardsahl, L. (1994). Sibling relationships from the preschool period through middle childhood and early adolescence. *Developmental Psychology, 30*, 315-324.
- Dunn, J., Slomkowski, C., Beardsahl, L., and Rende, R. (1994). Adjustment in middle childhood and early adolescence: links with earlier and contemporary sibling relationships. *Journal of Child Psychology and Psychiatry, 35*, 491-504.
- Eisenberg, L., & Kanner, L. (1956). Early infantile autism, 1943-55. *American Journal of Orthopsychiatry, 26*, 556-566.
- Elander, J., & Rutter, M. (1996). Use and development of the Rutter Parents' and Teachers' scales. *International Journal of Methods in Psychiatric Research, 6*, 63-78.
- Elliot, R., Fisher, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., et al. (2001). The prevalence of challenging behaviors: A total population study. *Research in Developmental Disabilities, 22*, 77-93.
- Evans, J., Jones, J., and Mansell, I. (2001). Supporting siblings: Evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour. *Journal of Intellectual Disabilities, 5*, 69-78.
- Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings - I. Chronically ill boys. *Journal of Child Psychology and Psychiatry, 25*, 459-476.
- Fisman, S., Wolf, L., & Noh, S. (1989). Marital intimacy in parents of exceptional children. *Canadian Journal of Psychiatry, 34*, 519-525.
- Fisman, S., & Wolf, L. (1991). The handicapped child: Psychological effects of parental, marital, and sibling relationships. In M. M. Konstantareas & J. H. Beitchman (Eds), *The Psychiatric Clinics of North America, Pervasive Developmental Disorders, 14*, 199-217.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry, 45*, 369-375.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 1532-1541.
- Folstein, S., & Rutter, M. (1988). Autism: Familial aggregation and genetic implications. *Journal of Autism and Developmental Disorders, 18*, 3-30.
- Fombone, E., Bolton, P., Prior, J., Jordan, H., & Rutter, M. (1997). A family study of autism: Cognitive patterns and levels in parents and siblings. *Journal of Child Psychology and Psychiatry, 38*, 667-638.

- Fombone, E., Simmons, H., Ford, T., Meltzer, H., & Goodman, R. (2001). Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 820-827.
- Furman, W., & Buhrmester, D. (1992). Age and sex differences in perceptions of networks of personal relationships. *Child Development*, 63, 103-115.
- Gamble, W., & Woulbroun, E. J. (1993). Measurement considerations in the identification and assessment of stressors and coping strategies. In Z. Stoneman & P. W. Berman (Eds.), *The effects of mental retardation, disability and illness on sibling relationships: Research issues and challenges* (pp. 287-319). Baltimore: Paul H. Brookes.
- Gas, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry*, 48, 167-175.
- Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, 50, 937-948.
- Gillberg, C., & Wing, L. (1999). Autism: not an extremely rare disorder. *Acta Psychiatrica Scandinavica*, 99, 399-406.
- Glasberg, B. A. (2000). The Development of siblings understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 30, 143-156.
- Glaser, B., & Strauss, A. (1991). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23, 147-163.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire. *Journal of Child Psychology and Psychiatry*, 40, 791-799.
- Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of American Academy of Child and Adolescent Psychiatry*, 40, 1337-1345.
- Greenberg, J. S., Seltzer, M. M., Hong, J. & Orsmond, G. L. (2006). Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*, 111, 229-249.
- Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Influences on current involvement and the expectation of future caregiving responsibility. *Psychiatric Services*, 50, 1214-1219.
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*, 11, 255-274.
- Harris, S. L., & Glasberg, B. E. (2003). *Siblings of Children with Autism: A Guide for Families*. Bethesda, MD: Woodbin House.
- Harter, S. (1985). *Manual for the Self-Perception Profile*. Denver: University of Colorado

- Harter, S., & Pike, R. (1983). The pictorial scale of perceived competence and social acceptance for young children denver, CO: University of Denver.
- Hastings, R. P. (2003a). Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 33*, 99-104.
- Hastings, R. P. (2003b). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disabilities, 33*, 141-150.
- Hastings, R. P. (2003c). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*, 231-237.
- Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders, 37*, 1485-1492.
- Hastings, R. P. (2008). Stress in parents of children with autism. In E. McGregor, M. Nunez, K. Williams, & J. Gomez (Eds.), *Autism: An Integrated View* (pp. 303-324). Oxford: Blackwell.
- Hastings, R. P., Beck, A. & Hill, C. (2005). Positive contributions made by children with intellectual disability in the family. Mothers' and fathers' perceptions. *Journal of intellectual disabilities, 9*, 155-165.
- Hastings, P. R., & Brown, T. (2002). Behaviour problems of autistic children, parental self-efficacy and mental health. *American Journal on Mental Retardation, 107*, 222-232.
- Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and Expressed Emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*, 48-61.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An Experiential Approach to Behaviour Change*. New York: Guilford.
- Haynes, S. N. (1992). *Models of causality in psychopathology. Toward dynamic, synthetic and nonlinear models of behaviour disorders*. Toronto: Maxwell Macmillan Canada.
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*, 847-882.
- Holroyd, J. & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down syndrome and childhood autism. *American Journal of Mental Deficiency, 80*, 431-436.
- Howlin, P., & Yates, P. (1990). A group for the siblings of children with autism. *Communication, 24*, 11-16.

- Hughes, C., Plumet, M., & Leboyer, M. (1999). Towards a cognitive phenotype for autism: Increased prevalence of executive dysfunction and superior spatial span amongst siblings of children with autism. *Journal of Child Psychology and Psychiatry*, *40*, 705-718.
- Jarrett, N., Payne, S., Turner, P., & Hillier, R. (1999). 'Someone to talk to' and 'Pain control': what people expect from a specialist palliative care team. *Palliative Medicine*, *13*, 139-144.
- Kaminsky, L., & Dewey, D. (2001). Sibling relationships of children with autism. *Journal of Autism and Developmental Disorders*, *33*, 1679-1690.
- Kaminsky, L., & Dewey, D. (2001). Sibling relationships of children with autism. *Journal of Autism and Developmental Disorders*, *33*, 399-410.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, *43*, 225-232.
- Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*, *27*, 39-57.
- Kazak, A. E. (1989). Families of chronically ill children: A systems and social ecological model of adaptation and challenge. *Journal of Consulting and Clinical Psychology*, *57*, 25-30.
- Kazdin, A. E., Kraemer, H. C., Kessler, R. C., Kupfer, D. J., & Offord, D. R. (1997). Contributions to risk factor research to developmental psychopathology. *Clinical Psychology Review*, *17*, 375-406.
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry*, *6*, 965-976.
- Knott, F., Lewis, C., & Williams, T. (2007). Sibling Interactions of Children with Autism: Development over 12 months. *Journal of Autism and Developmental Disorders*, *37*, 1987-1995.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., & Plien, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, *22*, 205-216.
- Kolvin, I. (1971). Studies in childhood psychoses: Diagnostic criteria and classification. *British Journal of Psychiatry*, *118*, 381-384.
- Konstantareas, M. M. (1991). Autistic, learning disabled and delayed children's impact on their parents. *Canadian Journal of Behaviour Science*, *23*, 358-375.
- Kovacs, M. (1992). *The children's depression inventory: Manual*. North Tonawanda, NY: Multi-Health Systems, Inc.
- Kovacs, M., & Beck, A. T. (1977). An empirical clinical approach toward a definition of childhood clinical depression. In J. G. Schulterbrandt & A. Raskin (Eds.), *Depression in childhood: Diagnosis treatment and conceptual models* (pp. 1-25). New York: Raven.
- Kraemer, H. C., & Blasey, C. M. (2004). Centring in regression analyses: A strategy to prevent errors in statistical inference. *International Journal of Methods in Psychiatric Research*, *13*, 141-151.
- Larson, R., Richards, M. H., Moneta, G., Holmbeck, G., & Duckett, E. (1996). Changes in adolescents' daily interactions with their families from ages 10 to

- 18: Disengagement and transformation. *Developmental Psychology*, 32, 744-754.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability research*, 50, 172-183.
- Lloyd, T., & Hastings, R. P. (2008). Psychological process variables as correlates of adjustment in mothers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52, 37-48.
- Lobato, D. J., & Kao, B. T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, 27, 711-716.
- Lobato, D. J., & Kao, B. T. (2005). Brief report: Family based group intervention for young siblings of children with chronic illness and developmental disability. *Journal of Pediatric Psychology*, 30, 678-682.
- Losh, M., & Piven, L. (2007). Social-cognition and the broad autism phenotype: identifying genetically meaningful phenotypes. *Journal of Child Psychology and Psychiatry*, 48, 105-112.
- Macks, J. R., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, 37, 1060-1067.
- Magana, A. Goldstein, J. Karno, M. Miklowitz, D., Jenkins, J. & Fallon, I. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research*, 17, 203-212.
- Mandleco, B., Olsen, S., Dyches, T., & Marshall, E. (2003). The relationship between family and sibling functioning in families raising a child with a disability. *Journal of Family Nursing*, 9, 365-396.
- Marsch, H. W. (1992). Self Description Questionnaire (SDQ) I: A theoretical and empirical basis for the measurement of multiple dimensions of preadolescent self-concept. An Interim test manual and research monograph. MArthur, New South Wales, Australia: University of Western Sydney, Faculty of Education.
- Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *British Journal of Developmental Disabilities*, 52, 19-28.
- Mates, T. E. (1990). Siblings of autistic children: Their adjustment at home and in school. *Journal of Autism and Developmental Disorders*, 20, 545-553.
- McCubbin, H.I., & Patterson, J.M. (1983). Family stress and adaptation to crisis: A Double ABCX Model of family behavior. In D. Olsen & B. Miller (Eds.), *Family studies review yearbook* (p. 87). Beverly Hills, CA: Sage.
- McHale, S. M., & Gamble, W. C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. *Developmental Psychology*, 25, 421-429.

- McHale, S. M., Kim, J., & Whiteman, S. D. (2006). Sibling relationships in childhood and adolescence. In P. Noller, & J. A. Feeney (Eds.), *Close relationships: Functions forms and processes* (pp. 127-149). New York, NY: Psychology press.
- McHale, S., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of siblings with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disabilities, 16*, 399-413.
- McKiney, B., & Patterson, R. A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Medicine, 12*, 133-150.
- Meltzer, H., Gatward, R., Goodman, R., & Ford, F. (2000). *Mental Health of Children and Adolescence in Great Britain*. London: HMSO.
- Miller, P. (2001) A study into the experiences of children who have a brother or sister with Autistic Spectrum Disorders. *Good Autism Practice, 2*, 13-27
- Minton, J., Campbell, M., Green, W. H., Jennings, S., & Samit, C. (1982). Cognitive assessment of siblings of autistic children. *Journal of the American Academy of Child Psychiatry, 21*, 256-261.
- Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. *Child Development, 56*, 289-302.
- Moore, E. & Kuipers, E. (1999). The measurement of expressed emotion in relationships between staff and service users: The use of short speech samples. *British Journal of Clinical psychology, 38*, 345-356.
- Morgan, S. B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders, 18*(2), 263-280
- Moser, M. R., Paternite, C. E., & Dixon, W. E, Jr. (1996). Late adolescents' feelings toward parents and siblings. *Merrill-Palmer Quarterly, 42*, 537-553.
- O'Hara, D. M., & Levy, J. M. (1984). Family adaptation to learning disability: A framework for understanding and treatment. *Learning Disabilities, 3*, 63-77.
- Opperman, S., & Alant, E. (2003). The coping responses of the adolescent siblings of children with severe disabilities. *Disability and Rehabilitation, 25*, 441-454.
- Orsmond, D. I., & Seltzer, M. M. (2006). Adolescent siblings of individuals with autism: A dathesis-stress model of the genetic vulnerability on well-being. Poster presented at the International Meeting for Autism Research, Montreal, Canada.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research, 51*, 682-696.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities, 13*, 313-320.
- Ozonoff, S., Rogers, S. J., Farnham, J. M., & Pennington, B. F. (1993). Can standard measures identify subclinical markers of autism? *Journal of Autism and Developmental Disorders, 23*, 429-441.
- Petalas, A. M., Hastings, R. P., Nash, R., Dowey, A., & Reilly, D. (Under review). "I like that he always shows who he is": The Perceptions and Experiences of

- Siblings with a Brother with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*.
- Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., and Dowey, A. (in press). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism*.
- Piers, E. V., & Harris, D. B. (1969). Piers-Harris Self-Concept Scale. Los Angeles, CA: Western Psychological Services.
- Pilowsky, T., Yirmiyia, N., Shalev, R. S., & Gross-Tsur, V. (2003). Language abilities of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 44, 914-925.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45, 855-865.
- Piven, J., Gayle, J., Chase, G. A., Fink, B., Landa, R., Wzorek, M. M., & Folstein, S. E. (1989). A family history study of neuropsychiatric disorders in the adult siblings of autistic individuals. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 177-183
- Piven, J., Palmer, P., Jacobi, D., Childress, D., & Stephan, A. (1997). Broader autism phenotype: Evidence from multiple incidence autism families. *American Journal of Psychiatry*, 154, 185-190.
- Plumet, M. H., Goldblum, M. C., & Leboyer, M. (1995). Verbal Skills in relatives of autistic females. *Cortex*, 31, 723-733.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression for research in the general population. *Applied Psychology Measures*, 1, 385-401.
- Radloff, L. S. (1991). The use of the Center for Epidemiological Studies Depression Scale in adolescents and young adults. *Journal of Youth and Adolescence*, 20, 149-166.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33(4), 383-394.
- Rivers, J. W., & Stoneman, Z. (In press). Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*.
- Rodrigue, J. R., Geffken, G. R., & Morgan, S. B. (1993). Perceived competence and behavioural adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23, 665-674.
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19, 371-379.
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1992). Psychosocial adaptation of fathers of children with autism, Down syndrome and normal development. *Journal of Autism and Developmental Disorders*, 22, 249-263.
- Roeyers, H., & Mycke, K. (1995). Siblings of children with autism, with mental retardation, and with a normal development. *Child: Care, Health and Development*, 21, 305-319.

- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters with autistic spectrum disorder. *Journal of Intellectual and Developmental Disabilities, 31*, 77-86.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10*, 65-84.
- Royers, H., & Mycke, K. (1995). Siblings of children with autism, with mental retardation, and with a normal development. *Child: Care, Health and Development, 21*, 305-319.
- Rutter, M. (1993). Resilience: some conceptual considerations. *Journal of Adolescent Health, 14*, 626-631.
- Sanders, J. L., & Morgan, S. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behaviour Therapy, 19*, 15-32.
- Scribman, L., O'Neill, R. E., & Koegel, R. L. (1983). Behavioral training for siblings of autistic children. *Journal of Applied Behavior Analysis, 16*, 129-183.
- Seltzer, M. M., Abbeduto, L., Kraus, M. W., Greenberg, J., & Swe, A. (2004). Comparison groups in autism family research: Down syndrome, Fragile X syndrome, and schizophrenia. *Journal of Autism and Developmental Disorders, 34*, 41-48.
- Sheehan, G., Darlington, Y., Noller, P., Feeney, J. A. (2004). Children's perceptions of their sibling relationships during parental separation and divorce. *Journal of Divorce and Remarriage, 41*, 69-94.
- Sibs (2008). Developing a service for siblings of disabled children. Retrieved October 4, 2008, from <http://www.sibs.org.uk/>
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 3*, 155-169
- Smalley, S. L., & Asarnow, R. F. (1990). Brief Report: Cognitive subclinical markers in autism. *Journal of Autism and Developmental Disorders, 20*, 270-278.
- Smalley, S. L., McCracken, J., & Tanguay, P. (1995). Autism, affective disorders, and social phobia. *American Journal of Medical Genetics (Neuropsychiatric Genetics), 60*, 19-26.
- Smith, J. A., Harre, R., & Van Langenhove, L. (1995). *Rethinking Methods in Psychology*. London: Sage publications Inc.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and methods* (219-240). London: Sage Publications.
- Smith, T., & Perry, A. (2005). A sibling support group for brothers and sisters of children with autism. *Journal on Developmental Disabilities, 11*(1), 77-88.
- Sparrow, S.S., Balla, D. A., & Cicchetti, D. V. (1984). *The Vineland Adaptive Behaviour Scale* (Interview edition survey form). Circle Pines, MN: American Guidance Service.
- Stoneman, Z. (1989). Comparison groups in research on families with mentally retarded members: A methodological and conceptual review. *American Journal of Mental Retardation, 94*, 195-215.

- Strain, P. S., & Danko, C. D. (1995). Caregivers' encouragement of positive interaction between preschoolers with autism and their siblings. *Journal of Emotional and Behavioral Disorders, 1*, 2-12.
- Summers, C. R., White, K. R., & Summers, M. (1994). Siblings of children with a disability: A review and analysis of the empirical literature. *Journal of social behavior and personality, 9*, 169-184.
- Sweeney, D. P., & Hoffman, C. D. (2004). Research issues in Autism Spectrum Disorders. In R. B. Rutherford, M. M. Quinn, & S. R. Mathur (Eds.), *Handbook of research in emotional and behavioral disorders* (pp. 302-317). New York: Guilford.
- Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities, 37*, 410-420.
- Thompson, A. B., Curtin, M. E., & O'Rear, M. R. (1994). The psychological adjustment of well siblings of chronically ill children. *Child Health Care, 23*, 211-226.
- Tomblin, B. J., Hafeman, L. L., & O'Brien, M. (2003). Autism and autism risk in siblings of children with specific language impairment. *International Journal of Language & Communication Disorders, 3*, 235-250.
- Updegraff, K. A., McHale, S. M., & Crouter, A. C. (2002). Adolescents' sibling relationship and friendship experiences: Developmental patterns and relationship linkages. *Social Development, 11*, 182-204.
- Van der Steene, G. (1998). *Unpublished Dutch Version of the Self-Description Questionnaire II* (ed. H. W. Marsh). Research Group Psychodiagnostic and Psychopathology, K. U. Leuven, Belgium.
- Verte, S., & Roeyers, H. (1998). *Unpublished Dutch Version of the Self-Description Questionnaire I* (ed. H. W. Marsh). Research Group Developmental Disorders, Ghent University, Belgium.
- Verte, S., Roeyers, H., & Buysse, A. (2003). Behavioral problems, social competence and self concept in siblings of children with autism. *Child: Care, Health & Development, 29*(3), 193-205.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*, 115-130.
- Williams P. D., Williams, A., Graff, J., Hanson, S., Stanton, A., Hafeman, C., Lieberman A., Leuenberg, K., Karlin-Setter, R., Ridder, I., Curry, H., Barnard, M., & Sanders, S. (2002). Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioural Medicine, 25*, 411-424.
- Wolf, L., Fisman, S., Ellison, D., & Freeman, M. D. (1998). Effect of sibling perception of differential parental treatment in sibling dyads with one disabled child. *Journal of American, Academic Child and Adolescent Psychiatry, 37*, 1317-1325.
- Wolf, L., Noh, S., Fisman, S., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental disorders, 19*, 157-166.

- Yalom, I. D. (2008). *Staring at the Sun: Overcoming the Dread of Death*. London: Piaktus Books.
- Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361 – 370.

Appendix A
Sibling Interview Protocol

Prior to commencing the interview session

1. Introduce yourself and tell the sibling a little about the interview process.
2. Obtain consent from the sibling and assure the sibling that everything they tell you will be treated confidentially.
3. Set up the required equipment and ask if the sibling is ready for you to begin.

Interview process and questionsIntroductory questions

- a. How old are you?
 - b. When is your birthday?
 - c. What year are you in school?
 - d. What is your favourite TV programme?
 - e. What is your favourite subject in school?
 - f. What is your favourite school holiday?
 - g. What do you like to do in free time?
 - h. Who are your friends?
-
- i. How old is.....?
 - j. When is 's birthday?
 - k. What year is in school?
 - l. What is 's favourite TV programme?
 - m. What is 's favourite subject in school?
 - n. What is 's favourite holiday?
 - o. What does like to do in free time?
 - p. Who are 's friends?

Sibling's concept of autism

I'd like you to tell me what you already know about autism; how would you describe autism to someone who had never heard it before.

- How do people get autism? Can you get rid of it?

How would things be different for If he/she didn't have autism?

When grows up how will he/she be different than he/she maybe would be if he/she didn't have autism.

- Ok, is there any other way would be different if he/she didn't have autism?

Do you ever talk with your friends about

- Why not/ how do you explain 's autism to them?
- How do you think they think/ would think?
- How do you feel about that?
- Is there anything you would like other people to know about.....?

Do you ever talk with your parent(s) about ?

- What kind of stuff do you talk about?

Sibling relationship

Tell me what it's like to be 's brother/ sister?

- Is there something you find difficult/ that bothers you about.....?
- Is there something you really like about

How much time do you spend with each other?

- (If not much) can you think of why that is?
- Did you used to spend more or less time together in the past? - (If yes - why do you think that was?)

What's it like for you when your friends meet

- Would you be happy to tell me a little more about that?

What good/ or fun things have happened to you with Recently?

What things have been difficult for you recently?

What kind of things do you do together?

Is there something you like doing best with.....?

Is there something you don't like to do with.....?

Is there anything you wish you could do with

- If didn't have * what other things would you do together?

If you could wave a magic wand would you change anything about?

- Is there anything you wish you could change for

What advice would you give to other brothers/ sisters of siblings with autism?

Are there any other questions that you think I could ask other brothers/sisters about growing up with a brother/sister with autism?

Is there anything else you would like to tell me?

At the end of the interview

1. Talk about how the information you acquired from the sibling will be used to help you design a larger study that might help siblings of children with autism.
2. Retell the story of the sibling in summary form emphasizing the positive features of both the sibling and the child with autism.
3. Thank the sibling for sharing his/her experiences with you.

* The interviewer will have obtained information on the terminology used within the home and between family members to refer to the condition of the child with autism.

Appendix B
Information Sheet for Families

Study Title

The Wales Study of Siblings of Children with Autism.

Project Team

Michael Petalas, Research Student

Richard Hastings, Professor of Psychology

Alan Dowey, Clinical Psychologist

Susie Nash, Postdoctoral research officer

The research is a collaboration between the University of Wales, Bangor and the National Autistic Society (NAS) Cymru, who are part funding the research along with the European Social Fund.

What is the purpose of the study?

We are interested in listening to what siblings of children with autism have to say about their experience of living with their brother or Sister with autism or Asperger's syndrome. We wish to better understand some of the issues that siblings are most concerned with and the needs that some children may have, relative to their experiences of having a sibling with autism. If future support systems or interventions are developed for siblings of children with autism, it is imperative that the children concerned have the opportunity to contribute and inform the development of these services. We would like to talk to a number of siblings from or around the North Wales area in order to get a good idea of the different experiences they have.

Invitation to participate

We wish to identify siblings between the ages of 9 and 14 years, with a brother or sister who has had a formal diagnosis of autism or Asperger's disorder, and who live in or around the area of North Wales. Please read the remainder of this information sheet carefully and complete the contact and consent form if you are interested in helping us with this research. If anything is unclear or you would like more information before you decide, please fill in the contact form only and we will phone you to discuss the project further and answer any questions you may have. We will try to contact each family only once. There is however, the possibility that you may receive a duplicate of this information sheet as we are distributing information via several organizations. If this is the case we apologise, you only need to apply once.

What are the benefits of taking part?

The main benefits of this research relate to improving the knowledge that we have about the needs that some siblings of children with autism have. By giving siblings the opportunity to tell us in their own words what it's like, for them, to have a brother or sister with autism, we will have a body of information that we can use to design research that aims to offer professionals a better understanding of what the siblings needs are and possible ways of meeting these needs. Research with siblings of children with autism is relatively underdeveloped and lacks consensus. Formal support services for these siblings are few and far between. Taking part in this research will help inform and improve developments in this area.

We plan to keep participants and their families up-to-date with the projects progress through and website which will include links to relevant organizations, a newsletter that we will post to participants, and a facility to request full copies of research publications associated with this project.

What are the risks of taking part?

We do not believe that the children that will be participating in this study are being put at risk in any way. There is the possibility however, that for some siblings, talking about their brother or sister with autism may lead them to becoming distressed. We will be happy to go through the interview process and the questions with the parents before we begin the interview with the children. The children that will participate in this study will know that they can stop talking at any point during the interview process, there will be no pressure whatsoever to answer any of the questions, and we will try to be as sensitive as we can to their needs.

All the information that the children provide will be treated as strictly confidential material, and will be kept securely locked in a filing cabinet without the names attached. The researchers alone will have access to the interview recordings and questionnaires.

Do we have to participate?

It is entirely up to you, the parents and children to decide if you would like to participate in this study. If you do decide to take part, please sign the initial contact form and return it in the envelope provided. You may keep this information sheet for your records. You will have the freedom to withdraw from this research at any time and without giving a reason.

What happens if we decide to take part?

We would like you to tell your child that will potentially be participating in the study all about the research and the interview process. You can use the 'information sheet for siblings' that we will have sent you if you want. Once you have told your child all about the research and you have checked that they have understood everything, please ask your child if he/she would be willing to participate in the study. If your child agrees to take part, please fill in and return the initial contact form, we will then go through the following contact process.

1. We will telephone you to answer any questions you may have and organize a time and date to visit you at your home and conduct a face-to-face interview.
2. Send you a consent form if you have not signed one already to say that you are willing to participate in the research. At this point we would like you to check again with your child that will be potentially participating in the study if they are still willing to take part. You will need to complete and return the consent form before the interview takes place. Michael Petalas will obtain consent from the child participant at the time of the interview.
3. After we have arranged a suitable time for you and your child, Michael will visit your home for the face-to-face interview with the sibling or you could also choose to visit Michael at the school of psychology in Bangor to have the interview there (we will pay for your travel expenses). During the interview Michael will be asking the sibling questions about his/her relationship and experiences with their brother or sister with autism. This will last for about 30 to 40 minutes.
4. After the interview process is over we will send you information on how the project is progressing and any prospective research and give you the address

of the project website. When we have the results of the study we will send you a summary of that. The information that will be produced may include short quotes and limited details on particular experiences. We will not identify individuals, unless extensive descriptions are used at which point we will re-contact the families to seek permission.

5. We plan on using the information we collect in developing a subsequent research study that will provide insight into the needs of siblings of children with autism and the processes that underlie them. We are hopeful that our research will lead to the development of a support system/ intervention that will directly and practically benefit siblings of children with autism whose needs are not being met at present.

What do I have to do now?

If you have read all of the information on this sheet and wish to discuss the study further or participate/ consent on behalf of your child to participate in the research, please return the attached contact form. If you decide not to take part, please discard this letter, you do not need to contact us.

All of the information that you give us will be treated as strictly confidential and kept securely locked in a filing cabinet without any information that can personally identify you. The only exception to this, which is standard practice for all interview-based research with children, is if child protection issues arise.

For further details and if you wish to contact the research team, our details are below.

Michael Petalas
Postgraduate Research Student
Intellectual and Developmental Disabilities Research Group
School of Psychology
University of Wales, Bangor
Adeilad Brigantia,
Penrallt Road
Bangor, Gwynedd
UK
LL57 2AS
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E-mail: psp202@bangor.ac.uk

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Dr. E. Charles Leek
Deputy Head of School
School of Psychology,
University of Wales, Bangor,
Adeilad Brigantia,
Penrallt Road,
Bangor, Gwynedd,
LL57 2AS

Contact Form

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

The Wales Study of Siblings of Children with Autism

Please read the following, place a tick in the appropriate boxes, and return the form to the address provided.

I would like more information before I consent to the participation of my child. *Please complete the information below.*

Please give us a contact number below so that Michael Petalas can contact you to discuss the study with you further and possibly arrange a convenient time for a home visit.

Your Name (please print) and relationship to the sibling of the child with autism:

Your contact address & telephone number:

Postcode

Telephone

Please tell us which days and what times of day are best to contact you and them:

Best time to contact you is: Morning Afternoon Evening

Specific Times

_____.

*Return this sheet to me at the university and I will contact you. Thank you for your time,
Michael Petalas.*

Research Consent Form

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

The Wales Study of Siblings of Children with Autism

Please complete the following and circle as necessary:

1) Have you read the all of the information on the Information sheet? YES/NO

Have you had an opportunity to ask questions and discuss this study? YES/NO

- Have you received satisfactory answers to all of your questions? YES/NO

2) Have you spoken to your child that will be potentially participating in the study about about the research? YES/NO

3) Is the child willing to be interviewed for the study? YES/NO

4) Is the child aware that he/she can withdraw from the study
...at any time?
...without giving a reason for withdrawing? YES/NO

I am willing for my child to participate in this study. YES/NO

Signature _____

Date _____

Name in block letters _____

Relationship to the child participant:

Address _____

_____ Postcode _____

Telephone Number _____

Appendix C
Information Sheet for Siblings

Title of the study

The Wales Study of Siblings of Children with Autism.

What is this study about?

Hello my name is Michael, I work at the University of Wales in Bangor, and I also work with children who have autism. I would like to speak with children who have a brother or sister with autism. If you have a brother or sister with autism, I would be very interested to hear all about you and the stories that you can tell me about your brother or sister. This will help me learn about the different experiences that you have with your brother or sister.

Invitation to take part

If your brother or sister has autism, you can help me by telling me what things are like for you, having a brother or sister with autism. If you would like to help me with my study, after reading this letter, then tell your parents if you would like to take part or not. You don't have to do anything that you don't want to.

If you decide that you would like to take part

You will help me by telling me what it's like to have a brother or sister who is special. There are many children like you who have brothers or sisters with autism and they each have different stories to tell about having a special brother or sister. You can tell me, for example, what things are good about having a brother or sister who is special and what things are not so good. I would really like to hear what you can tell me about this.

Do we have to participate?

You do not have to take part if you don't want to. Just tell your parents that you don't want to take part in this study. If you decide to take part, you can change your mind and decide against it at any time.

What happens if you decide to take part?

If you tell your parents that you would like to take part in this study, they will let me know and we will choose a date and time that you and your parents would like me to visit you at home. During my visit we shall talk together while your parents are in the other room. We will talk for about half an hour, but you can stop talking to me whenever you want if you decide that you don't want to continue, and I won't mind at all. Usually I won't discuss any of the things we talked about with your parents or anyone that is not part of the university research team without your permission.

Thank you for your Time

Appendix D
Information Sheet for Families: Welsh Version

Taflen wybodaeth i Deuluoedd

Teitl yr Astudiaeth

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

Tîm y Project

Michael Petalas, Myfyriwr Ymchwil

Richard Hastings, Athro Seicoleg

Alan Dowey, Seicolegydd Clinigol

Susie Nash, Swyddog Ymchwil Ôl-ddoethurol

Mae'r gwaith ymchwil hwn yn cael ei wneud ar y cyd rhwng Prifysgol Cymru,

Bangor a Chymdeithas Awtistiaeth Genedlaethol Cymru, sy'n ariannu'r ymchwil yn

rhannol ar y cyd â Chronfa Gymdeithasol Ewrop.

Beth yw pwrpas yr astudiaeth?

Mae gennym ddiddordeb mewn gwrando ar yr hyn sydd gan frodyr a chwiorydd plant

ag awtistiaeth i'w ddweud am eu profiad o fyw gyda'u chwaer neu eu brawd sydd ag

awtistiaeth neu syndrom Asperger. Rydym yn dymuno deall yn well rai o'r materion

sydd o'r pwys mwyaf i frodyr a chwiorydd a'r anghenion a all fod gan rai plant,

mewn perthynas â'u profiad o fod â brawd neu chwaer ag awtistiaeth. Os caiff

systemau cefnogi neu ymyriadau eu datblygu ar gyfer brodyr neu chwiorydd plant ag

awtistiaeth yn y dyfodol, yna mae'n hollbwysig bod y plant hyn yn cael y cyfle i

gyfrannu at ac i ddylanwadu ar ddatblygiad y gwasanaethau hyn. Hoffem siarad â

nifer o frodyr a chwiorydd o ogledd Cymru neu'r cyffiniau er mwyn cael syniad da

o'u profiadau gwahanol.

Gwahoddiad i gymryd rhan

Hoffem wybod am blant rhwng 9 ac 14 oed, sydd â brawd neu chwaer sydd wedi cael diagnosis ffurfiol o awtistiaeth neu anhwylder Asperger, ac sy'n byw yng ngogledd Cymru neu'r cyffiniau. Darllenwch weddill y daflen wybodaeth hon yn ofalus a llenwch y ffurflenni cyswllt a chaniatâd amgaeedig os oes gennych ddiddordeb mewn helpu yn yr ymchwil hon. Os yw rhywbeth yn aneglur, neu os hoffech chi fwy o wybodaeth cyn i chi benderfynu, llenwch y ffurflen gyswllt yn unig ac fe wnawn eich ffonio i drafod y project ymhellach ac ateb unrhyw gwestiynau a all fod gennych. Ceisiwn gysylltu â phob teulu unwaith yn unig. Mae'n bosib, fodd bynnag, y byddwch yn derbyn dau gopi o'r daflen wybodaeth hon gan ein bod yn dosbarthu gwybodaeth trwy gyfrwng nifer o sefydliadau. Os felly, rydym yn ymddiheuro. Dim ond unwaith y mae'n rhaid i chi lenwi'r ffurflenni.

Beth yw manteision cymryd rhan?

Prif fanteision yr ymchwil hwn fydd gwella'r wybodaeth sydd gennym am anghenion rhai brodyr a chwiorydd plant ag awtistiaeth. Trwy roi cyfle i blant i ddweud wrthym yn eu geiriau eu hunain sut brofiad yw bod â brawd neu chwaer ag awtistiaeth, bydd gennym gorff o wybodaeth y gallwn ei defnyddio i lunio gwaith ymchwil sy'n gallu cynnig gwell dealltwriaeth i weithwyr proffesiynol o anghenion y plant hyn a ffyrdd posib o gyfarfod â'r anghenion hyn. Ychydig o waith ymchwil sydd wedi cael ei wneud ar frodyr a chwiorydd plant ag awtistiaeth ac nid oes consensws. Prin a gwasgaredig yw'r gwasanaethau cefnogi ffurfiol i'r brodyr a'r chwiorydd hyn. Wrth gymryd rhan yn yr ymchwil hon byddwch yn helpu i lywio a gwella datblygiadau yn y maes hwn.

Ein cynllun yw rhoi'r newyddion diweddaraf i'r rhai sy'n cymryd rhan a'u teuluoedd am gynnydd y project trwy wefan a fydd yn cynnwys cysylltiadau â sefydliadau perthnasol, cylchlythyr y byddwn yn ei anfon at y rhai sy'n cymryd rhan, a chyfleuster i ofyn am gopiâu llawn o gyhoeddiadau ymchwil sy'n gysylltiedig â'r project.

Beth yw risgiau cymryd rhan?

Nid ydym yn credu bod y plant a fydd yn cymryd rhan yn yr astudiaeth hon yn agored i unrhyw fath o risg. Mae'n bosib, serch hynny, y bydd siarad am eu brawd neu eu chwaer ag awtistiaeth yn peri gofid i rai plant. Byddwn yn hapus i fynd trwy'r broses cyfweld a'r cwestiynau gyda'r rhieni cyn i ni ddechrau ar y cyfweiliad gyda'r plant. Bydd y plant fydd yn cymryd rhan yn yr astudiaeth hon yn gwybod y gallan nhw beidio â siarad ar unrhyw adeg yn ystod y broses cyfweld, ni fydd unrhyw bwysau o gwbl i ateb unrhyw un o'r cwestiynau, a byddwn yn ceisio bod mor sensitif ag y gallwn i'w hanghenion.

Bydd yr holl wybodaeth y bydd y plant yn ei darparu yn cael ei thrin yn gwbl gyfrinachol a bydd yn cael ei chadw'n ddiogel dan glo mewn cwpwrdd ffeilio heb fod eu henwau arni. Dim ond yr ymchwilwyr fydd yn cael mynd at y cyfweiliadau ar dâp a'r holiaduron.

Oes rhaid i ni gymryd rhan?

Chi eich hun, y rhieni a'r plant, sydd i benderfynu a hoffech gymryd rhan yn yr astudiaeth hon. Os penderfynwch gymryd rhan, llofnodwch y ffurflen cyswllt cyntaf a'i hanfon yn ôl atom yn yr amlen amgaeedig. Gellwch gadw'r daflen wybodaeth hon

ar gyfer eich cofnodion. Rydych yn rhydd i dynnu'n ôl o'r ymchwil hon ar unrhyw adeg a heb roi rheswm.

Beth fydd yn digwydd os byddwn yn penderfynu cymryd rhan?

Hoffem i chi egluro popeth am y broses ymchwil a chyfweld wrth eich plentyn a fydd o bosib yn cymryd rhan yn yr astudiaeth. Os dymunwch gallwch ddefnyddio'r 'daflen wybodaeth i frodyr a chwiorydd' a gawsoch gennym. Unwaith y byddwch wedi egluro popeth am yr ymchwil wrth eich plentyn ac wedi gwneud yn siŵr eu bod yn deall popeth, gofynnwch i'ch plentyn a fyddai'n fodlon cymryd rhan yn yr astudiaeth. Os bydd eich plentyn yn cytuno i gymryd rhan, llenwch y ffurflen cyswllt cyntaf a'i hanfon yn ôl, a byddwn yn dilyn y broses gyswllt ganlynol.

6. Byddwn yn eich ffonio i ateb unrhyw gwestiynau a all fod gennych ac i drefnu amser a dyddiad i ymweld â chi yn eich cartref a chynnal cyfweiliad wyneb yn wyneb.
7. Byddwn yn anfon ffurflen ganiatâd atoch os nad ydych wedi llofnodi un eisoes i ddweud eich bod yn fodlon cymryd rhan yn yr ymchwil. Ar yr adeg hon hoffem i chi ofyn eto i'ch plentyn a fydd o bosib yn cymryd rhan yn yr astudiaeth a ydyw'n dal i fod yn fodlon gwneud hynny. Mae angen i chi lenwi a dychwelyd y ffurflen ganiatâd cyn i'r cyfweiliad gael ei gynnal. Bydd Michael Petalas yn cael caniatâd y plentyn sy'n cymryd rhan adeg y cyfweiliad.
8. Ar ôl i ni drefnu amser addas i chi a'ch plentyn, bydd Michael yn ymweld â'ch cartref i gynnal cyfweiliad wyneb yn wyneb â'r plentyn, neu gallech chi ddewis ymweld â Michael yn yr Ysgol Seicoleg ym Mangor i gael y cyfweiliad yno (byddwn ni'n talu am eich costau teithio). Yn ystod y cyfweiliad bydd

Michael yn gofyn cwestiynau i'r plentyn am eu perthynas a'u profiadau gyda'u brawd neu eu chwaer ag awtistiaeth. Bydd cyfweiliadau'n para tua 30 i 40 munud.

9. Ar ôl i'r broses cyfweld ddod i ben byddwn yn anfon gwybodaeth atoch ynghylch sut mae'r project yn dod yn ei flaen ac am unrhyw ymchwil sydd ar y gweill ac yn rhoi cyfeiriad gwefan y project i chi. Pan fydd canlyniadau'r astudiaeth wedi dod i law byddwn yn anfon crynodeb atoch. Mae'n bosib y bydd y wybodaeth a gynhyrchir yn cynnwys dyfyniadau byr a manylion cyfyngedig am brofiadau neilltuol. Ni fyddwn yn enwi unigolion, oni bai fod disgrifiadau helaeth yn cael eu defnyddio. Mewn achos felly byddwn yn ail-gysylltu â theuluoedd i ofyn caniatâd.
10. Ein bwriad yw defnyddio'r wybodaeth yr ydym yn ei chasglu i ddatblygu astudiaeth ymchwil ddilynol a fydd yn rhoi dealltwriaeth o anghenion brodyr a chwiorydd plant ag awtistiaeth a'r prosesau sy'n sylfaen iddynt. Ein gobaith yw y bydd ein hymchwil yn arwain at ddatblygu system gefnogi/ymyrryd a fydd o fudd uniongyrchol ac ymarferol i frodyr a chwiorydd plant ag awtistiaeth nad yw eu hanghenion yn cael eu bodloni ar hyn o bryd.

Beth mae'n rhaid i mi ei wneud yn awr?

Os ydych wedi darllen yr holl wybodaeth ar y daflen hon ac yn dymuno trafod yr astudiaeth ymhellach neu gymryd rhan/rhoi caniatâd i'ch plentyn gymryd rhan yn yr astudiaeth, anfonwch y ffurflen ganiatâd ynghlwm yn ôl. Os penderfynwch beidio â chymryd rhan, taflwch y llythyr hwn, nid oes rhaid i chi gysylltu â ni.

Bydd yr holl wybodaeth y byddwch yn ei rhoi i ni yn cael ei thrin yn gwbl gyfrinachol a bydd yn cael ei chadw'n ddiogel dan glo mewn cwpwrdd ffeilio heb unrhyw wybodaeth sy'n gallu dangos pwy ydych chi. Yr unig eithriad i hyn yw os bydd materion yn ymwneud ag amddiffyn plant yn codi. Dyma'r arfer safonol ym mhob ymchwil ar sail cyfweiliadau gyda phlant.

I gael manylion pellach ac os ydych yn dymuno cysylltu â'r tîm ymchwil, mae ein manylion isod:

Michael Petalas
Myfyrwyr Ymchwil Ôl-raddedig
Grŵp Ymchwil Anhwylderau Deallusol a Datblygiadol
Ysgol Seicoleg
Prifysgol Cymru, Bangor
Adeilad Brigantia,
Ffordd Penrallt
Bangor, Gwynedd
DU
LL57 2AS
Ffôn: ++44 (0)1248 35 8706
E-bost: psp202@bangor.ac.uk

Os oes gennych unrhyw gwynion ynglŷn â'r ffordd y mae'r ymchwil hon yn cael ei chynnal, mae croeso i chi fynd ag unrhyw bryderon heb eu datrys at:

Dr. E. Charles Leek,
Dirprwy Bennaeth yr Ysgol
Ysgol Seicoleg,
Prifysgol Cymru, Bangor,
Adeilad Brigantia,
Ffordd Penrallt
Bangor, Gwynedd.
LL57 2AS

Ffurflen Gyswllt

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

Darllenwch y canlynol, ticiwch y blychau priodol, yna anfonwch y ffurflen yn ôl i'r cyfeiriad a nodir.

Hoffwn gael mwy o wybodaeth cyn i mi roi caniatâd i'm plentyn gymryd rhan. *Cwblhewch y wybodaeth isod.*

Rhowch rif cyswllt i ni isod fel y gall Michael Petalas gysylltu â chi er mwyn trafod yr astudiaeth gyda chi ymhellach ac o bosib drefnu amser cyfleus i ymweld â chi yn eich cartref.

Eich Enw (printiwch) a'ch perthynas â brawd neu chwaer y plentyn ag awtistiaeth:

Eich cyfeiriad cyswllt a'ch rhif ffôn:

Cod post

Rhif Ffôn

Dywedwch wrthym pa ddiwrnodau a pha adegau o'r dydd fyddai orau i gysylltu â chi ac â nhw:

Amser gorau o'r diwrnod i gysylltu â chi: Bore Prynawn Gyda'r nos

Amseroedd penodol

Anfonwch y daflen hon ataf yn y brifysgol ac fe wnaaf i gysylltu â chi. Diolch am eich amser.

Michael Petalas.

Research Consent Form

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

The Wales Study of Siblings of Children with Autism

Atebwch y cwestiynau isod, gan roi cylch o'u cwmpas yn ôl yr angen:

2) Ydych chi wedi darllen yr holl wybodaeth ar y daflen wybodaeth?

YDW/NAC YDW

Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?

YDW/NAC YDW

A ydych chi wedi derbyn atebion boddhaol i'ch holl gwestiynau?

YDW/NAC YDW

2) A ydych chi wedi siarad â'ch plentyn a fydd o bosib yn cymryd rhan yn yr astudiaeth am yr ymchwil?

YDW/NAC YDW

3) A ydyw'r plentyn yn fodlon cael ei gyfweld ar gyfer yr astudiaeth?

YDY/NAC YDY

4) A ydyw'r plentyn yn gwybod y caiff dynnu'n ôl o'r astudiaeth

...ar unrhyw adeg?

...heb roi rheswm am dynnu'n ôl?

YDY/NAC YDY

Rwyf yn fodlon i'm plentyn gymryd rhan yn yr astudiaeth hon.

YDW/NAC YDW

Llofnod _____

Dyddiad _____

Enw mewn priflythrennau _____

Perthynas â'r plentyn sy'n cymryd rhan:

Cyfeiriad _____

Cod post:

Rhif ffôn _____

Appendix E
Information Sheet for Siblings: Welsh Version

Taflen Wybodaeth i Frodyr a Chwiorydd

Teitl yr astudiaeth

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru

Beth yw pwrpas yr astudiaeth yma?

Helo. Fy enw i yw Michael. Rwy'n gweithio ym Mhrifysgol Cymru, Bangor, ac rwy'n gweithio hefyd gyda phlant sydd ag awtistiaeth. Hoffwn i siarad gyda phlant sydd â brawd neu chwaer ag awtistiaeth. Os oes gennych frawd neu chwaer ag awtistiaeth, byddwn i'n hoffi clywed popeth amdanoch chi a'r storïau y gallwch chi eu dweud wrthyf am eich brawd neu'ch chwaer. Bydd hyn yn fy helpu i ddysgu am y gwahanol brofiadau rydych yn eu cael gyda'ch brawd neu'ch chwaer ag awtistiaeth.

Gwahoddiad i gymryd rhan

Os ydyw eich brawd neu'ch chwaer ag awtistiaeth, gallwch fy helpu trwy ddweud wrthyf sut beth ydyw bod â brawd neu chwaer ag awtistiaeth. Os hoffech fy helpu gyda'r astudiaeth, ar ôl darllen y llythyr hwn, yna dywedwch wrth eich rhieni. Does dim rhaid i chi wneud unrhyw beth oni bai eich bod chi eisiau gwneud hynny.

Os ydych yn penderfynu yr hoffech chi gymryd rhan

Byddwch yn help i mi trwy ddweud wrthyf sut beth ydyw bod â brawd neu chwaer sy'n arbennig. Mae yna lawer o blant fel chi sydd â brodyr neu chwiorydd ag awtistiaeth ac mae gan bob un straeon gwahanol am fod â brawd neu chwaer sy'n arbennig. Gallwch chi ddweud wrthyf, er enghraifft, pa bethau sy'n dda am gael brawd neu chwaer sy'n arbennig a pa bethau sy ddim mor dda. Byddwn i wrth fy modd yn clywed popeth sydd gennych i'w ddweud.

Oes rhaid i ni gymryd rhan?

Does dim rhaid i chi gymryd rhan onibai eich bod chi eisiau gwneud hynny.

Dywedwch wrth eich rhieni nad ydych chi ddim eisiau cymryd rhan yn yr astudiaeth yma. Os ydych yn penderfynu cymryd rhan, gallwch newid eich meddwl a phenderfynu fel arall unrhyw bryd.

Beth fydd yn digwydd os byddwch yn penderfynu cymryd rhan?

Os byddwch yn dweud wrth eich rhieni yr hoffech gymryd rhan yn yr astudiaeth yma, byddan nhw'n gadael i mi wybod a byddwn yn dewis dyddiad ac amser y byddech chi a'ch rhieni yn hoffi i mi ymweld â chi yn eich cartref. Yn ystod yr ymweliad byddwn yn siarad gyda'n gilydd tra bydd eich rhieni yn yr ystafell arall. Byddwn yn siarad am ryw hanner awr, ond gallwch chi beidio â siarad gyda mi pryd bynnag byddwch chi eisiau, os ydych chi'n penderfynu nad ydych chi ddim am gario ymlaen, bydd hynny'n iawn gen i. Fel arfer fyddaf i ddim yn trafod unrhyw beth y buon ni'n siarad amdano gyda'ch rheini neu unrhyw un nad yw'n rhan o dîm ymchwil y brifysgol heb eich caniatâd.

Diolch yn fawr am eich amser

Appendix F
Information Letter

Astudiaeth o Frodyr a Chwirydd Plant ag Awtistiaeth yng Nghymru

Dear Sir/Madam,

I am contacting you to ask for your help with The Wales Study of Siblings of Children with Autism. The aim of this project is to better understand children's experience of having a sibling with autism and what contributes to this experience.

I would like to speak to siblings that are between the ages of 9 and 14, who do not have a disability, to understand more about what it's like to have a brother or sister with Autism or Asperger's syndrome. The information I gather will be used to inform future research with siblings of children with autism and might also be used in the development of different ways to support the needs of the siblings.

In order for the research to reflect a representative range of experiences, I would like to speak with as many siblings as possible. If you would like your child to participate in this project, please tell your child about this study and ask them if they would like to help us out with this research, then complete the attached form and return it to the address below.

I have included a suggested information letter for siblings that is written in the way that I might introduce myself to the child. You may also want to give this to your child to read or use it to base the discussion about the study with your child. I understand that talking about their brother or sister with autism may not be easy for some siblings. I will try and be as sensitive as possible to the needs of the siblings and they will be under no pressure to continue the interview or talk about anything that they would not feel comfortable with. Many thanks for your time.

Michael Petalas,

Phone: +441248 351151 ext 8706, e-mail: psp202@bangor.ac.uk

Address: School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2AS

Appendix G
Information Letter: Welsh Version



**Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth
yng Nghymru**

The Wales Study of Siblings of Children with Autism



Annwyl Syr/Fadam,

Rwy'n ysgrifennu atoch i ofyn am eich help gydag Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru. Nod y project hwn yw ennill gwell ddealltwriaeth o brofiad plant o gael brawd neu chwaer ag awtistiaeth a'r hyn sy'n cyfrannu at y profiad hwn.

Hoffwn i siarad gyda brodyr a chwiorydd sydd rhwng 9 ac 14 oed, nad ydynt yn anabl, i ddeall mwy am sut beth yw bod â brawd neu chwaer ag awtistiaeth neu syndrom Asperger. Bydd y wybodaeth y byddaf yn ei chasglu yn cael ei defnyddio fel sylfaen i ymchwil yn y dyfodol gyda brodyr a chwiorydd plant ag awtistiaeth a gellid ei defnyddio i ddatblygu gwahanol ffyrdd o gefnogi anghenion y brodyr a'r chwiorydd hyn.

Fel y bydd ein hymchwil yn cynrychioli'r holl ystod profiadau, hoffwn siarad â chynifer o frodyr a chwiorydd â phosib. Os hoffech i'ch plentyn gymryd rhan yn y project hwn, dywedwch wrth eich plentyn amdano a gofynnwch iddynt a hoffent ein helpu gyda'r gwaith ymchwil, yna llenwch y ffurflen amgaeedig a'i hanfon yn ôl i'r cyfeiriad isod.

Rwyf wedi cynnwys llythyr gwybodaeth i frodyr a chwiorydd sydd wedi ei ysgrifennu yn y ffordd y byddwn i'n fy nghyflwyno fy hun i'r plentyn. Efallai byddwch chi am roi hwn i'ch plentyn i'w ddarllen neu ei ddefnyddio i seilio'r drafodaeth am yr astudiaeth gyda'ch plentyn. Deallaf nad yw'n hawdd i rai brodyr a chwiorydd siarad am eu brawd neu eu chwaer ag awtistiaeth. Byddaf yn ceisio bod mor sensitif â phosib i anghenion y brodyr a'r chwiorydd ac ni fyddant o dan unrhyw bwysau i barhau'r cyfweiliad neu siarad am unrhywbeth os na fyddant yn teimlo'n gyfforddus. Diolch yn fawr am eich amser.

Michael Petalas

**Ysgol Seicoleg
Prifysgol Cymru Bangor
Adelad Brigantia, Ffordd Penrallt
Bangor, Gwynedd, LL57 2AS**

Ph: 3 (01248) 351151 ext 8706
Ffôn: (01248) 382599
e-bost: pap202@bangor.ac.uk



**School of Psychology,
University of Wales, Bangor
Adelad Brigantia, Penrallt
Bangor, Gwynedd, LL57 2AS**

Tel: (01248) 351151 ext 8706
Ffôn: (01248) 382599
e-mail: pap202@bangor.ac.uk

Appendix H
Demographic Questionnaire

Astudiaeth o Frodyr a Chwiorydd Plant ag Awtistiaeth yng Nghymru
The Wales Study of Siblings of Children with Autism

General Questionnaire for Completion by Parents/Guardians

The following questions ask for background information about you, your child with autism, and your typically developing child who will be participating in this study. Please tick the appropriate boxes or write in the spaces provided.

1. Are you male or female? Male Female

2. What was your age in years on your last birthday? _____

3. What is your current marital status?

Married, and living with spouse.....

Living with partner.....

Divorced/Separated/Single and NOT living with a partner.....

4. In total how many people currently live in your house? _____ Adults _____ Children

If there are other children living in the house how are they related to your child with autism (e.g. biological brother, step brother) and how old are they? – *Please list ALL children*

.....
.....
.....
.....

5. Please tick the boxes next to all of the educational qualifications that you hold

No formal educational qualifications.....

GCSE, CSE, GCE, O Levels or equivalent.....

GCE, A Levels, HNC, GNVQ or equivalent.....

HND, other Diploma, or equivalent.....

Polytechnic/University ordinary or honours degree.....

Masters or Doctoral degree.....

6. Do you currently have a job outside of the home?

Yes

No

If no, please go to question 8, otherwise please answer following questions.

What is your current job/occupation? (Please give a job title and a very brief description of your main duties).

7. Is your job/occupation full or part-time?

Full-time

Part-time

8. If you are living with your spouse/partner, do they currently have a job outside of the home?

Yes

No

If no, please go to question 10, otherwise please answer following questions.

What is your spouse/partner's current job/occupation? (Please give a job title and a very brief description of their main duties).

9. Is this job/occupation full or part-time?

Full-time

Part-time

10. What is your relationship to your child with autism spectrum disorder (ASD) (e.g., mother, father, stepmother, grandmother, adoptive parent)?

11. How old is your child with ASD? _____ years _____ months

12. Is your child with ASD male or female?

Male

Female

13. Please tick the boxes below to indicate any additional diagnoses/conditions that apply to your child with ASD.

Down syndrome

Cerebral Palsy

Fragile X syndrome

Other - please state

14. Does your child with ASD have a sensory impairment that interferes with his/her day to day life?

Yes No

If yes, what is this impairment?

Visual impairment? Yes

Hearing impairment? Yes

15. Does your child with ASD currently suffer from epileptic fits? Yes No

16. Does your child with ASD have problems with mobility that mean it is difficult for them to move around independently (e.g. needs to use a wheelchair)? Yes No

17. Does your child with ASD have any other health problems not already mentioned? Yes No

If yes, then please specify _____

18. Does your child with ASD normally live with you? Yes No

If no, then where do they live? _____

19. Does your child with ASD have intellectual or learning disabilities. Yes No

20. What is your relationship to your typically developing child (e.g., mother, father, stepmother, grandmother, adoptive parent)? _____

21. How old is your typically developing child? _____ years _____ months

22. Is your typically developing child male or female? Male Female

23. Recent data from research with families of children with special needs has shown that a family's financial resources are important in understanding family member's views and experiences. With this in mind, we would be very grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether those with high versus lower levels of financial resources have different experiences.

What is your current total annual family income? Please include a rough estimate of total salaries and other income (including benefits) before tax and national insurance/pensions.

Please tick one box only:

Less than

£15,000.....

£15,001 to

£25,000.....

£25,001 to

£35,000.....

£35,001 to

£50,000.....

£50,001 to

£75,000.....

£75,001 to

£100,000.....

£101,001 to

£150,000.....

£151,001 to

£200,000.....

£201,001 or

more.....

Please complete each section as honestly you can, even if you are not absolutely certain or the item seems daft! Follow the instructions for each questionnaire.

Thank you for your time.

Appendix I
Consent Form

To be completed and returned to the Researcher if you agree to take part



The Sibling Interview Study

The National
Autistic Society

Initial Consent and Contact Form to be completed by the main carer

✦ Signing and returning this form means that you agree to be contacted further about this research and for the sibling closest in age to the child with autism in the family to be interviewed. It also means that you consent to receiving questionnaire packs. Please answer the following questions about your family and provide your contact details.

1. Please confirm that you are the main carer for a child with autism between the ages of 5 and 17 years. YES

How old is your child with autismyears

What is your relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

2. Is there a secondary carer living in the home? YES / NO

If YES,
What is their relationship to the main carer (e.g. spouse, partner, mother, father, etc)

.....

What is their relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

3. Please provide information on the siblings (brothers or sisters) of the child with autism that currently live in the home?

Sibling 1, age:	years	Sibling 5, age:	Years
Sibling 2, age:	years	Sibling 6, age:	Years
Sibling 3, age:	years	Sibling 7, age:	Years
Sibling 4, age:	years	Sibling 8, age:	Years

Please fill out your contact details. This allows us to send you the questionnaire pack for our study.

Name

Address: _____

Postal Code: _____

We will also need the telephone of the main carer to ask some questions about the child with autism and their sibling. Please give details of the telephone number below and an indication of the best time for a researcher to contact the main carer.

Telephone no.: _____

The best time(s) to telephone the main carer are:
(e.g. Evenings between 5pm – 7pm; Mornings between 10am – 11.30am)

.....
.....
.....
.....

I have read the enclosed information sheet and agree to be sent a questionnaire pack for my family to participate in 'The Wales Study of Families of Children with Autism'.

Signature: _____

Date: _____

Name in Capitals: _____

Please tick this box if you would like to receive information in Welsh/or bilingually in Welsh and English in future where this is available.

Welsh
Bilingual

Appendix J
Demographic Questionnaire

The Wales Study of Families of Children with Autism

General Questionnaire for Completion by the Main Carer (The main carer is the person who spends the most time caring for the child with autism. This may be a mother, father, grandparent or foster parent. The main carer does not need to be a blood relative of the child with autism.)

The following questions ask for background information about you, your family and your child with autism. Please tick the appropriate response or write in the spaces provided.

1. Are you male or female? Please circle your response. **Male** **Female**

2. Please confirm your relationship to your child with autism spectrum disorder (ASD) (e.g., mother, father, stepmother, grandmother, adoptive parent)

.....

3. To which of the following ethnic groups do you consider yourself to belong? Please tick the appropriate box.

White - British	<input type="checkbox"/>	Any other Asian Background, please specify.....	<input type="checkbox"/>
White - Irish	<input type="checkbox"/>	Black/Black British - Caribbean	<input type="checkbox"/>
Any other White Background, please specify.....	<input type="checkbox"/>	Any other Black Background, please specify.....	<input type="checkbox"/>
Mixed - White and Black Caribbean	<input type="checkbox"/>	Mixed - White and Asian	<input type="checkbox"/>
Mixed - White and Black African	<input type="checkbox"/>	Asian/Asian British - Indian	<input type="checkbox"/>
Any other Mixed Background	<input type="checkbox"/>	Asian/Asian British - Bangladeshi	<input type="checkbox"/>
Asian/Asian British - Pakistani	<input type="checkbox"/>	Black/Black British - African	<input type="checkbox"/>

4. What is your date of birth?

5. What is your current marital status?

Married, and currently living with spouse or currently living with partner.....

Divorced/Separated/Single/widowed and NOT currently living with a partner.....

6. In total how many people currently live in your home? ___ Adults (age +18) ___ Children

7. Please tick the highest level of your educational qualifications.

- No formal educational qualifications.....
- Fewer than 5 GCSE's or O Level's, NVQ 1, or BTECH First Diploma.....
- 5 or more GCSE's or O Level's, NVQ 2, or equivalent.....
- 3 or more 'A' Levels, NVQ 3, BTECH National, or equivalent.....
- Polytechnic/University degree, NVQ 4, or equivalent.....
- Masters/ Doctoral degree, NVQ 5, or equivalent.....

- 8. Do you currently have a job outside the home?** YES NO
- Is your job/occupation full or part-time?** Full-time Part-time

- 9. If you are living with your spouse/partner, do they currently have a job outside of the home?**
- Yes No

- 10. If YES, is this job/occupation full or part-time?** Full-time Part-time

Your Child with Autism

Please answer the following questions about your child with ASD between the ages of 5 and 17 years old. If you have more than one child with ASD in this age range, please focus on the oldest child who is between 5 and 17 years of age.

- 11. Does your child have a formal diagnosis of an autism spectrum disorder? If so, please give details (e.g. Asperger's Syndrome, Autism, PDD-NOS)**
-

Please tell us how long ago this diagnosis was given and who made the diagnosis.

- How long ago was the diagnosis given (years/months).....
 - Who made the diagnosis (e.g. paediatrician, clinical psychologist).....
-

- 12. What is the date of birth of your child with autism?**

13. Is your child with autism male or female? Male Female

14. Please indicate below any additional diagnoses/conditions that apply to your child with autism.

Down syndrome <input type="checkbox"/>	Cerebral Palsy <input type="checkbox"/>
Fragile X syndrome <input type="checkbox"/>	ADHD/Hyperactivity <input type="checkbox"/>

Other - please specify _____

15. Does your child with autism have a sensory impairment that interferes with his/her day to day life? Yes No

If yes, please specify. Visual impairment Hearing impairment

16. Does your child with autism currently suffer from epileptic fits?

Yes No

17. Does your child with autism have problems with mobility that mean it is difficult for them to move around independently (e.g. needs to use a wheelchair)?

Yes No

18. Does your child with autism have any other health problems not already mentioned?

Yes No

If Yes, please specify _____

19. Does your child with autism normally live with you?

Yes No

If No, then where do they live? _____

20. Please tell us what type of school your child with autism attends

- Mainstream school with no additional support
- Mainstream school with additional support
- Special school
- Specialist autism unit in mainstream school
- Other, please specify

Sibling of Child with Autism (i.e. the sibling who is participating in the study)

Please answer the following questions about the sibling of the child with ASD between the ages of 5 and 17 years old. If there is more than one sibling in this age range, please focus on the sibling who is between 5 and 17 years of age and who is closest in age to the child with ASD.

21. What is the date of birth of your typically developing child?

22. Is your typically developing child male or female?

Male

Female

23. Does your typically developing child attend the same school as your child with autism? Please circle your response.

Same school

Different school

24. Recent data from research with families of children with special needs has shown that a family's financial resources are important in understanding family member's views and experiences. With this in mind, we would be very grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether those with high versus lower levels of financial resources have different experiences.

What is your current total annual family income? Please include a rough estimate of total salaries and other income (including benefits) before tax and national insurance/pensions.

Please tick one box only:

Less than £15,000.....

£15,001 to £25,000.....

£25,001 to £35,000.....

£35,001 to £45,000.....

£45,001 to £55,000.....

£55,001 to £65,000.....

£65,001 to 75,000.....

£75,001 to 85,000.....

£85,001 or more.....

25) Please indicate by placing a tick ✓ in the appropriate box if you have attended any of the following parent workshops or courses

	Please rate how satisfied you were with the support you received from the workshop that you attended.				
	Excellent	Very good	Good	Satisfactory	Poor
NAS Help! Programme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NAS Help!2 Seminar on siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NAS EarlyBird	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
More Than Words	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other parent workshop
please specify:

<i>Excellent</i>	<i>Very good</i>	<i>Good</i>	<i>Satisfactory</i>	<i>Poor</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If there are other children living in the house please tell us how they are related to your child with autism (e.g. biological brother, step brother) and their date of birth (DOB) (e.g. 03/07/80)? *Please list ALL children!* Place a tick next to the sibling that is closest in age to the child with autism (choose one sibling only).

Child 1. Sex:.....DOB DD/MM/YY Relationship to child.....

Any special needs, disabilities, or mental health difficulties? If yes, please state.....

.....

Child 2. Sex:.....DOB DD/MM/YY Relationship to child.....

Any special needs, disabilities, or mental health difficulties? If yes, please state.....

.....

Child 3. Sex:.....DOB DD/MM/YY Relationship to child.....

Any special needs, disabilities, or mental health difficulties? If yes, please state.....

.....

Child 4. Sex:.....DOB DD/MM/YY Relationship to child.....

Any special needs, disabilities, or mental health difficulties? If yes, please state.....

.....

Child 5. Sex:.....DOB DD/MM/YY Relationship to child.....

Any special needs, disabilities, or mental health difficulties? If yes, please state.....

.....

Appendix K
Strengths and Difficulties Questionnaire for Siblings

We would like you to complete this questionnaire for the typically developing sibling, closest in age, to your child with autism (this is the sibling that you ticked the box for, above. Please make sure that both you and the secondary carer are reporting on the same sibling). For each item, please circle Not True, Somewhat True or Certainly True. Please give your answers on the basis of your typically developing child's behaviour over the last six months. Thank you.

Is your child.....

	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	True	True	True
2. Restless, overactive, cannot stay still for long	True	True	True
3. Often complains of headaches, stomach-aches or sickness	True	True	True
4. Shares readily with other children (treats, toys, pencils etc)	True	True	True
5. Often has temper tantrums or a hot temper	True	True	True
6. Rather solitary; tends to play alone	True	True	True
7. Generally obedient, usually does what adults request	True	True	True
8. Many worries, often seems worried	True	True	True
9. Helpful if someone is hurt, upset or feeling ill	True	True	True
10. Constantly fidgeting or squirming	True	True	True
11. Has at least one good friend	True	True	True
12. Often fights with other children or bullies them	True	True	True
13. Often unhappy, down-hearted or tearful	True	True	True
14. Generally liked by other children	True	True	True
15. Easily distracted, concentration wanders	True	True	True
16. Nervous or clingy in new situations, easily loses confidence	True	True	True
17. Kind to younger children	True	True	True
18. Often lies or cheats	True	True	True
19. Picked on or bullied by other children	True	True	True
20. Often volunteers to help others (parents/teachers/other children)	True	True	True

21. Thinks things out before acting	Not True	Somewhat True	Certainly True
22. Steals from home, school or elsewhere	Not True	Somewhat True	Certainly True
23. Gets on better with adults than with other children	Not True	Somewhat True	Certainly True
24. Many fears, easily scared	Not True	Somewhat True	Certainly True
25. Sees tasks through to the end, good attention span	Not True	Somewhat True	Certainly True

Appendix L
Child with Autism Strengths and Difficulties Questionnaire

We would like you to complete this questionnaire for your **child with autism**. For each item, please circle Not True, Somewhat True or Certainly True. Please give your answers on the basis of your child with special needs' behaviour over the last six months. Thank you.

Is your child with autism...

	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	True	True	True
2. Restless, overactive, cannot stay still for long	True	True	True
3. Often complains of headaches, stomach-aches or sickness	True	True	True
4. Shares readily with other children (treats, toys, pencils etc)	True	True	True
5. Often has temper tantrums or a hot temper	True	True	True
6. Rather solitary, tends to play alone	True	True	True
7. Generally obedient, usually does what adults request	True	True	True
8. Many worries, often seems worried	True	True	True
9. Helpful if someone is hurt, upset or feeling ill	True	True	True
10. Constantly fidgeting or squirming	True	True	True
11. Has at least one good friend	True	True	True
12. Often fights with other children or bullies them	True	True	True
13. Often unhappy, down-hearted or tearful	True	True	True
14. Generally liked by other children	True	True	True
15. Easily distracted, concentration wanders	True	True	True
16. Nervous or clingy in new situations, easily loses confidence	True	True	True
17. Kind to younger children	True	True	True
18. Often lies or cheats	True	True	True
19. Picked on or bullied by other children	True	True	True
20. Often volunteers to help others (parents/teachers/other children)	True	True	True
21. Thinks things out before acting	True	True	True
22. Steals from home, school or elsewhere	True	True	True

23. Gets on better with adults than with other children	Not True	Somewhat True	Certain True
24. Many fears, easily scared	Not True	Somewhat True	Certain True
25. Sees tasks through to the end, good attention span	Not True	Somewhat True	Certain True

Appendix M
The Adolescent AQ Questionnaire

**The Adolescent (AQ) Questionnaire
Ages 12+ years**

NOTE: This questionnaire is to be completed by the parent/main carer for the typically developing child aged 12 to 15 years. Please complete all three pages.

Thank you.

Age of typically developing child.....

Please answer each of the following questions about your typically developing child or the typically developing child who is under your care by ticking a box that reflects your answer to the question most appropriately. If there is any question that you feel not able to comment, please ask your son, daughter, partner or the person to answer.

DO NOT MISS ANY STATEMENT OUT.

Examples

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
E1. S/he is willing to take risks.	√			
E2. S/he likes playing board games.			√	
E3. S/he finds learning to play musical instruments easy.		√		
E4. S/he is fascinated by other cultures.				√

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1. S/he prefers to do things with others rather than on her/his own.				
2. S/he prefers to do things the same way over and over again.				
3. If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind.				
4. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things.				
5. S/he often notices small sounds when others do not.				
6. S/he usually notices car number plates or similar strings of information.				
7. Other people frequently tell her/him that what s/he has said is impolite, even though s/he thinks it is polite.				
8. When s/he is reading a story, s/he can easily imagine what the characters might look like.				
9. S/he is fascinated by dates.				
10. In a social group, s/he can easily keep track of several different people's conversations.				
11. S/he finds social situations easy.				
12. S/he tends to notice details that others do not.				
13. S/he would rather go to a library than a party.				
14. S/he finds making up stories easy.				
15. S/he finds her/himself drawn more strongly to people than to things.				
16. S/he tends to have very strong interests, which s/he gets upset about if s/he can't pursue.				
17. S/he enjoys social chit-chat.				

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
18. When s/he talks, it isn't always easy for others to get a word in edgeways.				
19. S/he is fascinated by numbers.				
20. When s/he is reading a story, s/he finds it difficult to work out the characters' intentions.				
21. S/he doesn't particularly enjoy reading fiction.				
22. S/he finds it hard to make new friends.				
23. S/he notices patterns in things all the time.				
24. S/he would rather go to the theatre than a museum.				
25. It does not upset him/her if his/her daily routine is disturbed.				
26. S/he frequently finds that s/he doesn't know how to keep a conversation going.				
27. S/he finds it easy to "read between the lines" when someone is talking to her/him.				
28. S/he usually concentrates more on the whole picture, rather than the small details.				
29. S/he is not very good at remembering phone numbers.				
30. S/he doesn't usually notice small changes in a situation, or a person's appearance.				
31. S/he knows how to tell if someone listening to him/her is getting bored.				
32. S/he finds it easy to do more than one thing at once.				
33. When s/he talks on the phone, s/he is not sure when it's her/his turn to speak.				
34. S/he enjoys doing things spontaneously.				

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
35. S/he is often the last to understand the point of a joke.				
36. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.				
37. If there is an interruption, s/he can switch back to what s/he was doing very quickly.				
38. S/he is good at social chit-chat.				
39. People often tell her/him that s/he keeps going on and on about the same thing.				
40. When s/he was younger, s/he used to enjoy playing games involving pretending with other children.				
41. S/he likes to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).				
42. S/he finds it difficult to imagine what it would be like to be someone else.				
43. S/he likes to plan any activities s/he participates in carefully.				
44. S/he enjoys social occasions.				
45. S/he finds it difficult to work out people's intentions.				
46. New situations make him/her anxious.				
47. S/he enjoys meeting new people.				
48. S/he is a good diplomat.				
49. S/he is not very good at remembering people's date of birth.				
50. S/he finds it very easy to play games with children that involve pretending.				

Appendix N
Child AQ Questionnaire (4+)

Child AQ Questionnaire (4+)

NOTE: This questionnaire is to be completed by the parent/guardian for the typically developing child aged up to 11 yrs. Please complete all three pages. Thank you.

Age of typically developing child.....

Please answer each of the following questions about your typically developing child or the person who is under your care by ticking a box that reflects your answer to the question most appropriately. If there is any question that you feel not able to comment, please ask your son, daughter, partner or the person to answer.

	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
8. S/he prefers to do things with others rather than on her/his own.				
9. S/he prefers to do things the same way over and over again.				
10. If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind.				
11. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things.				
12. S/he often notices small sounds when others do not.				
13. S/he usually notices house numbers or similar strings of information.				
14. S/he has difficulty understanding rules for polite behaviour.				
51. When s/he is read a story, s/he can easily imagine what the characters might look like.				
52. S/he is fascinated by dates.				
53. In a social group, s/he can easily keep track of several different people's conversations.				
54. S/he finds social situations easy.				
55. S/he tends to notice details that others do not.				

56. S/he would rather go to a library than a birthday party.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
57. S/he finds making up stories easy.				
58. S/he is drawn more strongly to people than to things.				
59. S/he tends to have very strong interests, which s/he gets upset about if s/he can't pursue.				
60. S/he enjoys social chit-chat.				
61. When s/he talks, it isn't always easy for others to get a word in edgeways.				
62. S/he is fascinated by numbers.				
63. When s/he is read a story, s/he finds it difficult to work out the characters' intentions or feelings.				
64. S/he doesn't particularly enjoy fictional stories.				
65. S/he finds it hard to make new friends.				
66. S/he notices patterns in things all the time.				
67. S/he would rather go to the cinema than a museum.				
68. It does not upset him/her if his/her daily routine is disturbed.				
69. S/he doesn't know how to keep a conversation going with her/his peers.				
70. S/he finds it easy to "read between the lines" when someone is talking to her/him.				
71. S/he usually concentrates more on the whole picture, rather than the small details.				
72. S/he is not very good at remembering phone numbers.				
73. S/he doesn't usually notice small changes in a situation, or a person's appearance.				

74. S/he knows how to tell if someone listening to him/her is getting bored.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
75. S/he finds it easy to go back and forth between different activities.				
76. When s/he talk on the phone, s/he is not sure when it's her/his turn to speak.				
77. S/he enjoys doing things spontaneously.				
78. S/he is often the last to understand the point of a joke.				
79. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.				
80. If there is an interruption, s/he can switch back to what s/he was doing very quickly.				
81. S/he is good at social chit-chat.				
82. People often tell her/him that s/he keeps going on and on about the same thing.				
83. When s/he was in preschool, s/he used to enjoy playing games involving pretending with other children.				
84. S/he likes to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).				
85. S/he finds it difficult to imagine what it would be like to be someone else.				
86. S/he likes to plan any activities s/he participates in carefully.				
87. S/he enjoys social occasions.				
88. S/he finds it difficult to work out people's intentions.				
89. New situations make him/her anxious.				
90. S/he enjoys meeting new people.				

91. S/he is good at taking care not to hurt other people's feelings.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
92. S/he is not very good at remembering people's date of birth.				
93. S/he finds it very to easy to play games with children that involve pretending.				

Appendix O
Sibling Relationship Questionnaire

We would like you to complete this questionnaire about your typically developing child and your child with autism. Please read the questions and place a tick in the box that you think is right. Thank you.

The phrase "this sibling" refers to your child with autism

Blank lines (_____) refer to your typically developing child

<p>1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both _____ and this sibling do nice things for each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>2. Who usually gets treated better by mother, _____ or this sibling?</p>	<table border="1"> <tr> <td><input type="checkbox"/></td> <td><i>This sibling almost always gets treated better</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>This sibling often gets treated better</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>The children get treated about the same</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ often gets treated better</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ almost always gets treated better</i></td> </tr> </table>	<input type="checkbox"/>	<i>This sibling almost always gets treated better</i>	<input type="checkbox"/>	<i>This sibling often gets treated better</i>	<input type="checkbox"/>	<i>The children get treated about the same</i>	<input type="checkbox"/>	<i>_____ often gets treated better</i>	<input type="checkbox"/>	<i>_____ almost always gets treated better</i>
<input type="checkbox"/>	<i>This sibling almost always gets treated better</i>										
<input type="checkbox"/>	<i>This sibling often gets treated better</i>										
<input type="checkbox"/>	<i>The children get treated about the same</i>										
<input type="checkbox"/>	<i>_____ often gets treated better</i>										
<input type="checkbox"/>	<i>_____ almost always gets treated better</i>										
<p>3. How much does _____ show this sibling how to do things he or she doesn't know how to do?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>4. How much does this sibling show _____ how to do things he or she doesn't know how to do?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>5. How much does _____ tell this sibling what to do?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>6. How much does this sibling tell _____ what to do?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>7. Who usually gets treated better by father, _____ or this sibling?</p>	<p><input type="checkbox"/> <i>This sibling almost always gets treated better</i></p> <p><input type="checkbox"/> <i>This sibling often gets treated better</i></p> <p><input type="checkbox"/> <i>The children get treated about the same</i></p> <p><input type="checkbox"/> _____ <i>often gets treated better</i></p> <p><input type="checkbox"/> _____ <i>almost always gets treated better</i></p>										
<p>8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do _____ and this sibling care about each other?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>9. How much do _____ and this sibling go places and do things together?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>10. How much do _____ and this sibling insult and call each other names?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>11. How much do _____ and this sibling like the same things?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>12. How much do _____ and this sibling tell each other everything?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>13. Some siblings try to out-do or beat each other at things a lot, while other siblings don't do this much. How much do _____ and this sibling try to out-do each other?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>14. How much does _____ admire and respect this sibling?</p>	<table border="1"> <tr> <td style="text-align: center;">Very Little</td> <td style="text-align: center;">A Little</td> <td style="text-align: center;">Average</td> <td style="text-align: center;">A lot</td> <td style="text-align: center;">Very Much</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>15. How much does this sibling admire and respect _____?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>16. How much do _____ and this sibling disagree and quarrel with each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do _____ and this sibling cooperate with other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>18. Who gets more attention from mother, _____ or this sibling?</p>	<table border="1"> <tr> <td><input type="checkbox"/></td> <td><i>This sibling almost always gets more attention</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>This sibling often gets more attention</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>The children get about the same amount of attention</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ often gets more attention</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ almost always gets more attention</i></td> </tr> </table>	<input type="checkbox"/>	<i>This sibling almost always gets more attention</i>	<input type="checkbox"/>	<i>This sibling often gets more attention</i>	<input type="checkbox"/>	<i>The children get about the same amount of attention</i>	<input type="checkbox"/>	<i>_____ often gets more attention</i>	<input type="checkbox"/>	<i>_____ almost always gets more attention</i>
<input type="checkbox"/>	<i>This sibling almost always gets more attention</i>										
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<input type="checkbox"/>	<i>_____ often gets more attention</i>										
<input type="checkbox"/>	<i>_____ almost always gets more attention</i>										
<p>19. How much does _____ help this sibling with things he or she can't do by him or herself?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>20. How much does this sibling help _____ with things he or she can't do by him or herself?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>21. How much does _____ make this sibling do things?</p>	<table border="1"> <tr> <td>Very Little</td> <td>Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>22. How much does this sibling make _____ do things?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>23. Who gets more attention from father, _____ or this sibling?</p>	<p><input type="checkbox"/> <i>This sibling almost always gets more attention</i></p> <p><input type="checkbox"/> <i>This sibling often gets more attention</i></p> <p><input type="checkbox"/> <i>The children get about the same amount of attention</i></p> <p><input type="checkbox"/> _____ <i>often gets more attention</i></p> <p><input type="checkbox"/> _____ <i>almost always gets more attention</i></p>										
<p>24. How much do _____ and this sibling love each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>25. Some siblings play around and have fun with each other a lot, while other siblings don't do this much. How much do _____ and this sibling play around and have fun with each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>26. How much are _____ and this sibling mean to each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>27. How much do _____ and this sibling have in common?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>28. How much do _____ and this sibling share secrets and private feelings?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>29. How much do _____ and this sibling compete with each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>30. How much does _____ look up to and feel proud of this sibling?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>31. How much does this sibling look up to and feel proud of _____?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>32. How much do _____ and this sibling get angry at and get in arguments with each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>33. How much do both _____ and this sibling share with each other?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>34. Who does mother usually prefer, _____ or this sibling?</p>	<table border="1"> <tr> <td><input type="checkbox"/></td> <td><i>This sibling almost always is preferred</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>This sibling is often preferred</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>Both children are equally preferred</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ is often preferred</i></td> </tr> <tr> <td><input type="checkbox"/></td> <td><i>_____ is almost always preferred</i></td> </tr> </table>	<input type="checkbox"/>	<i>This sibling almost always is preferred</i>	<input type="checkbox"/>	<i>This sibling is often preferred</i>	<input type="checkbox"/>	<i>Both children are equally preferred</i>	<input type="checkbox"/>	<i>_____ is often preferred</i>	<input type="checkbox"/>	<i>_____ is almost always preferred</i>
<input type="checkbox"/>	<i>This sibling almost always is preferred</i>										
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<input type="checkbox"/>	<i>_____ is often preferred</i>										
<input type="checkbox"/>	<i>_____ is almost always preferred</i>										
<p>35. How much does _____ teach this sibling things that he or she doesn't know?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>36. How much does this sibling teach _____ things that he or she doesn't know?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>37. How much does _____ order this sibling around?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							
<p>38. How much does this sibling order _____ around?</p>	<table border="1"> <tr> <td>Very Little</td> <td>A Little</td> <td>Average</td> <td>A lot</td> <td>Very Much</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </table>	Very Little	A Little	Average	A lot	Very Much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very Little	A Little	Average	A lot	Very Much							
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>							

<p>39. Who does father usually prefer, _____ or this sibling?</p>	<table border="1"><tr><td data-bbox="1216 219 1287 311"><input type="checkbox"/></td><td data-bbox="1297 219 1829 311"><i>This sibling almost always is preferred</i></td></tr><tr><td data-bbox="1216 320 1287 412"><input type="checkbox"/></td><td data-bbox="1297 320 1829 412"><i>This sibling is often preferred</i></td></tr><tr><td data-bbox="1216 421 1287 512"><input type="checkbox"/></td><td data-bbox="1297 421 1829 512"><i>Both children are equally preferred</i></td></tr><tr><td data-bbox="1216 521 1287 613"><input type="checkbox"/></td><td data-bbox="1297 521 1829 613"><i>_____ is often preferred</i></td></tr><tr><td data-bbox="1216 622 1287 714"><input type="checkbox"/></td><td data-bbox="1297 622 1829 714"><i>_____ is almost always preferred</i></td></tr></table>	<input type="checkbox"/>	<i>This sibling almost always is preferred</i>	<input type="checkbox"/>	<i>This sibling is often preferred</i>	<input type="checkbox"/>	<i>Both children are equally preferred</i>	<input type="checkbox"/>	<i>_____ is often preferred</i>	<input type="checkbox"/>	<i>_____ is almost always preferred</i>
<input type="checkbox"/>	<i>This sibling almost always is preferred</i>										
<input type="checkbox"/>	<i>This sibling is often preferred</i>										
<input type="checkbox"/>	<i>Both children are equally preferred</i>										
<input type="checkbox"/>	<i>_____ is often preferred</i>										
<input type="checkbox"/>	<i>_____ is almost always preferred</i>										

Appendix P
The Hospital Anxiety and Depression Scale

This questionnaire is designed to help to show how you feel. Please read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response. Thank you.

I feel tense or 'wound up'

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

3
2
1
0

I feel as if I am slowed down

- Nearly all the time
- Very Often
- Sometimes
- Not at all

3
2
1
0

I still enjoy the things I used to enjoy

- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

0
1
2
3

I get a sort of frightened feeling like 'butterflies' in the stomach

- Not at all
- Occasionally
- Quite Often
- Very often

0
1
2
3

I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

3
2
1
0

I have lost interest in my appearance

- Definitely
- I don't take as much care as I should
- Sometimes
- Not at all

3
2
1
0

I can laugh and see the funny side of things

- As much as I always could
- Not quite as much now
- Definitely not so much now
- Not at all

0
1
2
3

I feel restless as if I have to be on the move

- Very much indeed
- Quite a lot
- Not very much
- Not at all

3
2
1
0

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- Not too often
- Very little

3
2
1
0

I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

0
1
2
3

I feel cheerful

- Never
- Not often
- Sometimes
- Most of the time

3
2
1
0

I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

3
2
1
0

I can sit at ease and feel relaxed

- 0
- 1
- 2
- 3

Definitely
Usually
Not Often
Not at all

I can enjoy a good book or television programme

Often
Sometimes
Not often
Very seldom

- 0
- 1
- 2
- 3

Appendix Q
Final Invite Letter



Dear Parent,

Re: How do brothers and sisters feel about growing up with a sibling with an Autism Spectrum Disorder?

Thank you for attending the *help!* Programme; it was a pleasure to meet you. For your information I have included a brief update of new resources that might be helpful for you and your family.

On a different note, I am also writing to you to let you know about a piece of research that may be of real interest to you. A shared concern for many parents who come onto the help programme is how best to support, not only their child with ASD, but their brothers and sisters. There is currently very little research to help us better understand the experiences of siblings, and even less research about effective ways to support them.

In light of this gap over the last two years The National Autistic Society has been working with the University of Wales - Bangor to learn more about sibling experiences. To this aim the research team is embarking on a large scale study of siblings across the UK. - If you are interested in taking part in the study or would like more information, please complete the interest form enclosed and return this to the Research team in the SAE provided. I realise that you may have already taken part in research studies, and it is entirely up to you if you would like to take part in the study.

It is our sincere hope that the knowledge gained from the study will benefit siblings of children with autism in a practical way, and will inform our work. We would be very happy to share the results of the study with you, and can assure you that any information you provide will be treated with the utmost respect and confidentiality. It will be subject to the high standards of professional integrity demanded by the University of Wales, and neither you or your family would be identified in any way.

The research is being conducted by Michael Petalas who is a postgraduate research student at the University of Wales - Bangor. Michael has a background both in research and in working directly with young people with Autism, he will be happy to answer any questions that you may have about the research and what it entails.

Thank you very much for taking the time to read this letter,

Yours Faithfully,

Andrew Powell

Head of *help!*

Information Sheet for Families

Study Title

The Autism Families Research Study

Project Team

Michael Petalas, Research Student

Richard Hastings, Professor of Psychology

Alan Dowey, Clinical Psychologist

Susie Nash, Postdoctoral Research Officer

Helen Joannidi, Trainee Clinical Psychologist

Louise Hall, Trainee Clinical Psychologist

The research is a partnership between the University of Wales, Bangor and the National Autistic Society (NAS) Cymru, who are funding part of the research along with the European Social Fund. We are interested in hearing from any family caring for a child with an ASD (autism spectrum disorder) who is between 5 and 17 years of age.

What is the purpose of the study?

We are interested in exploring how families of children with autism are affected by the experience of living with a child with ASD (e.g. autism, Asperger's syndrome). In particular, we wish to better understand the perspective of siblings (brothers and sisters) and how parents and carers cope with a child with autism in the family. We would like to get information from a number of families around the UK in order to get a good idea of the different experiences they have. We will be providing a report on the results of our research to the NAS and so hope that the information will be used in future planning of support for families of children with ASD.

What are the benefits of taking part?

The main benefit of this research is to improve the knowledge that we have about the needs of families of children with autism. By giving families the opportunity to tell us about their experiences living with a child with autism, we will have information that we can use to help professionals have a better understanding of what these families' needs are, and how to best support these needs. There is relatively little research on families of children with autism and their experiences. We hope that this research will help improve services for families of children with autism.

What are the risks of taking part?

We do not believe that the families taking part in this study are being put at risk in any way. There is a small possibility however, that for some people, answering questions about their family member with autism may be distressing. If you take part in this study, you will be able to withdraw at any time, and there will be no pressure whatsoever to answer any of the questions. Information and advice about further support will be provided if requested. If needed, please contact Michael Petalas on the telephone number below.

All the information that you and your family provide will be treated as strictly confidential material, and will be kept securely locked in a filing cabinet without names attached. The researchers alone will have access to the telephone interview recordings and questionnaires. The only exception to this, which is standard practice, will be if an individual discloses information relating to child abuse, intent to harm self or others, in which case the researcher has a duty to report such information.

Do we have to take part?

It is entirely up to you to decide if you would like to participate in this study. If you do decide to take part, please fill in the consent and contact forms enclosed and return them in the envelope provided. You may keep this information sheet for your records. You will have the freedom to change your mind at any time and without giving a reason. However, if you have sent back the initial consent form to say that you and your family will take part, and you have not sent back the questionnaires after one month, we may send you a reminder in the post.

What will happen to me if I take part in this research?

Once you have sent us your consent and contact form, we will send you a questionnaire pack to fill in. In addition, Mike, Louise, or Helen will telephone you (only if you have agreed via your consent and contact form) to talk about your child with ASD and your typically developing (without ASD) child that is closest in age to your child with autism - if there is one in the home. The phone call is expected to last for approximately 45 minutes. The questionnaire pack will contain one, two, or three questionnaires depending on the information you provide us with in your contact form. The yellow forms will be for the primary carer (this is the adult in the home that spends the most time caring for the child with ASD, i.e. a parent, partner, grandparent, foster parent, etc), The green forms will be for the secondary carer (this is the adult in the home that also cares for the child with ASD but spends less time doing so than the primary carer, i.e. a parent, partner, grandparent, foster parent, etc). Finally, the blue forms will be, for the typically developing sibling that is aged between 5 and 17 years and that is closest in age to the child with autism. You will be asked to choose only one typically developing sibling and make sure that both the primary carer, and the secondary carer are reporting on the same sibling, and that sibling is also the one filling in the blue forms (siblings between 5 and 8 years of age will not be completing any forms themselves). We will give you a freepost envelope to return all questionnaires. If you are a primary carer of a child with autism we want to hear from you, even if there isn't a secondary carer or a typically developing sibling in the home.

While we are able to provide you with Welsh versions of some of the forms, regrettably, the questionnaires are available in English only. This is because the questionnaires have only been published in English and translating them would invalidate their use for research purposes. We appreciate your understanding.

For further details and if you wish to contact the research team, please contact Mike Petalas by telephone, email or post:

Michael Petalas
Postgraduate Research Student
Intellectual and Developmental Disabilities Research Group
School of Psychology
University of Wales, Bangor
Adeilad Brigantia,
Penrallt Road
Bangor, Gwynedd
UK
LL57 2AS
Tel: ++44 (0)1248 351151 extention: 8706
E-mail: psp202@bangor.ac.uk

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Dr. Oliver Turnbull
Head of School
School of Psychology
University of Wales, Bangor
Adeilad Brigantia
Penrallt Road
Bangor, Gwynedd
LL57 2AS

To be completed and returned to the Researcher if you agree to take part

The Autism Families Research Study

Initial Consent and Contact Form to be completed by the main carer

Signing and returning this form means that you agree to be contacted further about this research. It also means that you consent to receiving questionnaire packs. Please answer the following questions about your family and provide your contact details. This will allow us to send you the correct questionnaire pack for the study.

4. Please confirm that you are the main carer for a child with autism between the ages of 5 and 17 years. YES

How old is your child with autismyears

What is your relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

5. Is there a secondary carer living in the home? YES / NO

If YES,
What is their relationship to the main carer (e.g. spouse, partner, mother, father, etc)

.....

What is their relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

6. Does the child with autism have any siblings (brothers or sisters) that currently live in the home? YES / NO

If YES, please list the ages of the siblings below.

Sibling 1, age:	years	Sibling 5, age:	Years
Sibling 2, age:	years	Sibling 6, age:	Years
Sibling 3, age:	years	Sibling 7, age:	Years
Sibling 4, age:	years	Sibling 8, age:	Years

Please fill out your contact details. This allows us to send you the questionnaire pack for our study.

Name

Address: _____

Postal Code: _____

We will also need the telephone of the main carer to ask some questions about the child with autism and their sibling. Please give details of the telephone number below and an indication of the best time for a researcher to contact the main carer.

Telephone no.: _____

The best time(s) to telephone the main carer are:
(e.g. Evenings between 5pm – 7pm; Mornings between 10am – 11.30am)

.....
.....
.....
.....

I have read the enclosed information sheet and agree to be sent a questionnaire pack for my family to participate in 'The Wales Study of Families of Children with Autism'.

Signature: _____ Date: _____

Name in Capitals: _____

Please tick this box if you would like to receive information in Welsh/or bilingually in Welsh and English in future where this is available.

Welsh
Bilingual

Appendix R
Reminder Letter

Michael Petalas
 Postgraduate Research Student
 Intellectual and Developmental Disabilities Research Group (IDDRG)
 Adeilad Brigantia, Penrallt Road
 Bangor, Gwynedd
 LL57 2AS
 Tel: ++44 (0)1248 351151 ext 8706
 E-mail: psp202@bangor.ac.uk

26 November 2008

Dear Primary Carer,

I am writing with reference to the questionnaire(s) we sent to you from the Autism Families Research Study. If you are still happy to complete the questionnaires then please send them using the freepost envelopes provided. If at the time you receive this reminder you have already sent the questionnaires to us, we apologise for this, please ignore our reminder. If you would now like more information about the study or help with completing the questionnaires, or would like us to send you another copy of the questionnaires please contact me. If you no longer wish to complete the questionnaires, please send them back in the envelope provided and I will not contact you again. I look forward to hearing from you soon.

Best Regards,

Michael Petalas

Postgraduate Research Student

• PRIFYSGOL CYMRU •
 UNIVERSITY OF WALES
BANGOR



Appendix S
Final Invite: Welsh Version

Annwyl Riant,

Parthed: Sut mae brodyr a chwiorydd yn teimlo am dyfu mewn cartref gyda brawd neu chwaer ag Anhwylder ar y Sbectrwm Awtistaidd?

Diolch yn fawr i chi am fynychu'r rhaglen help!; roedd yn bleser eich cyfarfod. Er gwybodaeth rwyf wedi cynnwys gwybodaeth am adnoddau newydd a allai fod o help i chi a'ch teulu.

Ar nodyn gwahanol, ysgrifennaf atoch hefyd i roi gwybod i chi am ddarn o ymchwil a allai fod o ddiddordeb mawr i chi. Un pryder sy'n gyffredin i lawer o rieni sy'n mynychu'r rhaglen help yw sut orau i gefnogi, nid yn unig eu plentyn ag ASD, ond eu brodyr a'u chwiorydd. Ychydig iawn o ymchwil a wnaed hyd yn hyn i'n helpu i ddeall profiadau brodyr a chwiorydd yn well, a llai fyth am ffyrdd effeithiol o'u cefnogi.

Oherwydd y diffyg yma dros y ddwy flynedd ddiwethaf mae'r Gymdeithas Awtistiaeth genedlaethol wedi bod yn gweithio gyda Phrifysgol Cymru, Bangor i ddysgu mwy am brofiadau brodyr a chwiorydd. I'r perswyl hwn mae'r tîm ymchwil yn cychwyn ar astudiaeth fawr o frodyr a chwiorydd ar draws y DU. - Os oes gennych ddiddordeb mewn cymryd rhan yn yr astudiaeth neu os hoffech gael mwy o wybodaeth, llenwch y ffurflen datgan diddordeb amgaeedig a'i hanfon yn ôl at y tîm Ymchwil yn yr amlen barod. Rwyf yn ymwybodol efallai eich bod eisoes wedi cymryd rhan mewn astudiaethau ymchwil, a chi sydd i benderfynu a hoffech gymryd rhan yn yr astudiaeth.

Rydym yn gobeithio'n fawr y bydd y wybodaeth a geir o'r astudiaeth o fudd ymarferol i frodyr a chwiorydd plant ag awtistiaeth, ac yn gymorth i'n gwaith. Byddem yn hapus iawn i rannu canlyniadau'r astudiaeth gyda chi, a gallaf eich sicrhau y bydd unrhyw wybodaeth a ddarparwch yn cael ei thrin yn gwbl gyfrinachol ac â'r parch mwyaf. Bydd yn ddarostyngedig i'r safonau onestrwydd proffesiynol uchel y mae Prifysgol Cymru yn mynnu cadw atynt, ac ni fyddwn yn eich enwi chi na'ch teulu mewn unrhyw ffordd.

Bydd y gwaith ymchwil yn cael ei wneud gan Michael Petalas sy'n fyfyrwr ymchwil ôl-raddedig ym Mhrifysgol Cymru, Bangor. Mae gan Michael gefndir mewn ymchwil ac mewn gweithio'n uniongyrchol gyda phobl ifanc gydag Awtistiaeth, a bydd yn hapus i ateb unrhyw gwestiynau a all fod gennych am yr ymchwil a beth fydd yn digwydd.

Diolch yn fawr iawn i chi am roi o'ch amser i ddarllen y llythyr hwn.

Yn gywir

Andrew Powell

Pennaeth *help!*

Taflen Wybodaeth i Deuluoedd

Teitl yr Astudiaeth

Astudiaeth Ymchwil Teuluoedd ag Awtistiaeth

Tîm y Project:

Michael Petalas, Myfyriwr Ymchwil

Richard Hastings, Athro Seicoleg

Alan Dowey, Seicolegydd Clinigol

Susie Nash, Swyddog Ymchwil Ôl-ddoethuriaeth

Helen Joannidi, Seicolegydd Clinigol dan Hyfforddiant

Louise Hall, Seicolegydd Clinigol dan Hyfforddiant

Partneriaeth yw'r ymchwil rhwng Prifysgol Cymru, Bangor a Chymdeithas Awtistiaeth Genedlaethol Cymru, sy'n ariannu rhan o'r ymchwil gyda Chronfa Gymdeithasol Ewrop. Hoffem glywed gan unrhyw deulu sy'n gofalu am blentyn gydag ASD (Anhwylder Sbectrum Awtistaidd) sydd rhwng 5 ac 17 oed.

Beth yw pwrpas yr astudiaeth hon?

Mae gennym ddiddordeb mewn ymchwilio i sut mae'r profiad o fyw gyda phlentyn ag ASD (e.e. awtistiaeth, syndrom Asperger) yn effeithio ar deuluoedd. Yn enwedig, hoffem ddeall yn well safbwynt brodyr a chwiorydd a sut mae rhieni a gofalwyr yn ymdopi pan fydd plentyn ag awtistiaeth yn y teulu. Hoffem gael gwybodaeth gan nifer o deuluoedd o amgylch y DU er mwyn cael syniad da o'r profiadau gwahanol maent yn eu cael. Byddwn yn rhoi adroddiad ar ganlyniadau ein hymchwil i'r Gymdeithas Awtistiaeth Genedlaethol a'r gobaith yw y caiff y wybodaeth ei defnyddio wrth gynllunio cefnogaeth i deuluoedd plant ag ASD yn y dyfodol.

Beth yw manteision cymryd rhan?

Prif fantais yr ymchwil hon yw gwella'r wybodaeth sydd gennym am anghenion teuluoedd â phlant ag awtistiaeth. Trwy roi cyfle i deuluoedd i ddweud wrthym am eu profiadau'n byw gyda phlentyn ag awtistiaeth, cawn wybodaeth y gallwn ei defnyddio i helpu gweithwyr proffesiynol i ddeall yn well beth yw anghenion y teuluoedd hyn, a'r ffordd orau i gefnogi'r anghenion hyn. Cymharol ychydig o ymchwil sydd ar deuluoedd plant ag awtistiaeth a'u profiadau. Y gobaith yw y bydd yr ymchwil hon yn helpu i wella gwasanaethau i deuluoedd plant ag awtistiaeth.

Beth yw risgiau cymryd rhan?

Nid ydym yn credu bod teuluoedd sy'n cymryd rhan yn yr astudiaeth hon yn wynebu unrhyw fath o risg. Mae posiblwydd bach, fodd bynnag, y bydd rhai pobl yn ei dechrau teimlo'n ofidus wrth ateb cwestiynau am yr aelod o'r teulu ag awtistiaeth. Os cymerwch ran yn yr astudiaeth hon, cewch dynnu'n ôl ar unrhyw adeg, ac ni fydd unrhyw bwysau o gwbl arnoch i ateb unrhyw un o'r cwestiynau. Darperir gwybodaeth a chyngor am gefnogaeth bellach os oes angen. Os oes angen, cysylltwch â Michael Petalas ar y rhif ffôn isod.

Bydd yr holl wybodaeth yr ydych chi a'ch teulu'n ei ddarparu'n cael ei thrin yn gwbl gyfrinachol, a chaiff ei chadw'n ddiogel dan glo mewn cabinet ffeilio heb enwau arni. Dim ond yr ymchwilwyr fydd yn cael mynd at y recordiadau o'r cyfweiliadau ffôn a'r

holiaduron. Yr unig eithriad i hwn, sy'n ymarfer safonol, fydd os bydd unigolyn yn datgelu gwybodaeth yn ymwneud â cham-drin plant, y bwriad i anafu'r hunan neu eraill. Mewn achos felly mae gan yr ymchwilydd ddyletswydd i adrodd am wybodaeth o'r fath.

Oes raid i ni gymryd rhan?

Chi yn unig sydd i benderfynu a hoffech gymryd rhan yn yr astudiaeth hon. Os penderfynwch gymryd rhan, llenwch y ffurflenni cydsynio a chysylltu amgaeedig a'u hanfon yn ôl yn yr amlen a ddarparwyd. Gellwch gadw'r daflen wybodaeth hon at eich cofnodion. Byddwch yn rhydd i newid eich meddwl ar unrhyw adeg heb roi rheswm. Ond, os ydych wedi anfon y ffurflen gydsynio gychwynnol yn ôl yn dweud y byddwch chi a'ch teulu'n cymryd rhan, ac nad ydych wedi anfon yr holiaduron yn ôl ar ôl mis, mae'n bosib y byddwn yn anfon nodyn atgoffa atoch yn y post.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan yn yr ymchwil hon?

Unwaith byddwch wedi anfon eich ffurflen gydsynio a'ch ffurflen gysylltu, byddwn yn anfon pecyn holiadur atoch i'w lenwi. Hefyd, bydd Mike, Louise, neu Helen yn eich ffonio (dim ond os ydych wedi cytuno trwy eich ffurflenni cydsynion a chysylltu) i siarad am eich plentyn sydd ag ASD a'r brawd neu chwaer agosaf mewn oedran ato neu ati (plentyn heb ASD ac yn datblygu yn ôl normau) - os oes un yn y cartref. Disgwylir y bydd yr alwad ffôn yn parhau am ryw 45 munud. Bydd y pecyn holiaduron yn cynnwys un, dau neu dri o holiaduron yn dibynnu ar y wybodaeth yr ydych yn ei rhoi i ni yn eich ffurflen gysylltu. Bydd y ffurflenni melyn ar gyfer y prif ofalwr (dyma'r oedolyn yn y cartref sy'n treulio'r cyfnod mwyaf yn gofalu am y plentyn ag ASD h.y. rhiant, partner, taid neu nain, rhiant maeth etc.) Bydd y ffurflenni gwyrdd ar gyfer yr ail ofalwr (dyma'r oedolyn yn y cartref sydd hefyd yn gofalu am y plentyn ag ASD ond sy'n treulio llai o amser yn gwneud hynny na'r prif ofalwr h.y. rhiant, partner, taid neu nain, rhiant maeth etc.) Yn olaf defnyddir y ffurflenni glas ar gyfer y brawd neu chwaer rhwng 5 a 17 oed sy'n datblygu'n arferol ac sydd agosaf mewn oedran at y plentyn ag awtistiaeth. Gofynnir i chi ddewis dim ond un brawd neu chwaer sy'n datblygu'n arferol a gwneud yn siwr bod y prif ofalwr a'r ail ofalwr yn adrodd ar yr un brawd neu chwaer, ac mai'r brawd hwnnw neu'r chwaer honno sy'n llenwi'r ffurflenni glas (ni fydd brodyr neu chwiorydd rhwng 5 ac 8 oed yn llenwi unrhyw ffurflenni eu hunain). Byddwn yn rhoi amlen radbost i chi i anfon yr holl holiaduron yn ôl. Os ydych yn brif ofalwr plentyn ag awtistaeth hoffem glywed gennych, hyd yn oed os nad oes ail ofalwr neu frawd neu chwaer sy'n datblygu'n arferol yn y cartref.

Er y gallwn roi fersiynau Cymraeg i chi o rai o'r ffurflenni, gwaetha'r modd, dim ond fersiynau Saesneg o'r holiaduron sydd gennym. Mae hyn oherwydd bod yr holiaduron wedi cael eu cyhoeddi mewn Saesneg a byddai eu cyfieithu yn eu gwneud yn annilys at bwrpasau ymchwil. Diolch i chi am ddeall hyn.

I gael rhagor o fanylion ac os dymunwch gysylltu â'r tîm ymchwil, cysylltwch â Mike Petalas trwy ffôn, e-bost neu bost:

Michael Petalas
Myfyriwr Ymchwil Ôl-raddedig
Grŵp Ymchwil Anabledau Deallusol a Datblygol
Ysgol Seicoleg
Prifysgol Cymru, Bangor
Adeilad Brigantia,
Heol Penrallt
Bangor, Gwynedd
DU
LL57 2AS
Ffôn: ++44 (0)1248 351151 estyniad: 8706
E-bost: psp202@bangor.ac.uk

Os oes gennych unrhyw gwynion am y ffordd y mae'r ymchwil hon yn cael ei chynnal mae croeso i chi fynd i'r afael ag unrhyw bryderon sydd heb eu datrys i:

Dr. Oliver Turnbull
Pennaeth yr Ysgol
Ysgol Seicoleg
Prifysgol Cymru, Bangor
Adeilad Brigantia,
Heol Penrallt
Bangor, Gwynedd
LL57 2AS

Astudiaeth Ymchwil Teuluoedd ag Awtistiaeth

Ffurflen Gydsynio a Chyswllt i'w llenwi gan y prif ofalwr

Os byddwch yn llofnodi ac yn dychwelyd y ffurflen hon cymerwn eich bod yn cytuno i ni gysylltu â chi eto am yr ymchwil hon. Golyga hefyd eich bod yn cytuno i dderbyn pecynnau holiaduron. Atebwch y cwestiynau canlynol am eich teulu a rhowch eich manylion cyswllt. Bydd hyn yn ein galluogi i anfon y pecyn holiaduron cywir atoch ar gyfer yr astudiaeth.

7. Cadarnhewch mai chi yw'r prif ofalwr i blentyn ag awtistiaeth rhwng 5 ac 17 oed.
 IE

Beth yw oed eich plentyn ag awtistiaeth?oed.

Beth yw eich perthynas â'r plentyn ag awtistiaeth (e.e. mam, tad, nain, taid, rhiant maeth etc.)?

.....

8. Oes ail ofalwr yn byw yn y tŷ? OES / NAC OES

Os OES,

Beth yw eu perthynas â'r prif ofalwr (e.e. gŵr, gwraig, partner, mam, tad etc.)

.....

Beth yw eu perthynas â'r plentyn ag awtistiaeth (e.e. mam, tad, nain, taid, rhiant maeth etc.)?

.....

9. Oes gan y plentyn ag awtistiaeth unrhyw frodyr neu chwiorydd sy'n byw yn y tŷ ar hyn o bryd? OES / NAC OES

Os OES, rhestrwch oed y brodyr a'r chwiorydd isod.

Brawd/chwaer 1:	Oed	Brawd/chwaer 5, :	Oed
Brawd/chwaer 2:	Oed	Brawd/chwaer 6, :	Oed
Brawd/chwaer 3:	Oed	Brawd/chwaer 7, :	Oed
Brawd/chwaer 4:	Oed	Brawd/chwaer 8, :	Oed

Llenwch eich manylion cyswllt. Mae hyn yn ein galluogi i anfon y pecyn holiaduron sy'n gysylltiedig â'r astudiaeth atoch.

Enw

Cyfeiriad:

Cod Post:

Bydd angen rhif ffôn y prif ofalwr hefyd i ofyn rhai cwestiynau am y plentyn ag awtistiaeth a'r brawd/ chwaer. Rhowch fanylion y rhif ffôn isod a syniad o'r amser gorau i ymchwilydd gysyllu â'r prif ofalwr.

Rhif ffôn:

Yr amser(oedd) gorau i ffonio'r prif ofalwr yw:

(e.e. Nosweithiau rhwng 5pm – 7pm; Boreau rhwng 10am – 11.30am)

.....
.....
.....

Rydw i wedi darllen y daflen wybodaeth amgaeedig a chytunaf i dderbyn pecyn holiaduron fel y gall fy nheulu gymryd rhan yn "Astudiaeth o Deuluoedd ag Awtistiaeth yng Nghymru".

Llofnod:

Dyddiad :

Enw mewn Priflythrennau:

Ticiwch y blwch hwn os hoffech dderbyn gwybodaeth yn Gymraeg neu'n ddwyieithog yn Gymraeg a Saesneg yn y dyfodol pan fydd hyn ar gael.

Cymraeg

Dwyieithog

Appendix T
Consent and Demographic forms

Annwyl Riant /Gofalwr

Diolch yn fawr i chi am gytuno i gymryd rhan yn ein hymchwil i deuluoedd plant ag awtistiaeth. Dyma'r pecyn y bydd ei angen arnoch ar gyfer rhan gyntaf yr astudiaeth.

Dylai'r pecyn hwn gynnwys:

- i) Holiaduron i bob aelod o'r teulu sydd wedi cytuno i lenwi holiadur.
- ii) Amlen i bob aelod o'r teulu i selio ei holiadur ynddi.
- iii) Amlen fawr i anfon popeth yn ôl atom.

Cyfarwyddiadau i Lenwi'r Pecyn Holiaduron:

Mae'r Pecyn Holiaduron mewn tair rhan. Yn dibynnu ar y wybodaeth a anfonwyd gennych am eich teulu yn y ffurflen gydsynio gychwynnol, byddwn yn anfon un, dwy neu dair rhan atoch.

Mae'r pecyn melyn i'w lenwi gan famau neu brif ofalwyr*. Mae'r pecyn gwyrdd i'w lenwi gan bartneriaid. ** Mae'r pecyn glas i'w lenwi gan frodyr neu chwiorydd ***. Mae'n bosib nad ydych wedi derbyn pob un o'r tair rhan, mae hyn yn dibynnu ar y wybodaeth a roddwyd gennych am eich teulu o'r llythyr gwreiddiol a anfonwyd atoch. Mae ffurflen gydsynio ar wahân ar y blaen i bob rhan a gaiff ei datgysylltu o'r holiadur gan yr ymchwilwyr pan anfonir yr holiaduron yn ôl.

Os gwelwch yn dda:

- 1) Rhowch bob rhan o'r pecyn holiaduron i'r person priodol yn eich teulu. *Melyn i'r fam neu'r prif ofalwr, gwyrdd i'r partner a glas i frawd neu chwaer eich plentyn ag awtistiaeth.*
- 2) Rhaid i bawb sy'n llenwi rhan lofnodi'r ffurflen gydsynio a llenwi'r atebion i'r holiadur.
- 3) Ar ôl gorffen yr holiadur dylent ei selio yn yr amlen briodol.
- 4) Yna dylid rhoi rhannau gwahanol yr holiadur gyda'i gilydd yn yr amlen fwy a'i phostio'n ôl at y tîm ymchwil.

Bydd fydd yn digwydd nesaf?

Ar ôl derbyn yr holiaduron byddwn yn ffonio'r fam neu'r prif ofalwr ym mhob teulu rhwng Hydref 2007 a Chwefror 2008. Bydd un o'r ymchwilwyr yn rhoi cyfweiliad dros y ffôn a byddwn yn gofyn i chi am eich plant ac yn gofyn rhai cwestiynau am eich plentyn ag awtistiaeth. Bydd rhan o'r cyfweiliad ffôn yn cael ei recordio os ydych yn cytuno.

Mae'r holl wybodaeth yr ydych yn ei rhoi i ni yn cael ei thrin fel gwybodaeth gwbl gyfrinachol a'i chadw'n ddiogel dan glo mewn cabinet ffeilio heb unrhyw wybodaeth a allai ddangos pwy ydych chi. Bydd y ffurflenni cydsynio'n cael eu datgysylltu o'r holiaduron. Mae'r holl wybodaeth yn gyfrinachol ac ni chaiff ei rhoi i unrhyw un arall. Yr unig eithriad i hyn yw os dywedir rhywbeth yn ystod y cyfweiliad ffôn sy'n swnio fel pe bai plentyn yn cael ei frifo neu mewn perygl o gael ei frifo. Mewn achos felly, ein dyletswydd gyfreithiol yw rhoi'r wybodaeth hon i rywun arall.

Os ydych eisiau help gyda'ch ffurflen, cysylltwch â ni a byddwn yn hapus i'ch helpu i lenwi eich ffurflenni.

* Y partner neu'r ail ofalwr yw'r ail oedolyn yn y teulu, sy'n treulio llai o amser yn edrych ar ôl y plentyn ag awtistiaeth. Gall hwn fod yn fam, yn dad, yn nain neu'n daid, yn rhiant maeth neu'n ŵr/gwraig neu bartner y prif ofalwr/ Nid oes raid i'r partner fod yn briod â'r prif ofalwr

*** Os oes mwy nag un brawd neu chwaer gan y plentyn ag awtistiaeth hoffem i'r brawd neu'r chwaer agosaf mewn oedran lenwi'r ffurflen.

Ffurflen Gydsynio i Ymchwil i'r Prif Ofalwr

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

Llenwch y canlynol a rhowch gylch o amgylch eich ateb:

3) Ydych chi wedi darllen yr holl wybodaeth ar y ffurflen Gwybodaeth?

YDW/NAC YDW

2) Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?

YDW/NAC YDW

3) Ydych chi wedi cael atebion rhesymol i'ch holl gwestiynau?

YDW/NAC YDW

4) Ydych chi'n fodlon cymryd rhan yn yr astudiaeth holiadur ac i'r wybodaeth a rowch i ni gael ei defnyddio yn yr ymchwil hon?

YDW/NAC YDW

5) Ydych chi'n gwybod y gellwch newid eich meddwl a pheidio â chymryd rhan yn yr astudiaeth

...ar unrhyw adeg?

...Heb roi rheswm?

YDW/NAC YDW

6) Ydych chi'n fodlon cael eich cyfweld dros y ffôn, i ran o'r cyfweiliad gael ei recordio, ac i ni ddefnyddio'r wybodaeth hon ar gyfer ein hymchwil?

YDW/NAC YDW

7) Os oes brawd neu chwaer i'r plentyn ag awtistiaeth sydd rhwng 5 ac 17 oed ydych chi'n cytuno iddynt gymryd rhan yn yr astudiaeth holiaduron, ac i ni ddefnyddio'r wybodaeth hon yn ein hymchwil?

YDW/NAC YDW

Llofnod _____

Dyddiad _____

Enw mewn priflythrennau _____

Cyfeiriad _____

_____ Cod post _____

Rhif ffôn _____

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

Holiadur Cyffredinol i'w lenwi gan y Prif Ofalwr (y prif ofalwr yw'r person sy'n treulio'r amser mwyaf yn gofalu am y plentyn ag awtistiaeth). Gall yr unigolyn hwn fod yn fam, yn dad, yn nain neu'n daid, neu'n rhiant maeth. Nid oes raid i'r prif ofalwr berthyn trwy waed i'r plentyn ag awtistiaeth.)

Mae'r cwestiynau canlynol yn gofyn am wybodaeth gefndir amdanoch chi, eich teulu a'ch plentyn ag awtistiaeth. Ticiwch yr ateb priodol neu ysgrifennwch yn y bylchau a ddarperir.

1. Ai gwryw neu fenyw ydych chi? Rhowch gylch o gwmpas eich ateb. Gwryw Benyw

2. Nodwch eich perthynas â'r plentyn ag anhwylder sbectrwm awtistaidd (ASD) (e.e. mam. tad. llysfam, nain, rhiant mabwysiadol

.....

3. I ba un o'r grwpiau ethnig canlynol ydych yn perthyn yn eich barn chi? Ticiwch y blwch priodol.

Gwyn- Prydeinig	Unrhyw gefndir Asiaidd arall Nodwch.....
Gwyn - Gwyddelig	Du/ Du Prydeinig - Caribiaidd
Unrhyw gefndir Gwyn arall Nodwch.....	Unrhyw gefndir Du arall Nodwch.....
Gwyn a Charibiaidd du	Cymysg – Gwyn ac Asiaidd
Cymysg – Gwyn ac Affricanaidd du	Asiaidd/Asiaidd Prydeinig - Indiaidd
Unrhyw gefndir Cymysg arall	Asiaidd/Asiaidd Prydeinig - Bangladeshi
Asiaidd/Asiaidd Prydeinig - Pacistani	Du/ Du Prydeinig - Affricanaidd

4. Beth yw eich dyddiad geni?

D	D	M	M	B	B
---	---	---	---	---	---

5. Beth yw eich statws priodasol presennol?

Wedi priodi ac yn byw ar hyn o bryd gyda'r gŵr/wraig neu'n byw ar hyn o bryd gyda phartner.....

Wedi ysgaru/ wedi gwahanu/ sengl/ gweddw a DDIM yn byw gyda phartner ar hyn o bryd.....

6. Faint o bobl sy'n byw yn eich tŷ chi i gyd? ___ Oedolyn (oed +18) ___ Plentyn

7. Ticiwch lefel uchaf eich cymwysterau addysgol.

- Dim cymwysterau addysgol ffurfiol.....
- Llai na 5 TGAU neu Lefel O, NVQ 1, neu Ddiploma Cyntaf BTech.....
- 5 neu fwy o TGAU neu Lefel O, NVQ 2, neu gyfwerth.....
- 3 neu fwy o Lefel A, NVQ 3, BTECH Cenedlaethol, neu gyfwerth.....
- Gradd Bolytechnig/Prifysgol. NVQ4 neu gyfwerth.....
- Gradd Meistr/Doethurol, NVQ5 neu gyfwerth.....

8. Oes gennych swydd y tu allan i'r cartref ar hyn o bryd? OES NAC OES

Ydych chi'n gweithio'n llawn amser neu'n rhan amser? Llawn amser Rhan amser

9. Os ydych yn byw gyda'ch gŵr/gwraig/partner, oes ganddo ef/hi swydd y tu allan i'r cartref ar hyn o bryd?

Oes Nac oes

10. Os OES, ydy'n gweithio'n llawn amser neu'n rhan amser? Llawn amser Rhan amser

Eich Plentyn ag Awtistiaeth

Atebwch y cwestiynau canlynol am eich plentyn gydag ASD rhwng 5 ac 17 oed. Os oes gennych fwy nag un plentyn gydag ASD yn yr ystod oedran hon, canolbwyntiwch ar y plentyn hynaf sydd rhwng 5 ac 17 oed.

11. Ydy eich plentyn wedi cael diagnosis ffurfiol o anhwylder y sbectrwm awtistiaeth? Os felly, rhowch fanylion (e.e. Syndrom Asperger, Awtistiaeth, PDD-NOS,

Dywedwch wrthym pa mor hir yn ôl y rhoddwyd y diagnosis hwn a phwy a'i rhoddodd.

- Pa mor hir yn ôl y rhoddwyd y diagnosis (blynyddoedd/misoedd).....
- Pwy wnaeth y diagnosis (e.e. paediatregydd, seicolegydd clinigol).....

12. Beth yw dyddiad geni eich plentyn ag awtistiaeth?

D	D	M	M	B	B
---	---	---	---	---	---

13. Ai bachgen neu ferch yw eich plentyn ag awtistiaeth?
Merch

Bachgen

14. Nodwch isod unrhyw ddiagnoses/cyflyrau ychwanegol sydd ar eich plentyn ag awtistiaeth.

Syndrom Down

Palsi'r Ymennydd

Syndrom Fragile X

ADHD/Gorfywiogrwydd

Arall – rhowch fanylion _____

15. A oes gan eich plentyn ag awtistiaeth nam ar y synhwyrau sy'n amharu ar ei f/bywyd bob dydd?

Oes

Nac oes

Os oes, rhowch fanylion. Nam ar y synhwyrau

Nam ar y clyw

16. Ydy eich plentyn ag awtistiaeth yn dioddef ar hyn o bryd o ffitiau epileptig?

Ydy

Nac ydy

17. Oes gan eich plentyn ag awtistiaeth broblemau symud sy'n golygu ei bod yn anodd iddynt symud o gwmpas yn annibynnol (e.e. angen defnyddio cadair olwyn)?

Oes

Nac oes

18. Oes gan eich plentyn ag awtistiaeth unrhyw broblemau iechyd eraill na soniwyd amdanynt eisoes?

Oes

Nac oes

Os oes, rhowch fanylion _____

19. Ydy eich plentyn ag awtistiaeth yn byw gyda chi fel rheol?

Oes

Nac

Os Na, yna ble maent yn byw? _____

20. Dywedwch wrthym pa fath o ysgol mae eich plentyn ag awtistiaeth yn ei mynychu.

Ysgol prif lif heb ddim cymorth ychwanegol

Ysgol prif lif gyda chymorth ychwanegol

Ysgol arbenigol

Uned awtistiaeth arbenigol mewn ysgol prif lif.

Arall¹- rhowch fanylion

Brawd neu Chwaer y Plentyn ag Awtistiaeth (h.y. y brawd neu'r chwaer sy'n cymryd rhan yn yr astudiaeth).

Atebwch y cwestiynau canlynol am frawd neu chwaer y plentyn ag ASD rhwng 5 ac 17 oed. Os oes mwy nag un brawd neu chwaer yn yr ystod oedran hon, canolbwyntiwch ar y brawd neu'r chwaer sydd rhwng 5 ac 17 oed ac sydd agosaf mewn oedran i'r plentyn ag ASD.

21. Beth yw dyddiad geni eich plentyn sy'n datblygu'n arferol?

D	D	M	M	B	B
---	---	---	---	---	---

22. Ai bachgen neu ferch yw eich plentyn sy'n datblygu'n arferol?

Bachgen

Merch

23. Ydy eich plentyn sy'n datblygu'n arferol yn mynd i'r un ysgol â'ch plentyn ag awtistiaeth? Rhowch gylch o gwmpas eich ateb.

Yr un ysgol

Ysgol wahanol

24. Mae data diweddar o ymchwil gyda theuluoedd plant ag anghenion arbennig wedi dangos bod adnoddau ariannol teulu yn bwysig er mwyn deall safbwyntiau a phrofiadau aelod o'r teulu. Gyda hyn mewn golwg, byddem yn ddiolchgar iawn pe baech yn gallu ateb y cwestiwn ychwanegol isod. Nid oes gennym ddiddordeb mewn union incwm eich teulu, ond hoffem ystyried a yw profiadau pobl ag adnoddau ariannol sylweddol yn wahanol i brofiadau pobl ag adnoddau ariannol llai.

Beth yw cyfanswm incwm blynyddol cyfredol eich teulu? Cynhwyswch amcangyfrif bras o gyfanswm cyflogau ac incwm arall (gan gynnwys budd-daliadau) cyn treth ac yswiriant cenedlaethol/pensiynau.

Ticiwch un blwch yn unig:

Llai na £15,000.....

£15,001 i £25,000.....

£25,001 i £35,000.....

£35,001 i £45,000.....

£45,001 i £55,000.....

£55,001 i £65,000.....

£65,001 I 75,000.....

£75,001 I 85,000.....

£85,001 neu fwy.....

25) Nodwch trwy roi tic 4 yn y blwch priodol os ydych wedi mynychu unrhyw un o'r gweithdai neu gyrsiau canlynol i rieni.

	Ticiwch os ydych wedi mynych u	Nodwch pa mor fodlon oeddech ar y gefnogaeth a gawsoch gan y gweithdy y buoch yn ei fynychu.				
NAS <i>Help!</i> Rhaglen		Ardderch og	Da iawn	Da	Boddhaol	Gwael
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NAS <i>Help!</i> 2 Seminar ar frodyr/chwiorydd		Ardderch og	Da iawn	Da	Boddhaol	Gwael
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NAS EarlyBird		Ardderch og	Da iawn	Da	Boddhaol	Gwael
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

More Than Words		Ardderch og	Da iawn	Da	Boddhaol	Gwael
Gweithdy arall i rieni – rhowch fanylion:		Ardderch og	Da iawn	Da	Boddhaol	Gwael

Ffurflen Gydsynio Ymchwil i ail ofalwyr

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

Llenwch y canlynol a rhowch gylch o amgylch eich ateb:

Ydych chi wedi darllen yr holl wybodaeth ar y ffurflen Gwybodaeth?

YDW/NAC YDW

2) Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?

YDW/NAC YDW

3) Ydych chi wedi cael atebion rhesymol i'ch holl gwestiynau?

YDW/NAC YDW

4) Ydych chi'n fodlon cymryd rhan yn yr astudiaeth holiadur ac i'r wybodaeth a rowch i ni gael ei defnyddio yn yr ymchwil hon?

YDW/NAC YDW

5) Ydych chi'n gwybod y gellwch newid eich meddwl a pheidio â chymryd rhan yn yr astudiaeth

...ar unrhyw adeg?

...Heb roi rheswm?

YDW/NAC

YDW

Llofnod _____

Dyddiad _____

Enw mewn priflythrennau _____

Cyfeiriad _____

_____ Cod post _____

Rhif ffôn _____

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

Holiadur Cyffredinol i'w lenwi gan yr ail Ofalwr (Yr ail ofalwr yw'r ail oedolyn yn y tŷ, sy'n treulio llai o amser yn gofalu am y plentyn ag awtistiaeth). Gall yr unigolyn hwn fod yn dad, yn fam, yn nain neu'n daid, yn rhiant maeth neu'n wŵr/gwraig/partner y prif ofalwr. Nid oes raid i'r ail ofalwr berthyn trwy waed i'r plentyn ag awtistiaeth.)

Mae'r cwestiynau canlynol yn gofyn am wybodaeth gefndir amdanoch chi, eich teulu a'ch plentyn ag awtistiaeth. Ticiwch yr ateb priodol neu ysgrifennwch yn y bylchau a ddarperir.

1. Ai gwryw neu fenyw ydych chi? Rhowch gylch o gwmpas eich ateb. **Gwryw**
Benyw

2. Beth yw eich perthynas â'r plentyn ag anhwylder sbectrwm awtistaidd (ASD) (e.e. mam. tad. llysfam, nain, rhiant mabwysiadol)?

.....

3. I ba un o'r grwpiau ethnig canlynol ydych yn perthyn yn eich barn chi? Ticiwch y blwch priodol.

Gwyn- Prydeinig	Unrhyw gefndir Asiaidd arall Nodwch.....
Gwyn - Gwyddelig	Du/ Du Prydeinig - Caribiaidd
Unrhyw gefndir Gwyn arall Nodwch.....	Unrhyw gefndir Du arall Nodwch.....
Gwyn a Charibiaidd du	Cymysg – Gwyn ac Asiaidd
Cymysg – Gwyn ac Affricanaidd du	Asiaidd/Asiaidd Prydeinig - Indiaidd
Unrhyw gefndir Cymysg arall	Asiaidd/Asiaidd Prydeinig - Bangladeshi
Asiaidd/Asiaidd Prydeinig - Pacistani	Du/ Du Prydeinig - Affricanaidd

4. Beth yw eich dyddiad geni?

D	D	M	M	B	B
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5. Beth yw eich statws priodasol presennol?

Wedi priodi ac yn byw ar hyn o bryd gyda'r gŵr/wraig neu'n byw ar hyn o bryd gyda phartner.....

Wedi ysgaru/ wedi gwahanu/ sengl/ gweddw a DDIM yn byw gyda phartner ar hyn o bryd.....

6. Ticiwch lefel uchaf eich cymwysterau addysgol.

Dim cymwysterau addysgol ffurfiol.....

Llai na 5 TGAU neu Lefel O, NVQ 1, neu Ddiploma Cyntaf BTech.....

5 neu fwy o TGAU neu Lefel O, NVQ 2, neu gyfwerth.....

3 neu fwy o Lefel A, NVQ 3, BTECH Cenedlaethol, neu gyfwerth.....

Gradd Bolytechnig/Prifysgol. NVQ4 neu gyfwerth.....

Gradd Meistr/Doethurol, NVQ5 neu gyfwerth.....

7. Oes gennych swydd y tu allan i'r cartref ar hyn o bryd?

OES

NAC OES

Os OES ydych chi'n gweithio'n llawn amser neu'n rhan amser?
amser

Llawn amser

Rhan amser

Eich Plentyn ag Awtistiaeth

Atebwch y cwestiynau canlynol am eich plentyn gydag ASD rhwng 5 ac 17 oed. Os oes gennych fwy nag un plentyn gydag ASD yn yr ystod oedran hon, canolbwyntiwch ar y plentyn hynaf sydd rhwng 5 ac 17 oed.

11. Ydy eich plentyn wedi cael diagnosis ffurfiol o anhwylder y sbectwm awtistiaeth? Os felly, rhowch fanylion (e.e. Syndrom Asperger, Awtistiaeth, PDD-NOS,

.....

12. Beth yw dyddiad geni eich plentyn ag awtistiaeth?

D	D	M	M	B	B
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13. Ai bachgen neu ferch yw eich plentyn ag awtistiaeth? Bachgen Merch

14. Nodwch isod unrhyw ddiagnoses/cyflyrau ychwanegol sydd ar eich plentyn ag awtistiaeth.

Syndrom Down Palsi'r Ymennydd

Syndrom Fragile X ADHD/Gorfywiogrwydd

Arall – rhowch fanylion _____

15. A oes gan eich plentyn ag awtistiaeth nam ar y synhwyrau sy'n amharu ar ei f/bywyd bob dydd?

Oes Nac oes

Os oes, rhowch fanylion. Nam ar y synhwyrau Nam ar y clyw

16. Ydy eich plentyn ag awtistiaeth yn dioddef ar hyn o bryd o ffitiau epileptig?

Ydy Nac ydy

17. Oes gan eich plentyn ag awtistiaeth broblemau symud sy'n golygu ei bod yn anodd iddynt symud o gwmpas yn annibynnol (e.e. angen defnyddio cadair olwyn)?

Oes Nac oes

18. Oes gan eich plentyn ag awtistiaeth unrhyw broblemau iechyd eraill na soniwyd amdanynt eisoes?

Oes Nac oes

Os oes, rhowch fanylion _____

19. Ydy eich plentyn ag awtistiaeth yn byw gyda chi fel rheol?

Ydy Nac ydy

Os Na, yna ble mae'n byw? _____

20. Dywedwch wrthym pa fath o ysgol mae eich plentyn ag awtistiaeth yn ei mynychu.

- Ysgol prif lif heb ddim cymorth ychwanegol
- Ysgol prif lif gyda chymorth ychwanegol
- Ysgol arbenigol
- Uned awtistiaeth arbenigol mewn ysgol prif lif.
- Arall – rhowch fanylion

Brawd neu Chwaer y Plentyn ag Awtistiaeth (h.y. y brawd neu'r chwaer sy'n cymryd rhan yn yr astudiaeth).

Atebwch y cwestiynau canlynol am frawd neu chwaer y plentyn ag ASD rhwng 5 ac 17 oed. Os oes mwy nag un brawd neu chwaer yn yr ystod oedran hon, canolbwyntiwch ar y brawd neu'r chwaer sydd rhwng 5 ac 17 oed ac sydd agosaf mewn oedran i'r plentyn ag ASD.

21. Beth yw dyddiad geni eich plentyn sy'n datblygu'n arferol?

D	D	M	M	B	B
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22. Ai bachgen neu ferch yw eich plentyn sy'n datblygu'n arferol?

Bachgen

Merch

23. Ydy eich plentyn sy'n datblygu'n arferol yn mynd i'r un ysgol â'ch plentyn ag awtistiaeth? Rhowch gylch o gwmpas eich ateb.

Yr un ysgol

Ysgol wahanol

Ffurflen Gydsynio i Ymchwil i Frawd neu Chwaer Plentyn ag Awtistiaeth

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

Llenwch y canlynol a rhowch gylch o amgylch eich ateb:

Ydych chi wedi darllen yr holl wybodaeth ar y ffurflen Gwybodaeth ac wedi cael cyfle i'w thrafod?

YDW/NAC YDW

2) Ydych chi wedi cael cyfle i ofyn cwestiynau am yr astudiaeth yma?
YDW/NAC YDW

3) Ydych chi'n hapus â'r atebion i'ch holl gwestiynau?
YDW/NAC YDW

Ydych chi'n hapus i gymryd rhan yn yr astudiaeth holiadur?
YDW/NAC YDW

4) Ydych chi'n gwybod y gallwch benderfynu peidio â llenwi'r holiadur
...ar unrhyw adeg?
...Heb roi rheswm?
YDW/NAC YDW

Llofnod _____

Dyddiad _____

Enw mewn priflythrennau _____

Cyfeiriad _____

_____ Cod post _____

Rhif ffôn _____