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SOPHIE EYRES MA (Hons), PGCE

**SUPPORTING SIBLINGS OF CHILDREN WITH AUTISTIC
SPECTRUM DISORDERS (ASD)**

SECTION A

**The Impact of Childhood Autistic Spectrum Disorder (ASD) upon
Non-Affected Siblings and the Utility of Sibling Group
Interventions: Directions for Future Research**

Word count: 5497 (57)

SECTION B

**Support Groups for Siblings of Children with Autistic Spectrum
Disorders: A Pilot Study**

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SECTION C

**Critical Appraisal:
Support Groups for Siblings of Children with Autistic Spectrum
Disorders**

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Declaration

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SUMMARY

Section A

A review of current research literature relating to the impact of child ASD upon non-affected siblings and the utility of sibling group interventions. The first section summarises and critiques studies relating to the social, emotional and behavioural adjustment of siblings, including consideration of potential mediating factors and discussion of methodological issues. The second section considers evidence for one intervention for this group, ASD-specific sibling support groups. The review suggests that inconsistencies remain within the sibling research literature and that there is a clear need for UK-based outcome research.

Section B

A within group, mixed methods pilot study to investigate the utility of support groups for siblings of children with ASDs. Sibling rated self-concept, anxiety and anger and parent rated emotional difficulties were collected before and after the groups and at follow up. The study also includes thematic analysis of a focus group, which explores children's experiences of the group.

Section C

A critical appraisal of the study conducted in section B and a reflective account of the process. This includes consideration of research skills learnt, future adaptations, clinical implications and ideas for future research.

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Section A

The Impact of Childhood Autistic Spectrum Disorder (ASD) upon Non-Affected Siblings and the Utility of Sibling Group Interventions: Directions for Future Research

Word Count: 5497 (57)

ABSTRACT

This review considers research literature relating to the impact of child ASD upon non-affected siblings and explores the utility of sibling group interventions. The first section of the review will summarise and critique studies relating to the social, emotional and behavioural adjustment of siblings, including consideration of potential mediating factors and discussion of methodological issues. The second section will consider evidence for one intervention for this group, ASD-specific sibling support groups. Suggestions for future studies will be discussed.

Fifteen studies were identified relating to sibling adjustment and nine relating to sibling support groups. Some reported an increased risk of social, emotional and behavioural difficulties in non-affected siblings whilst others found no negative or positive effects of having an ASD sibling. Findings relating to mediating factors were also mixed. Most studies had relatively small sample sizes and lacked statistical power. Several studies included siblings of children with ASDs within generic support groups for other disabilities. However, despite an increase in U.K. ASD-specific sibling groups, few related studies were identified to support these. Canadian research findings indicated improved ASD knowledge and a more positive self concept following sibling involvement in an ASD-specific support group.

Inconsistencies remain within the literature relating to sibling adjustment. Larger, better controlled studies with multiple informants may facilitate clearer conclusions and deeper exploration about the factors mediating sibling adjustment. ASD-specific support groups may be of benefit and there is a clear need for UK-based outcome research. Whilst anecdotal reports are of value, larger more controlled studies, which utilise standardised outcome measures, are warranted.

1. INTRODUCTION

Approximately 1% of the UK child population is diagnosed with some form of Autism or related Autistic Spectrum Disorders (ASDs). This number represents a notable increase upon previous prevalence estimates and it is possible that it may continue to grow (Baird et al., 2006).

Autism spectrum disorder (ASD) describes a lifelong, pervasive developmental disability (American Psychiatric Association (APA), 1994; Baird et al., 2006). Central to diagnosis are impairments in three key areas ('triad of impairments') which affect the way in which an individual interacts with his/her social world; social interaction, verbal and non-verbal communication and flexibility of thought (social imagination) (Wing & Gould, 1979). Challenging, unpredictable, repetitive and ritualistic behaviours are also common (Altiere & von Kluge, 2009; Lord, Hyun Kim & DiMartino, 2011). The exact manifestation of impairments can vary significantly between individuals, hence the term 'Autistic Spectrum'. Conditions such as 'classic autism' are located at the most 'severe' end of the ASD continuum, whereas those such as Asperger syndrome are at the 'higher functioning' end. Substantial variations can also be found in common comorbid diagnoses such as sensory and learning disabilities.

There is currently some debate concerning the term 'ASD'. For example proposed changes to the DSM-5 would exclude Asperger syndrome as a distinct diagnosis and instead subsume this within the term ASD (APA, 1994; 2010). These proposals have prompted much controversy amongst researchers (Ghaziuddin, 2010). More radical debate has suggested that ASDs, particularly high functioning autism, do not constitute a disability at all, but simply reflect a differing communication style (Baron-Cohen, 2000; Crosby, 1999). However for

children, the term ASD is currently adopted by the National Institute for Clinical Excellence (NICE, 2011).

Regardless of severity, ASD can have a life-long functional, financial and social impact upon an individual and their family (Altiere & von Kluge, 2009; Brugha et al., 2009; Knapp, Romeo & Beecham, 2009). For the individual, the social nature of impairment can render the world confusing and anxiety provoking. Rigid adherence to routines, obsessions (or ‘special interests’) and exaggerated, repetitive or self-stimulatory behaviours may be deployed by the individual as coping strategies. However, paradoxically, these can generate further social adjustment difficulties for the individual and the associated consequences for family members can be extremely challenging (Altiere & von Kluge, 2009; Smith & Elder, 2010).

This paper will provide an overview of impact on the family of living with a child with a disability, and more specifically, with ASD. This introduction will be followed by a more detailed review of the research literature relating to the impact of child ASD on non-affected siblings. Literature relating to the social, emotional and behavioural adjustment of siblings will be summarised and critiqued. This will include discussion of methodological issues and potential mediating factors for sibling effects. Finally, the review will consider literature pertaining to effective support services for siblings of children with ASDs. Specific focus will be placed upon research relating to sibling group interventions. The review will conclude by considering current issues and gaps within the existing literature, including implications for future research.

1.1. Family impact of disability

It is known that living with a disabled child can have profound effects upon the family system. A recent literature review identified a number of key areas (Harris, 2008). Firstly, families with a disabled child can encounter a number of practical problems compared to those without. These include juggling daily activities such as shopping and cleaning with providing care for their child, and difficulties with transport. There are also financial challenges; the cost of raising a disabled child can be increased due to additional living necessities such as expensive equipment or clothing. Further, given that accessing child care can be more complicated, it is often difficult for the primary caregiver to work fulltime (Harris, 2008).

There are also emotional challenges. Firstly, parents must adjust to discovering their child is disabled (Harris, 2008). Psychodynamic theorists suggest that this can be a devastating experience where parents must grieve the loss of the 'perfect child'. This can bring associated guilt, anger and loss and can often provoke disruptions in child-parent attachment (Goldberg, Magrill, Hale, Damaskinidou & Tham, 1995; Hollins & Sinason, 2000; Sinason, 1992). Such feelings can be re-experienced as the child moves through different phases of the family life cycle. At each stage, parents are reminded that their child may not follow 'typical development', such as finding work, meeting a partner, leaving home and having children (Blackman, 2003). Understandably, research suggests that parents of disabled children are more likely to experience stress, anxiety and worry about their child's future than other parents (Harris, 2008; Phillips, 1999). This may provoke increased expectation and investment on other, non disabled children in the family (Reichman, Corman & Noonan, 2008).

Given these practical and emotional demands, it is perhaps unsurprising that parents are at increased risk of mental health difficulties such as stress, depression and anxiety (Harris, 2008; Phillips, 1999). There may also be secondary impacts upon parenting style and family relationships, with parental separation more likely in families with a disabled child (Harris, 2008; Reichman et al., 2008). However, it is also important to note research that has shown benefits of living with a disabled child, including increased family cohesion, resilience and positive connections to community groups (Reichman et al., 2008).

1.2 Family impact of ASD

ASD is a particularly challenging disability for family members (Benson & Karlof, 2008; Smith & Elder, 2010). The behavioural difficulties that often accompany ASD, as well as the ‘unseen’ nature of the disorder can place notable demands upon families (Baker et al., 2003; Meaden, Stoner & Angell, 2010). Social deficits and a lack of adherence to social norms can bring additional challenges including constraints on family leisure activities (Altieri & von Kluge, 2009; Mactavish & Schleien, 2004). Indeed, several studies have noted increased stress levels in parents of children with ASDs, when compared to parents of children with other or no disabilities (Olsson & Hwang, 2001; Singer, 2006). This stress can impact negatively on family well-being. Several studies have found high levels of psychological distress in parents of children with ASDs, including depression, anxiety and anger (Benson & Karlof, 2009; Blacher, Neece & Paczkowski, 2005; Bromley, Hare, Davison & Emerson, 2004). However, there can also be positive influences on the family system including increased tolerance, deeper understanding of disability and improved ‘life perspectives’, whereby things were no longer ‘taken for granted’ (Taunt & Hastings, 2002).

2. SIBLING LITERATURE

2.1 Rationale for review

Research considering the family impact of ASD has continued to increase. This is important as the family system plays a crucial role in supporting child developmental outcome (Altiere & von Kluge, 2009). However, according to family systems theory, families are organised into several ‘subsystems’ (e.g. parents, siblings, spouse) which interact and mutually influence each other (Minuchin, 1974, described in Nichols & Schwartz, 2004; Stoneman & Brody, 1993). Despite this, a dominant focus of ASD family research has been upon the impact of ASD on the parental and spousal subsystems. Until recently, the sibling subsystem has been comparatively understudied (Harris, 2008; Meaden et al., 2010; Smith & Elder, 2010).

Within the past 10 years, disability researchers have begun to recognise the importance of studying non-affected siblings. This is a crucial development as it is known that having a brother or sister with a disability can significantly impact upon siblings. Firstly, these children can experience stressors such as reduced parental attention, increased carer/household responsibilities, isolation from peers and increased pressure to achieve as the ‘healthy’ sibling (Dodd, 2004; Lobato, 1983; McHale & Gamble, 1989). For siblings of children with an ASD, there can be additional challenges, such as learning to cope with associated stereotyped and difficult behaviours. Given the often ‘invisible’ nature of the disability, children may also encounter negative reactions to their sibling from the public and peers (Morgan, 1988; Roeyers & Mycke, 1995). Secondly, sibling interactions can provide a context for social and emotional development and may have a profound impact upon well-being (Dunn & Kendrick, 1982). It is thus important to explore the way in which this

relationship may be influenced by disability. Considering the sibling subsystem will facilitate a broader, more comprehensive understanding of the family impact of ASD. This includes the way in which that impact may be mediated by complex interactions between subsystems and other demographic factors (Stoneman, 2005). Finally, a deeper understanding of the functioning of families living with ASD enables the development of informed support systems and interventions that are better adapted to family needs (National Autistic Society, 2003). Such approaches may assist and support individual family members in managing and adapting to life-long developmental stressors, which in turn, impact upon the individual with an ASD.

2.2 Structure

The first section of the review will summarise and critique studies relating to the social, emotional and behavioural adjustment of children with ASD siblings, including potential mediating factors. This will be followed by a discussion of methodological issues. The second section will consider evidence for sibling group interventions. Finally, any gaps within the literature and associated implications for research will be discussed.

2.3 Methods and search strategy

The literature reviewed in this study was identified through computer based searches of the following databases: Psychinfo (2000-2011), Web of Knowledge (2000-2011) and Wiley Interscience (2000-2011). Additional papers were identified through manual searches of reference sections and an internet search using 'Google Scholar'. Search terms are described fully in appendix A. The review focused upon literature within the past 10 years.

Following application of exclusion criteria, 15 studies were identified for the first part of the review (social, emotional and behavioural adjustment of children with ASD siblings) and 9 for the second part (sibling group interventions). Studies were critically assessed for methodological quality and contribution to the literature base using a systematic framework (Greenhalgh, 2001). This involved the consideration of several 'essential areas' including study originality, generalisability/participant recruitment, systematic bias, sample size and whether the study design, methods and statistics were appropriate.

3. LITERATURE REVIEW

3.1 Social, emotional and behavioural adjustment of children with ASD siblings

Earlier studies report mixed findings regarding the adjustment of non-affected siblings. Several researchers have reported that siblings of children with ASDs have an increased risk of psychological and behavioural problems when compared to other siblings. These include internalising and externalising difficulties such as anxiety, depression, anger and aggressive behaviours (Bagenholm & Gilberg, 1991; Fisman et al., 1996; Gold, 1993; Rodrigue, Geffken & Morgan, 1993; Wolf, Fisman, Ellison & Freeman, 1998). Other studies however, have found no differences in adjustment for children who have a sibling with ASD, or positive effects, such as closer sibling relationships and improved empathy and social competence (Ferrari, 1984; Mates, 1990).

3.1.1 Negative effects

These inconsistencies have continued in more recent studies. Firstly, several researchers report an increased risk of negative psychological adjustment in children who have an ASD siblings compared to siblings of typically developing children (Fisman et al.,

2000; Petalas et al., 2009; Ross & Cuskelly, 2006; Rossiter & Sharpe, 2001; Verte, Roeyers & Buysse, 2003). Hastings (2003a) found that compared to a normative sample, siblings of children with ASD (n=22) were rated by their mothers as having significantly more behaviour problems and less prosocial behaviour (Strengths and Difficulties Questionnaire (SDQ), Goodman, 1997; 2001). Ross and Cuskelly (2006) noted a significantly higher risk of internalising difficulties (depression and anxiety) in 25 siblings of children with ASDs (15=male, mean age = 10.64), with 40% of mothers reporting difficulties in the clinical range (Child Behaviour Checklist (CBCL), Achenbach, 1991). Similarly, Verte et al. (2003) found that parents of siblings of children with High Functioning Autism (HFA) (n=29, 17=male) reported significantly higher levels of both internalising and externalising behaviour problems than parents of siblings of children without disorders (CBCL). A particular strength of this study was its use of both indirect (maternal reports) and direct (sibling self report) measures of adjustment.

In one of the few longitudinal sibling studies, Fisman et al. (1996; 2000) noted enduring negative adjustment effects for children with a sibling with Pervasive Developmental Disorder (PDD) across a 3 year period. At initial measurement, siblings of PDD children (n=46) had significantly higher internalising and externalising difficulties than children with Down syndrome siblings (n=45) and matched controls (n=46) (Parent and teacher rated Survey Diagnostic Instrument, CBCL). Parent reported externalising and teacher reported internalising difficulties persisted at 3 year follow up ($p < 0.05$; $p < 0.06$). Although the authors also collected sibling ratings of self concept, perceived social support and sibling conflict as independent variables across the two time-points, these were not reported. Finally, Petalas et al. (2009) asked 49 mothers to rate the adjustment of non-affected siblings of children with intellectual disabilities (ID) and ASD (N=24, 12=male,

mean age = 10.36) and without ASD (n=25, male=15, mean age=11). Data for 15 of the ID with ASD group were also available at 18 month follow up (male=9, mean age=12.68). The SDQ was used to rate adjustment and the authors cite good psychometric properties. Mothers reported marginally significantly more emotional problems for siblings in the ID with ASD group when compared to ID only and also to a U.K. normative sample (both ps = 0.05). The former group was also more likely to score within the abnormal range for emotional problems and prosocial behaviour (both ps<0.01) and these difficulties remained stable at 18 month follow up. The authors conclude that siblings of children with ASD and ID may be at increased risk of emotional problems.

3.1.2 Neutral or positive effects

Other more recent studies have suggested no negative effects of having a sibling with ASD, with some reporting benefits (Hastings, 2003b; 2007; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Mascha & Boucher, 2006; Pilowsky et al., 2004; Taunt & Hastings, 2002). Hastings (2003b) explored maternal SDQ ratings for 78 siblings of children with ASD who were attending Applied Behaviour Analysis programs. Behavioural or emotional adjustment problems did not significantly increase when compared to a normative sample. Similarly, Hastings (2007) found no significant differences in adjustment for siblings of children with ASDs (n=24), Down's syndrome (n=26) and intellectual disabilities (n=25) over a 2 year period (maternal rated SDQ). Kaminsky and Dewey (2002) compared adjustment of siblings of children with ASD (n=30), Down's syndrome (n=30) and typically developing children (n=30). All three groups were similarly well adjusted (parent reported CBCL) and all siblings reported low levels of loneliness and good social support. However, as the authors recognise, a high number of participants' parents (77%) attended support groups and this may have influenced results. These findings are supported by Pilowsky et al.

(2004) with siblings of children with ASDs showing similar levels of adjustment compared to siblings of children with developmental language delay or unknown genetic etiology.

Finally, some researchers have indicated positive influences of having a sibling with ASD on children's adjustment. Taunt and Hastings (2002) conducted qualitative interviews with parents about the family impact of having a child with developmental disabilities. Parents reported a number of benefits for siblings including increased sensitivity and opportunities to learn about difference. Mascha and Boucher (2006) interviewed 14 children about the experience of having a sibling with ASD. Whilst all identified negative factors (e.g. aggression and embarrassing behaviour of sibling), the majority of siblings (n=10) were also able to identify positive aspects including having fun together and increased maturity and understanding.

3.2 Mediators and moderators

Inconsistencies in the research literature have prompted deeper exploration into factors which may mediate the influence of ASD siblings on non-affected children. Namely, why do some siblings adjust more positively than others? Several studies have noted additional factors that may influence sibling adjustment, including family size and socio-economic status (SES), with larger families and higher SES associated with better adjustment. Gender and relative age of siblings are also related to adjustment (Hastings, 2007; Kaminsky & Dewey, 2002, Macks & Reeve, 2007; Petalas et al., 2009; Verte et al., 2003). Verte et al. (2003) for example noted that 6-11 year olds with a sibling with HFA were more prone to difficulties than 12-16 year olds. Older siblings of HFA, particularly females, tended to have higher social competence and more positive self concept when compared to matched controls. Similarly, Kaminsky and Dewey (2002) noted higher social competence in

older, female siblings of children with ASD ($p < 0.01$), though it is important to note the small samples in both studies. Petalas et al. (2009) reported heightened emotional problems in children with a sibling with ASD and ID, whose sibling was older and male. Similarly, post hoc analyses in the Hastings (2003a) study suggested poorer adjustment for male children who were younger than their ASD sibling. Other studies have contradicted these findings however, suggesting that children who are older than their ASD sibling may have more adjustment problems than those who are younger (e.g. Rodrigue et al., 1993). Finally, disability specific factors related to the child with ASD may also influence their siblings. For example Hastings (2007) noted that the severity of behaviour problems of the disabled sibling predicted behavioural adjustment of non-affected siblings two years later (regression analyses, $p < 0.001$).

It is possible that demographic risk factors may act collectively. Macks and Reeve (2007) noted a number of combined demographic risk factors linked to poorer adjustment in siblings of children with ASD ($n=51$) when compared to siblings of non-disabled children ($n=35$). These were being male, only having one sibling, having low SES and being older than the sibling with ASD. In absence of these risk factors, children with ASD siblings actually showed enhanced psychological adjustment and a more positive self concept compared to siblings of non disabled children ($p < 0.003$, Piers-Harris Children's Self Concept scale, Piers, 1984). As demographic risk factors increased, poor adjustment became more likely. The authors argue that their results may explain some of the contradictory findings of earlier studies. Benson and Karlof (2008) proposed that inconsistent findings may be due to the failure of many researchers to adjust for increased genetic vulnerability in children with an ASD sibling. This was explored by comparing adjustment in siblings of children with ASDs who were either diagnosed ($n=19$) or not diagnosed ($n=53$) with other non-medical

disabilities themselves. The siblings who also had a diagnosis themselves showed significantly poorer adjustment and prosocial behaviour than those who did not (parent SDQ ratings). Siblings without a diagnosis did not generally differ from a normative reference population, with the exception of increased emotional problems ($p < 0.001$). For this non-diagnosed sibling group (but not diagnosed siblings), several social factors significantly predicted adjustment ratings 2 years later, including severity of ASD for the reference sibling, family climate and parental involvement in ASD educational programmes. Other researchers have noted the mediating effect of social support on sibling adjustment. Hastings (2003b) noted that social support offered to families moderated the impact of ASD severity on sibling adjustment. Greater social support was associated with fewer adjustment difficulties in siblings, particularly for children whose siblings had less severe ASD. Similarly, Kaminsky and Dewey (2002) noted that siblings of children with ASD whose parents attended support groups displayed fewer adjustment problems compared to those whose parents did not (CBCL). However it is important to recognise that the majority of parents attended support groups (77%) and hence numbers in each comparison group would be relatively small.

Clearly the picture is more complicated than it first appears. In attempting to account for variability in sibling adjustment, Stoneman and Brody (1993) have proposed a useful conceptual framework, the 'family context model'. The model outlines both direct and indirect influences on sibling relationship quality and adjustment. Direct influences may include individual sibling characteristics (such as age, gender, birth order and nature of disability) and direct interactions between siblings, through which a non-disabled sibling may learn aggressive or compassionate behaviours. Parenting practices will also exert a direct effect on siblings, by reinforcing positive behaviours or punishing negative interactions for example. Indirect influences may include factors such as economic difficulties and parent

stress levels, which in turn impact upon parenting practices. Indirect and direct factors will interact and mutually influence each other: A child with ASD and challenging behaviour for example, may deplete the availability of parental resources for a non-disabled sibling, in turn provoking sibling jealousy and anger (Stoneman & Brody, 1993; Stoneman 2005). This suggests there may be several routes which may mediate sibling adjustment.

3.3 Methodological issues

A number of methodological factors may also account for inconsistencies in the sibling literature. Firstly, it is notable that the majority of the quantitative studies have relatively small sample sizes (approximately 15-25 siblings). Only a small number have larger samples (Benson & Karlof, 2008; Fisman et al., 2000; Hastings, 2003b; Macks & Reeve, 2007). Consequently, statistical power is limited, particularly in cases where extensive post hoc analyses are undertaken (Kaminsky & Dewey, 2002). This also renders generalisation difficult, particularly as a large proportion of studies have been undertaken in non-U.K. countries. Future research should seek to address these difficulties. Secondly, although the majority of the reported studies utilise reliable and valid standardized outcome measures, many only report data from one informant, usually maternal ratings (e.g. Benson & Karlof, 2008; Petalas et al., 2009). This could be problematic as it is known that there is often disagreement between parent and sibling subjective reports (Lobato, Barbour, Hall & Miller, 1987; Macks & Reeve, 2007). Macks and Reeve (2007) for example, noted that parent reports of sibling behaviour tended to be more negative than those of siblings. The authors suggest this finding may explain discrepancies in earlier sibling research and highlight the need for more multiple informant based studies. Further, many of the studies are cross

sectional and only measure sibling adjustment at a single time-point. Given that some of these variables can be dynamic and subject to change, follow up data are clearly needed.

Hodapp, Gliddin & Kaiser (2005) argue that a number of challenges exist within current research on siblings and disability. These include methodological challenges (e.g. sample size), measurement (e.g. type or source of measurement), developmental perspectives (e.g. age effects, changes over time), mediating and moderating variables, cultural issues and balanced views of both positive and negative outcomes. In a recent review, Meaden, Stoner & Angell (2010) used these themes to critically analyse 12 studies relating to ASD sibling adjustment. Most reviewed studies showed mixed findings in terms of sibling adjustment and many of Hodapp et al.'s issues remained to be addressed. The authors concluded that *'currently there are more questions than answers as to the best way to support siblings of children with ASD'* (p. 98, Meaden et al., 2010).

3.4 Interventions

'Effective social support can buffer some of the negative effects of family stress on siblings with disabilities' (Stoneman, 2005, p.343)

The above findings imply that adjustment of siblings may be amenable to change and hence targeted support may be beneficial. Indeed, the Department of Education and Skills (2007) has stipulated the need for 'focussed, effective support' in order to 'promote emotional and social development for disabled children and their siblings, to help to improve outcomes for all' (pp. 9, Aiming high for disabled children: Better support for families). Further, the benefits of providing children with information about their siblings' condition is a consistent theme in the research literature (Harris, 2008). Hence further exploration of how best to support siblings has clear implications for future service provision. However despite this,

there are still relatively few studies that consider support services for siblings of children with ASD and their families (Reichman et al., 2008; Smith & Elder, 2010). As Harris (2008) writes, *'experimental studies of the impact of service provision are rare and in their absence, justification for what constitutes an effective service is often taken from user views'* (p.366).

3.4.1 Sibling support groups

Evidence from studies of siblings of children with disabilities has suggested the potential utility of sibling support groups (Burke & Montgomery, 2000; Dodd, 2004). Whilst the time period, length and targeted age range of different support groups can vary, their basic aim generally remains constant: The 'Sibs' organisation for example, has proposed a generic model for all support groups. This model, F.R.A.M.E., suggests that groups should be designed to be Fun, Reduce isolation, Acknowledge feelings, Model coping strategies and Enhance knowledge of disability (F.R.A.M.E. model, Sibs Organisation, www.sibs.org.uk). The Sibs organisation does not offer any direct psychological theory or evidence for this model. However, the principles of F.R.A.M.E. can be broadly linked with the theories of the group psychotherapist Dr Irvin Yalom (2005). Yalom postulates a number of 'therapeutic factors' which provide the agents of change in any group therapeutic experience, including installation of hope, universality, information giving, altruism, improving social skills, imitative behaviour, interpersonal learning, catharsis and group cohesiveness. Both 'installation of hope' and 'universality' for example, apply to the aim of 'Reducing isolation' in the F.R.A.M.E model. Children may feel that that they are 'the only one' experiencing particular difficulties, or 'unacceptable' feelings about their sibling. The experience of finding understanding from other children facing similar situations can reduce these anxieties, providing a powerful sense of relief. 'Imitative behaviour' and 'information giving' are

linked with ‘Modelling coping strategies’ and ‘Enhancing knowledge’ within F.R.A.M.E. and also draw upon social and constructivist learning theories (e.g. Bandura, 1986; Vygotsky, 1933;1935, both cited in Crain, 2008). Thus children learn actively through social discourse, observation and imitating facilitators and peers. Such practices promote greater perceived control and can foster improvements in coping and self efficacy (Yalom, 2005). Siblings also benefit from sharing personal coping strategies and offering help to peers within the group, in turn improving their own self esteem. Finally, having ‘Fun’ and ‘Acknowledging feelings’ can offer the experience of ‘group belonging’ (cohesiveness) and ‘catharsis’ (release of emotions). For many children this can offer a powerful emotional experience. For siblings of children with disabilities, involvement in these sibling groups has been associated with a range of positive outcomes including enhanced knowledge of disability, increased involvement with their disabled sibling, increased coping strategies, reduced isolation and increased self esteem (Dodd, 2004; Evans, Jones & Mansell, 2001; Naylor & Prescott, 2004).

3.4.2 Sibling support groups for ASD

3.4.2.1 ‘Non-specific’ sibling groups

Several studies of generic support groups have included children who have a sibling with ASD. Lobato and Kao (2002; 2005) evaluated 2 support groups for siblings of children with chronic illness and developmental disabilities in the USA. Both studies involved a similar 6 session intervention programme, but with different age groups; 8-13 year old (n=54, 23% had a sibling with ASD) and 4-7 year old siblings (n=43, 35% had a sibling with ASD). In both studies, children’s knowledge of their siblings’ disability and sibling connectedness (how connected they felt to peers with similar circumstances) increased significantly post intervention and this was maintained at 3 month follow up. There were also significant

increases in perceived self competence for the younger group (Pictorial Scale of Perceived Self Competence & Social Acceptance for Young Children, Harter & Pike, 1983), though this was not assessed for the older children. Parent reported behavioural adjustment (CBCL) improved post intervention and at 3 month follow up for the older siblings only. Whilst these findings seem promising, it is important to note that several of the measures used were unstandardised, psychometric properties are unreported and the authors themselves suggest that more controlled studies are required. D'Arcy et al. (2005) used mixed methods to evaluate a four session sibling group in Ireland. The authors state that some of their participants (n=16) had a sibling with 'intellectual disabilities', though it is unclear whether any had siblings with ASDs. Qualitative findings suggested beneficial effects of the group, including increased knowledge, reduced isolation and opportunity to share feelings and coping strategies. There were no significant increases in sibling self esteem (Piers-Harris Self Concept Scale). These qualitative findings have been supported by other studies. Dodd (2004), interviewed 4-11 year old children with disabled siblings (n=77, 6 had siblings with ASDs) following their attendance at a two day support group. A consistent theme was the extent to which siblings and parents had valued the group, including feeling 'special' and less isolated. Finally, two studies have analysed sibling groups with a slightly different format, including a five day residential group and a fifteen week group which met for two hours each weekday (Phillips, 1999; Williams et al., 2003). The former study was targeted at 7-15 year old children with siblings with chronic illness and developmental disabilities including ASD (n=252). The latter group was for 9-12 year old African American children from low income families, who had developmentally disabled siblings (n= 180). An advantage of both studies is their use of larger samples and better controlled methodology, including the use of control groups. Williams et al. (2003) noted significant improvements in knowledge about/attitude

towards disability, social support, self-esteem, behaviour problems and mood for siblings who had attended the full support group compared to those in the control groups. Phillips' (1999) findings included significantly improved socioemotional adjustment (depression, anxiety, self-esteem), perceived social support and decreased sibling stress in the intervention group, compared to controls. An added advantage of this study was the inclusion of children from a low socioeconomic background, who tend to be under-represented in other studies. However, the feasibility of such a high intensity intervention is questionable in clinical practice.

3.4.2.2 ASD-specific support groups

Additional challenges specific to having a sibling with ASD have led to the establishment of 'ASD-specific' support groups. Canadian research has reported improved knowledge of autism and a more positive self concept (Piers-Harris Self Concept Scale) following sibling involvement in an 8 session, ASD-specific support group (Smith & Perry, 2005). Participants were 26 siblings aged 6-16 years, 12 of whom had borderline to clinically significant behavioural adjustment difficulties (CBCL). Contrary to the authors' predictions, there were no significant decreases in sibling anger and resentment post group. However, these results may have been influenced by the choice of outcome measure, which was a 4 item, unstandardised measure with only fair reliability (coefficient alpha=0.61). Thus further investigation using standardised anger outcome measures would be required before any strong conclusions can be drawn. Finally, as this study lacked a control group, it is difficult to conclude whether its positive findings for self concept were due to the sibling group per se or to other factors.

Despite positive anecdotal reports, there is a relative lack of U.K. studies investigating ASD-specific sibling groups (Cooke & Semmens, 2010; Howlin & Yates, 1990; Knott, 2009). Knott (2009) evaluated a 4 session ASD-specific sibling group for 7-11 year olds with ASD siblings (n=19). Anecdotally, children described their enjoyment of the group and of meeting other siblings. Qualitative findings also suggested improved knowledge of Autism post-group, in that children were able to provide more specific examples of ASD symptoms. Unfortunately only one standardised outcome variable was assessed and this indicated that children's beliefs about their sibling relationship were unchanged following the group ($p>0.05$, Sibling Relationship Questionnaire, Furman & Buhrmester, 1985). A recent study by Cooke and Semmens (2010) reported increased knowledge of ASD for 8-12 year old children following attendance at an 8 session sibling group. Parents also reported their children showed increased patience with their siblings and greater understanding of why they may be treated differently. However, whilst these results appear promising, there were only 12 children in the study, from one specific U.K. location. This places limits upon generalisability, particularly given that 3 of the siblings were also from the same family. Moreover, no standardised outcome measures were used; parents completed a 12 item evaluation questionnaire and knowledge of autism was assessed by asking the children to draw a poster. Thus, it is difficult to draw any strong conclusions from this study and more controlled investigation is warranted.

3.5 Future research

The current review suggests that inconsistencies remain within the literature relating to sibling adjustment. Some studies have indicated an increased risk of a range of social, emotional and behavioural difficulties for non-affected siblings of children with ASD.

However other studies have not found any negative effects, with some suggesting there may be benefits to having an ASD sibling. There are similar contradictions in findings relating to mediating factors. It is possible that methodological issues may account for some of these inconsistencies. For example, most of the studies had relatively small samples, lacked adequate statistical power and only collected single informant outcome measures. Thus larger, better controlled studies with multiple informants may facilitate stronger conclusions to be generated. Larger samples may also allow a deeper exploration of factors that mediate sibling adjustment. Given the potentially dynamic and interacting nature of such factors, research that draws upon family context models may also be of benefit.

Nonetheless, targeted support to families with an ASD child, including their siblings, is warranted. One potentially fruitful area is that of ASD-specific sibling support groups. There is a clear need for UK-based outcome research within this area, given the relative lack of identified studies in this review. Whilst Canadian research has suggested some potential benefits, siblings' experiences of ASD-specific support groups remain largely unexplored in the U.K. (Smith & Perry, 2005). Thus at present, it is unknown whether ASD-specific groups may also be useful for U.K. children. Further, with the exception of two of the measures used by Smith and Perry (2005), there is a lack of standardised outcomes used by sibling group researchers. Whilst anecdotal reports are of value, larger better controlled studies, which utilise standardised outcome measures, are warranted. This would enable stronger conclusions to be drawn and ultimately, identification of the most appropriate support for siblings of children with ASDs.

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Section B

**Support Groups for Siblings of Children with Autistic
Spectrum Disorders: A Pilot Study**

Word Count: 7971 (191)

ABSTRACT

Background: Having a brother or sister with an Autistic Spectrum Disorder (ASD) can be challenging for non-affected siblings. These children may experience reduced parental attention, isolation from peers and difficult sibling behaviours. This pilot study aimed to investigate the utility of support groups for siblings of children with ASDs.

Methods: A within group, mixed methods design was used with a pre-intervention baseline. Participants were 35 children, aged 7-15 years, with an ASD sibling. All were attending ASD-specific sibling group interventions across the South East of England. Sibling rated self-concept, anxiety and anger and parent-rated emotional difficulties were collected at pre group, post group and follow up. One group also participated in a focus group.

Results: Results indicated significant improvements in self concept and significant decreases in anger and anxiety following participation in an ASD-specific sibling group. Anxiety continued to decrease at 3 month follow up. Parent-rated sibling emotional difficulties did not change. All siblings valued the groups. Four main themes were identified from qualitative data: Siblings valued the opportunity to meet similar others, have fun, learn new information about ASD and apply this knowledge to their own situation.

Conclusions: The present pilot study extends existing literature on ASD-specific sibling groups. This is one of the first studies to combine qualitative data with standardised outcome measures. Participation in an ASD-specific support group may be associated with more positive self concept and decreased anger and anxiety. Given inherent study limitations, further, controlled research studies are warranted.

Keywords: Sibling, Intervention, Group, Autistic Spectrum Disorder

INTRODUCTION

Having a brother or sister with a disability can have a notable impact upon family life for non-affected siblings. For example, these children can experience stressors such as reduced parental attention, increased carer/household responsibilities, isolation from peers and increased pressure to achieve as the 'healthy' sibling (Dodd, 2004; Lobato, 1983; McHale & Gamble, 1989). For siblings of children with an Autistic Spectrum Disorder (ASD), there can be additional challenges, such as learning to cope with associated stereotyped and difficult behaviours. Given the often 'invisible' nature of the disability, children may also encounter negative reactions to their sibling from the public and peers (Morgan, 1988; Roeyers & Mycke, 1995).

Such stressors have provoked increased research interest in the psychological development of unaffected siblings. A number of researchers have reported an increased risk of psychological and behavioural problems in siblings of children with ASDs, when compared to siblings of typically developing children (Hastings, 2003a; Petalas et al., 2009). These include internalising difficulties such as anxiety and depression (e.g. Fisman et al., 1996; Gold, 1993; Ross & Cuskelly, 2006; Verte et al., 2003) and externalising difficulties such as anger and aggressive behaviour (e.g. Bagenholm & Gilberg, 1991; Rodrigue, Geffken & Morgan, 1993; Verte et al., 2003; Wolf et al., 1998). Conversely, other researchers have noted no negative effects of having a sibling with ASD, compared to typically developing siblings or those with other disabilities (Hastings 2003b; 2007; Kaminsky & Dewey, 2002; Pilowsky et al., 2004). Some researchers have actually indicated positive influences for sibling adjustment. This includes improved emotional adjustment and more positive self-concept (e.g. Macks & Reeve, 2007; Taunt & Hastings, 2002).

Such inconsistencies suggest a more complex relationship between having a brother or sister with ASD and psychological adjustment. Indeed, adjustment may also be mediated by other factors such as family size and socio-economic status (SES), with larger families and higher SES associated with improved adjustment (Kaminsky & Dewey, 2002; Macks & Reeve, 2007). Gender and relative age of siblings can also be factors, with some studies noting heightened emotional difficulties in children with a male, older sibling with ASD (e.g. Hastings, 2003a; Petalas et al., 2009; Verte et al., 2003). Additionally, children who were female and older than their ASD sibling showed higher social competence and more positive social concept (Kaminsky & Dewey, 2002). However, findings remain contradictory and some studies have reported reverse effects of relative sibling ages (e.g. Rodrigue et al., 1993). Finally, severity of behavioural difficulties of the child with ASD can also negatively impact upon sibling emotional adjustment, whilst parental involvement in education can be a protective factor (Benson & Karloff, 2008; Hastings, 2007).

These findings imply that adjustment of siblings is amenable to change and hence targeted support may be of particular benefit. Indeed, the Department of Education and Skills (2007) has stipulated the need for 'focussed, effective support' in order to 'promote emotional and social development for disabled children and their siblings, to help to improve outcomes for all' (pp. 9, *Aiming high for disabled children: better support for families*). The benefit of providing children with information about their siblings' condition is also a consistent theme in the research literature (Harris, 2008). Hence further exploration of how best to support siblings is highly appropriate and has clear implications for future service provision (Stoneman, 2005). However, despite this, there are still relatively few studies which explore support services for siblings of children with ASD and their families, particularly in the U.K. (e.g. Reichman et al, 2008; Smith & Elder, 2010).

Sibling support groups

Evidence from studies of siblings of children with disabilities has suggested the potential utility of sibling support groups (Burke & Montgomery, 2000; Dodd, 2004). Whilst the time period, length and targeted age-range of different support groups can vary, their basic premise generally remains constant: The ‘Sibs’ organisation for example, has proposed a generic model for all support groups. This model, F.R.A.M.E., suggests that groups should be designed to be Fun, Reduce isolation, Acknowledge feelings, Model coping strategies and Enhance knowledge of disability (F.R.A.M.E. model, Sibs Organisation, www.sibs.org.uk). The Sibs organisation does not offer any direct psychological theory or evidence for the F.R.A.M.E. model. However the principles of F.R.A.M.E. can be broadly linked with the theories of the group psychotherapist, Dr Irvin Yalom (2005). Yalom postulates a number of ‘therapeutic factors’ that are the agents of change in any group therapeutic experience, including installation of hope, universality, information giving, altruism, improving social skills, imitative behaviour, interpersonal learning, catharsis and group cohesiveness. Both ‘installation of hope’ and ‘universality’ for example, apply to the aim of ‘Reducing isolation’ in the F.R.A.M.E. model. Children may often feel they are ‘the only one’ experiencing particular difficulties, or ‘unacceptable’ feelings about this sibling. The experience of finding understanding from other children facing similar situations can reduce these anxieties, providing a powerful sense of relief.

For siblings of children with disabilities, group participation has been associated with a range of positive outcomes including enhanced knowledge of disability, increased coping strategies, reduced isolation & increased self-esteem (Dodd, 2004; Evans, Jones & Mansell, 2001; Naylor & Prescott, 2004).

Additional challenges unique to having a sibling with ASD have led to the establishment of 'ASD-specific' support groups. Canadian research findings have reported improved knowledge of autism and a more positive self concept (Piers Harris Self Concept Scale; Piers, 1984) following sibling involvement in an 8 session, ASD-specific support group (Smith & Perry, 2005). However, despite positive anecdotal reports, U.K research within this area is limited (Cooke & Semmens, 2010; Howlin & Yates, 1990; Knott, 2009). Siblings' experiences of ASD-specific support groups, and the potential benefits of such groups, remain largely unexplored. Further, as the Smith & Perry (2005) study lacked a comparison group or other experimental controls, it is difficult to conclude whether its positive findings for self concept were due to the sibling group per se or to other generic factors. A more detailed research study would enable a more controlled investigation of these issues with a U.K. sample and would clearly add to the research base.

The present pilot study aimed to investigate the utility of support groups for siblings of children with ASDs, from the perspectives of siblings and their parents. A primary aim was to ascertain whether Smith and Perry's (2005) findings would be supported within a U.K sample. This study sought to further extend these findings with the inclusion of a baseline control period and follow up assessments. It was hypothesized that participation in a sibling support group would lead to improved social and emotional functioning and more positive self concept. Secondary aims were to explore siblings' own accounts of group participation and to identify additional demographic factors which may moderate the benefits of attending. Finally, it was hoped that this pilot study would help to establish effective methodologies and provide the basis for future, larger research trials.

Research questions and hypotheses

Primary hypotheses

Participation in an ASD-specific sibling support group will lead to

1. Increase in positive ratings of self concept (reported by siblings)
2. Decreased ratings of anger and anxiety (reported by siblings)
3. Improved behavioural and emotional functioning of siblings (reported by parents/carers)

Secondary research question

1. What are siblings' experiences of sibling support groups?

METHODS

Participants

Participants were a convenience sample of children aged 7-15 years with a brother or sister with an ASD, who were taking part in sibling groups in London and the South East. All siblings who were about to join these groups, as well as their parents/carers were invited to take part in the study. There were no exclusion criteria. All 37 families who were approached agreed to take part. Analyses were conducted on a final sample of 35 participants. Two children withdrew from their group following the initial session (one child withdrew due to family circumstances, and the other declined to participate). The parent of this child explained that being dyslexic, he had been worried about having to write in the group. The

mean age of participating siblings was 9.6 years and 17 were female. Of all participants, 46% were older than their sibling with ASD and 37% were younger. Demographic characteristics of participants are summarised in Table 1.

Sibling groups

Siblings were attending ASD-specific sibling groups in one of 4 community or NHS paediatric hospital settings. Group characteristics are summarised in table 2. Most groups were targeted at the 7-13 age range, with the exception of one group for older children. Each group was led by at least 2 facilitators, who included trainee and assistant clinical psychologists, social workers and specialist sibling workers. Groups were delivered in a variety of formats: Just under half of participants attended groups of a day in length (n=17, 49%) and the remainder attended groups lasting more than a day (n=18, 51%). However all groups utilised the F.R.A.M.E model and all facilitators had attended training at the Sibs organisation. Thus all groups aimed to provide fun activities, reduce isolation (via meeting other siblings) and share and normalise feelings and coping strategies with practical exercises. All groups also included psycho-education about ASD, such as ‘ask the expert’ sessions, when children were able to question a specialist clinical psychologist. Children were encouraged to apply their knowledge to their own and each others’ situations. For example in an ‘agony aunt letter’ game, children were required to respond to requests for help from ‘other children’ with ASD siblings.

Table 1**Demographic Details of Participants (n= 35)**

Variable	n=35
Sibling age: Mean (SD)	9.6 years (2.3)
Range	7 to 15
ASD sibling age: Mean (SD)	10.2 years (3.9)
Range	5 to 19
Relative sibling age: n (%)	
Older than ASD sibling	13 (37.1)
Younger than ASD sibling	16 (45.7)
Missing	6 (17.1)
Sibling gender: n (%)	
Female	17 (48.6)
Male	18 (51.4)
ASD gender: n (%)	
Female	4 (10.8)
Male	28 (35.7)
Missing	5 (13.5)
Additional siblings at home: n (%)	
Yes (1 or more)	17 (48.6)
No additional siblings	16 (45.7)
Missing	2 (5.7)
Number of adults at home: n (%)	
One	5 (14.3)
Two or more	29 (82.8)
Missing	1 (2.9)
Marital status mother: n (%)	
Married/civil partnership/cohabiting	25 (71.4)
Divorced/separated/single	6 (17.1)
Missing	4 (11.4)
Marital status father: n (%)	
Married/civil partnership/cohabiting	27 (77.1)
Divorced/separated/single	2 (5.7)
Missing	6 (17.1)
Mother work status: n (%)	
Full time work	7 (20)
Part time work/work from home	14 (40)
Not working	10 (28.6)
Missing	4 (11.4)
Father work status: n (%)	
Full time work	25 (71.4)
Part time work/work from home	1 (2.9)
Not working	2 (5.7)
Missing	7 (20)

Home programs with ASD child: n (%)	
Yes	4 (11.4)
No	25 (71.4)
Missing	6 (17.1)

Table 2**Sibling group characteristics**

Sibling group	Format	Length	Participants n (%)	Age range (years)
Group A	Community	1 day	8 (22.9)	7-11
Group B	Community	1 day	7 (20)	12-15
Group C	Community	1 day	2 (5.7)	7
Group D	Community	3 full days	3 (8.6)	8-9
Group E	NHS Hospital	4 weekly sessions	4 (11.4)	8-10
Group F	NHS Hospital	4 weekly sessions	7 (20)	7-11
Group G	NHS Hospital	4 weekly sessions	4 (11.4)	7-13

Design

Given the current lack of U.K. research within this area, a mixed methods pilot study was considered most appropriate. This would not only enable exploration of the identified research questions, but would also help to determine effective methodologies for future studies. The main quantitative element of the study involved a within participant design with a non-treatment baseline period. Participants completed outcome measures at 4 time-points; 4-6 weeks pre intervention, pre-intervention, post-intervention and 3 months post-intervention. This enabled 3 study phases of baseline, intervention and 3 month follow-up.

The study also incorporated a qualitative element. This involved a small focus group of siblings and open responses to evaluation questionnaire items.

Measures

Quantitative measures included parent/carer and sibling reports. The importance of using multiple informants in sibling research has been highlighted previously (Ferrari 1984; Gold, 1993). The following measures (see appendix B) were selected to measure primary and secondary outcome variables:

Self concept

Piers-Harris Children's Self Concept Scale, Second Edition (Piers, 1984; Piers & Herzberg, 2002).

In order to assess whether the findings of Smith and Perry (2005) would be supported (Hypothesis 1), the same measure of self-concept was selected for this study. The Piers-Harris scale is the most frequently cited children's self concept scale in the research literature and has been used in previous sibling research (Butler & Gasson, 2005). The Piers-Harris 2 is a revision of the original 80 item version, whereby outdated items were deleted. The scale includes 60 true/false items with a total self-concept score and 6 domain scores. The latter assess self concept across the following areas: Behavioural Adjustment, Intellectual/School, Physical Appearance and Attributes, Freedom from Anxiety, Popularity and Happiness/Satisfaction. Higher scores indicate more positive self concept. Raw scores are transformed to standardised T scores with mean of 50 and standard deviation of 10. The original scale has been shown to be a valid and reliable measure of self concept for children of 7-18 years (Butler & Gasson, 2005; Kelley, 2005; Piers, 1984). For the revised version, Chronbach's alpha coefficients for total and domain scores range from 0.60 – 0.93, indicating

adequate internal consistency. Initial reviews have also supported the validity of the Piers-Harris 2 (Kelley, 2005; Oswald, 2005).

Behavioural and emotional adjustment

The Strengths and Difficulties Questionnaire (SDQ): Informant rated version for children between 4-16 years old. (Goodman, 1997; 2001).

The parent rated SDQ was selected to assess the prediction that participation in a sibling group would lead to improved parent ratings of behavioural and emotional functioning (Hypothesis 3). The SDQ is a 25 item measure of behavioural and emotional adjustment, which takes approximately 5 minutes to complete. Respondents are required to use a 3 point Likert scale to rate the extent to which each of 25 attributes apply to their child. The 25 items cover 4 problem domains (Emotional Symptoms, Conduct Problems, Hyperactivity-Inattention, Peer Problems) and Pro-social Behaviour. The former 4 can be summed to generate a Total Difficulties score. This scale has been used in several previous research studies with siblings of children with developmental disabilities (Hastings, 2003; 2007; Petalas et al., 2009). The scales inclusion of both positive and negative outcomes is particularly appropriate in light of previous research findings, in that there can be both beneficial and negative effects of having a sibling with ASD.

The SDQ has been shown to have good reliability and validity for identifying behavioural difficulties in children (Goodman, 2001). Several studies have demonstrated good reliability with siblings of children with developmental disabilities (Hastings, 2003; 2007; Petalas et al., 2009). For example for the SDQ subscales, Petalas et al. (2009) demonstrated Chronbach's alpha coefficients ranging from 0.62-0.89.

Anger and Anxiety

Beck Youth Inventories (BYI): Second edition for children and adolescents. Anxiety & Anger subscales (Beck, Beck, Jolly, & Steer, 2005).

The BYI Anger and Anxiety subscales were selected to assess the prediction that sibling group participation would lead to reduced anger and anxiety (Hypothesis 2). The BYI scales are designed for use with children of 7-18 years. Each subscale contains 20 statements about thoughts, feelings and behaviours associated with a child's current emotional state. Children rate the extent to which they agree with each statement on a scale of 0 (never) to 3 (always). Items within each scale are summated to generate a total score, with higher scores indicating greater levels of anger or anxiety. Scores can also be transformed to standardised T scores which are age and gender appropriate. The scales have shown good reliability and validity and correlate highly with other similar measures. Alpha coefficients range from 0.87 to 0.89 for 7-10 year olds, 0.89-0.92 for 11-14 year olds and 0.92 to 0.96 for 15-18 year olds (Beck et al., 2005).

Demographics

Parents initially completed a demographic questionnaire, including information about the age/gender of each child, parental occupation, marital status and any home programs completed with the child with ASD (appendix D).

Qualitative measures

Evaluation questions regarding group experiences

At the end of each group, all children completed an evaluation questionnaire. This was included to address the secondary research question regarding children's experiences of the sibling group. The form included 6 items scored on a Likert style response format (0-4,

‘smiley’ faces, (appendix C)) as well as 2-3 open ended questions asking what children liked about the group, how it was helpful and what they would change in future. These items were chosen following discussion with a facilitator who had already run several sibling groups.

Post group focus group with siblings

The focus group included general questions to explore children’s group experiences. Potential questions were discussed with the specialist clinical psychologist also involved in running groups for children with ASD siblings. A number of key questions were selected (Table 3). These provided a basic framework with additional questions and prompts being used to facilitate expansion of particular responses.

Table 3

Semi structured focus group questions

<p>1. Introductory questions</p> <ul style="list-style-type: none">• Why did you do this group?• Did you want to do it?• Are you pleased you did it? If so why?
<p>2. Key questions</p> <ul style="list-style-type: none">• If you were going to recommend this group to a friend, what would you tell them?• What would you say was unhelpful?• Do you think anybody has noticed a change in you, since you’ve been coming to this group?
<p>3. Ending</p> <ul style="list-style-type: none">• What will you remember about this group in a few weeks?

Ethics and consent process

Multi-site NHS ethical approval for the study was granted by the NHS National Research ethics board. The study was also approved locally via R & D departments within each participating NHS Trust (appendix E). Potential participants were initially approached via their sibling group facilitator, who disseminated study information sheets (appendix F). Families were then offered the opportunity to discuss the study further before deciding whether to take part. Participants were assured that if they declined to take part, or wished to withdraw, this would not affect their child's participation in the group. The consent and assent process was recorded on consent forms. A separate information sheet was provided for the focus group (appendix G).

Procedure

Details of the recruitment process and participant flow are illustrated in Figure 1 and described below.

Stage One: *'Wait-list'* Assessments (4-6 weeks prior to each sibling group)

Approximately 4-6 weeks prior to each group's first meeting, group leaders distributed the first set of questionnaires to participants. This included the parent (SDQ, demographic questionnaire) and child measures (Piers-Harris 2, Beck Anger and Anxiety scales). These were returned to the researcher in a prepaid reply envelope or at the first sibling group. Due to short notice regarding the start time of two of the sibling groups, this stage was omitted and participants began at stage two (see below).

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Stage Two: Baseline Assessments (initial sibling group meeting): All assessments (with the exception of the demographic questionnaire) were repeated immediately prior to each initial sibling group session. These were administered by the researcher, who was available to answer any remaining questions participants may have had about the study.

Stage Three: Post-group Assessments (final sibling group meeting): The researcher attended the final session of each group to re-administer all parent and child measures. In the case of 1 day sibling groups, parents were asked to complete and return forms in a pre-paid envelope, within the week following the group. Children also completed the evaluation questionnaire at this stage.

Stage Four: 3 Month Follow-up Questionnaires: At 3 months following the final group session, all participants were sent a final set of questionnaires to complete in the post. A pre-paid envelope was provided in which to return these. Due to practical time constraints, the final sibling group (group G, see table 2) was excluded from this stage.

Post-group Focus Group: Children in group G (n=4) were also invited to participate in the focus group, which was conducted following the final group session at the support group setting. This was conducted, audio-recorded and transcribed by the researcher.

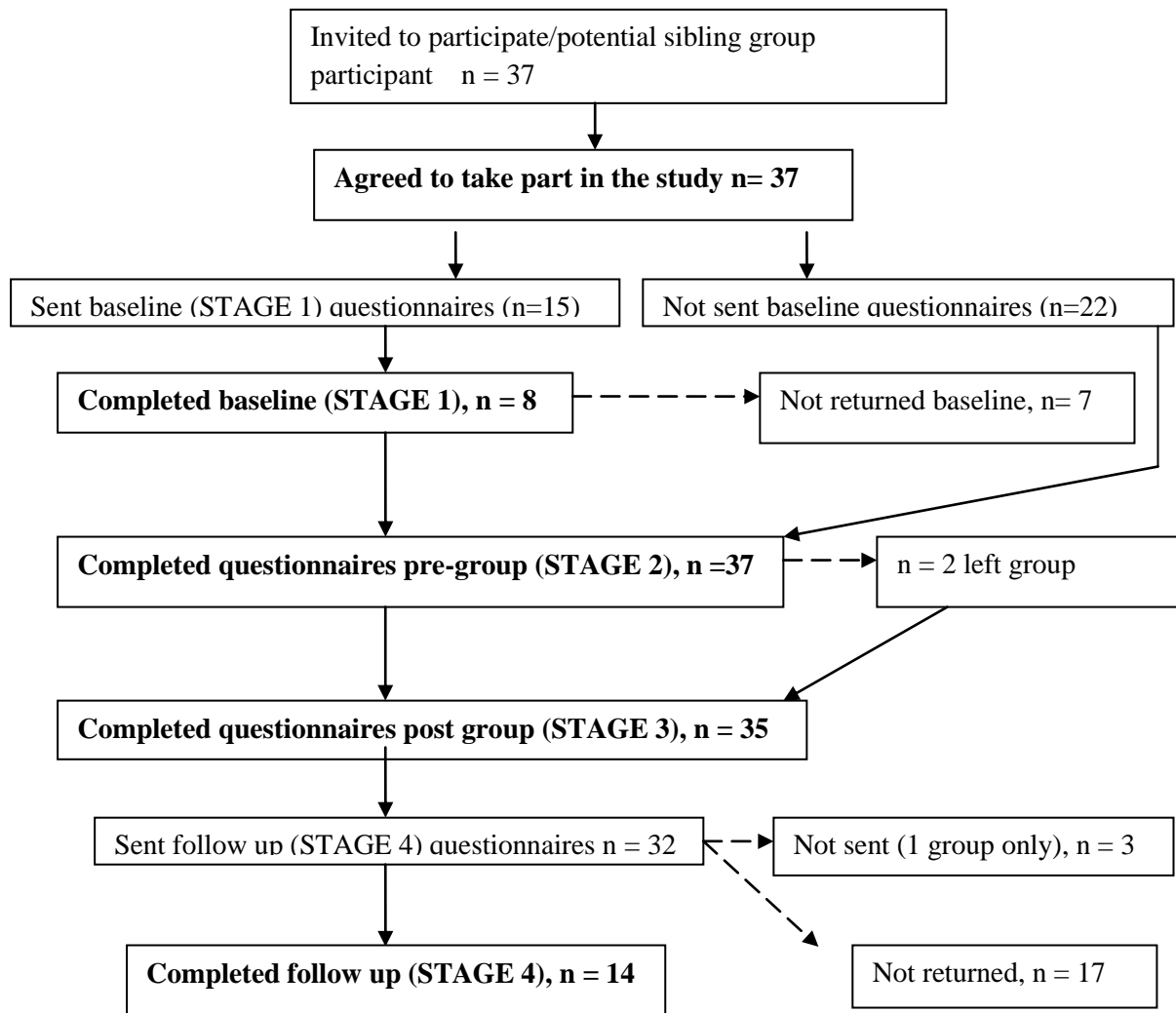


Figure 1. Study process and participant flow.

Data Analysis

Quantitative data

Initial exploratory analyses were conducted to check that data from each measure met parametric assumptions. This included visibly checking histograms of change scores for normality and assessing Z statistics for skewness and kurtosis. Given the small sample size, Z statistics above a critical value of 1.96 were taken to denote significant deviation from normality, at the 5% level (Field, 2009). Homogeneity of variance was not assessed as this is

not applicable for repeated measures. Where data violated parametric assumptions, non-parametric alternatives were used. Data from the evaluation form were summarised using descriptive statistics and a histogram.

Given the variable response rate within each study phase, data analysis was planned in three separate stages. Firstly, paired T tests (Wilcoxon matched pairs) were used to assess stability of all measures over the non-intervention baseline period. Paired-sample t tests were also used to compare pre and post intervention scores at the second stage. Finally, repeated measures ANOVAs (Friedman's ANOVAs) were used to assess change across the 3 time points of pre intervention, post intervention and 3 month follow up. Bonferroni adjustments for multiple comparisons were not applied to these analyses. It has been argued that such adjustments can be overly conservative and increase the likelihood of Type 2 errors (Perneger, 1998). As a measure of caution however, significance was evaluated at the two tailed level for all analyses, despite the study predictions of improved scores. Pearson's correlation coefficients (r) were used to calculate effect sizes (Field, 2009). Here, r values of 0.1 were considered to denote a small effect, 0.3 a medium effect and 0.5 a large effect (Cohen, 1988; 1992).

Power analyses

Power calculations followed recommendations of Field (2009) and Cohen (1988; 1992). For within subjects pre and post analyses, these were based on previous effect sizes for sibling populations of 0.5 for the Piers Harris measure and 0.55 for SDQ total scores (Hastings, 2003; Smith & Perry, 2005). In order to detect similar effect sizes, with 0.8 power and 0.05 alpha, the required sample size would be 21 and 16 participants respectively.

Qualitative data

A basic thematic analysis was conducted to analyse focus group data and open ended responses from the evaluation questionnaire. The analysis followed the methods of Braun and Clarke (2006) and the data-driven, inductive approach of Boyatzis (1998), whereby emergent themes were identified. This involved the following stages;

i. Familiarisation: The focus group transcript and questionnaire responses were read by the author. Initial thoughts regarding potential themes were noted.

ii. Generation of initial codes: Segments of text were assigned to initial codes and a draft code list was generated. According to Boyatzis (1998), the unit of coding is ‘...the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way’ (p.63).

iii. Searching for themes: Codes from stage ii were grouped conceptually and organised into broader themes.

iv. Reviewing & defining themes: Candidate themes were reviewed according to Patton’s (1990) criteria for internal homogeneity (coherent data within a theme) and internal heterogeneity (meaningful distinctions between themes) (as cited in Braun & Clarke, 2006, p.91). Where appropriate, codes and themes were collapsed or divided further. Themes were then summarised in terms of key aspects. To check reliability, the focus group transcript was read by both the author and the specialist clinical psychologist also involved in running groups for children with ASD siblings. Identified themes were subsequently discussed to clarify that these adequately portrayed siblings’ experiences.

RESULTS

Quantitative analysis

Exploratory analyses

At baseline, all 3 measures met the parametric assumptions, with the exception of the SDQ hyperactivity subscale which showed significant kurtosis ($p < 0.05$). For pre and post test scores, Piers-Harris 2 and SDQ Total Difference scores met parametric assumptions. However two SDQ subscales and Beck anger and anxiety scores showed significant deviation from a normal distribution (Z kurtosis (SDQ Peer Problems, SDQ Prosocial Behaviour) both $ps < 0.05$; Z kurtosis and Z Skewness (Beck Anger, Beck Anxiety) all $ps < 0.05$). For follow up analyses, total scores for all 3 measures met parametric assumptions, though 3 subscales significantly deviated from normality (Z kurtosis & Z skewness (SDQ Peer Problems, Piers Harris Intellectual Status) both $ps < 0.05$; Z skewness (PH Freedom from Anxiety), $p < 0.05$). For measures which deviated from normality, non parametric statistics were used.

Missing data

A small proportion of measures had missing data. For Beck Anger and Anxiety scales, one person missed one of the 20 items (5%) at each time point. For the Piers Harris, seven participants at time 1 and five participants at time 2 missed between 1- 4 of the 60 items (1.6-6.7%). Three participants at time 1 and one at time 2 missed one of the 25 SDQ items (4%).

For the SDQ and Beck inventories it was possible to impute any missing items via substituted means, following recommended guidelines (Beck et al., 2005; Goodman, 2001). For Piers Harris 2 scores, missing values were scored as 0, in the direction of low self concept. This

followed guidelines in the manual, which assumes that children may omit responses due to embarrassment about marking low self concept items (Piers & Herzberg, 2002).

Phase 1: Non-intervention baseline group analyses (n=8)

Eight participants returned postal questionnaires 6 weeks before the group and immediately before the group. This left 8 matched pairs for analysis over the baseline period. For the Piers-Harris 2 questionnaire, paired t-tests revealed no significant differences between total self concept T scores at baseline (mean baseline = 51.2, SE=3.56) and immediately before the group (mean pre group = 51.14, SE=3.47), $t(6) = 0.073$, $p > 0.05$. Scores in the baseline period were also unchanged for individual domain scores (all $ps > 0.05$).

For Beck Anxiety, there was no significant differences between T scores at baseline (mean baseline anxiety = 45.29, SE=2.78; and pre-group (mean pre-group anxiety = 42.71, SE=2.57), $t(6) = 1.279$, $p > 0.05$. T scores for anger were also unchanged over the non intervention baseline period (mean baseline anger=44.42, SE=3.66, mean pre-group anger = 41.14, SE=1.76), $t(6) = 0.996$, $p > 0.05$.

Finally SDQ total difficulties scores showed no change over the baseline period (mean SDQ baseline = 12.33, SE = 4.86, mean SDQ pre-group = 11.83, SE = 4.52), $t(5) = 1.17$, $p > 0.05$. Individual subscale scores were similarly unchanged (all $ps > 0.05$).

For the 8 participants who returned baseline data, scores on all measures were outside the clinical range (average ranges). This suggested that their functioning in all areas remained unproblematic over the baseline period prior to group participation.

Phase 2: Pre and post test analyses (n=35)

Pre-post test analyses addressed the primary research hypotheses, which predicted improved scores on all measures following the sibling group intervention. Summary scores for all outcome variables for before and after the group are provided in Table 4. As can be seen in Table 4, there were significant improvements in total Piers Harris 2 self concept ratings following participation in a sibling group. This supports Hypothesis 1, which predicted more positive sibling ratings of self concept. On consideration of the six individual domain scores, statistically significant improvements were found for the Freedom from Anxiety subscales. All Piers Harris effect sizes were within the small range (Cohen 1988; 1992).

Anger and Anxiety T scores decreased significantly following the sibling group intervention, supporting Hypothesis 2 (Beck Anger and Anxiety, both p s < 0.01). Both effect sizes were in the medium range and both moved from average to below average clinical severity ranges (Beck et al., 2005).

Contrary to predictions, there were no significant differences in SDQ Total Difficulties or individual subscale scores following participation in a sibling group. Thus Hypothesis 3, which predicted improvements in (parent reported) sibling emotional and behavioural functioning, is not supported.

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Table 4
Mean scores, standard deviations, t values, significance and effect sizes for primary outcome measures pre and post sibling group

	Pre sibling group				Post sibling group			t (df) or Wilcox. z	Significance	effect size (r)
	n	mean (S.D.)	Median (range)	clinical range (mean)	mean (S.D.)	median (range)	clinical range (mean)			
Primary outcomes										
Piers Harris 2 Total	33	49.21(9.2)	48 (28-69)	average	51.06(7.74)	50 (28-66)	average	-2.23 (32)	p=0.03*	0.13
Beck Anxiety	31	47.71	46 (31-92)	average severity	42.84(7.42)	41 (31-60)	below average	2.47	p=0.01**	-0.31
Beck Anger	32	46.35(12.5)	43 (30-93)	average severity	42.13(7.67)	42 (30-64)	below average	2.45	p=0.01**	-0.31
SDQ Total difficulties	27	11.06(6.46)	8 (1-24)	normal	10.54(6.58)	9 (0-25)	Normal	0.79(26)	n.s.	
Subscales										
PH Behav. adjust.	33	50.12(9.97)	54 (33-62)	average	50.97(8.7)	54 (33-62)	average	-0.72(32)	n.s.	
PH Intellect. status	33	49.12(8.81)	48 (29-65)	average	49.72(8.01)	48 (29-65)	average	-0.57(32)	n.s.	
PH Phys appearance	33	48.55(9.9)	48 (29-65)	average	50.58(10.1)	52 (23-65)	average	-1.75(32)	n.s.	
PH Freedom anxiety	33	49.03(9.27)	48 (31-65)	average	52.03(8.41)	51 (35-65)	average	-2.98(32)	p=0.006**	0.22
PH Popularity	33	49.88(8.03)	51 (35-59)	average	51.94(7.57)	54 (33-68)	average	-1.07(32)	n.s.	
PH Happiness	33	50.63(8.01)	50 (31-68)	average	51.48(6.85)	51 (37-59)	average	-1.55(32)	n.s.	
SDQ Prosocial behav.	27	8.31(2.23)	9 (2-10)	normal	8.18(2.11)	9 (2-10)	normal	-0.32	n.s.	
SDQ Emot.symptoms	27	3.83(2.21)	4 (1-8)	normal/ borderline	3.46(2.33)	4 (0-8)	normal/ borderline	1.77(26)	n.s.	
SDQ Hyperactivity	27	3.5(3.28)	3 (0-10)	normal	3.19(3.25)	3 (0-10)	normal	0.94(26)	n.s.	
SDQ Conduct prms	27	1.93(2.34)	1 (0-9)	normal	2(2.32)	1 (0-10)	normal	-0.28(26)	n.s.	
SDQ Peer problems	27	1.8(1.7)	1 (0-6)	normal	1.78(1.72)	1 (0-6)	normal	0	n.s.	

*p<0.05 **p<0.01, n.s. = not significant, 2 tailed.

Note: Piers Harris high score = more positive, all others high score = negative

Phase 3: Follow up analyses (n=14)

Fourteen participants returned at least one of the set of measures, enabling analysis of changes across pre intervention, post intervention and 3 month follow up. Summary scores of change across time points for total scores for each measure can be found in Table 5. Beck Anxiety scores decreased significantly across the time points ($F(2,24) = 9.02, p < 0.01$). Post hoc analyses indicated a significant decrease in scores between pre intervention and follow up, with a large effect size ($r=0.74$). There were also significant decreases in parent rated SDQ total difficulties scores ($F(2,24) = 3.64, p < 0.05$). Post hoc analyses indicated a large, significant decrease in scores between pre group and follow up ($r=0.55$). These results differed from the pre-post test analyses, where scores did not change. Piers Harris Total and Beck Anger scores showed small improvements over time, though these were non-significant.

Individual SDQ and Piers Harris subscale scores did not change significantly over time (all $p > 0.05$). The only exception was the SDQ Emotional Symptoms subscale, which decreased significantly immediately post intervention (pre group mean = 3.69, $SE=0.67$; post group mean = 3, $SE=0.69$) and continued to decrease at 3 month follow up (follow up mean=2.3, $SE=0.62$), ($V=0.69, F(2,11) = 12.196, p < 0.01$). (NB: Mauchly's test indicated that the assumption of sphericity had been violated ($\chi^2(2)=8.83, p < 0.05$) and hence multivariate tests are reported ($\omega=0.64$)). Post hoc analyses indicated a significant decrease between pre group and follow up with a large effect size ($r=0.7$).

Further analyses were conducted to compare demographic characteristics of this follow up group (n=14) with participants who did not complete follow ups (n=21). These indicated no

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significant differences between the 2 groups for variables such as age, gender, relative sibling age or other siblings at home ($t(33)=0.03$, $p>0.05$, $\chi^2(1)=0.69$; 0.02; 2.43, all $ps > 0.05$).

Table 5**Mean scores, standard deviations, F statistics and effect sizes for primary outcome measures at pre group, post group and 3 month follow up**

Primary outcomes	n	Pre-test		Post-test		3 month Follow up		F (Df)	significance	effect size(r)
		mean(SD)	median (range)	mean(SD)	median (range)	mean(SD)	median (range)			
Piers Harris 2 total	14	51.36(9.38)	49(40 to 69)	52.64(7.54)	50 (40 to 66)	54.36(7.99)	56.5(44 to 72)	0.83 (1.13, 14.7) ^a	n.s.	
Beck anxiety	13	45.08(7.22)	45(36 to 59)	42.62(8.14)	40(31 to 60)	40.08(6.29)	38(31 to 54)	9.02(2,24)	p=0.001**	0.74 (pre gp vs follow up)
Beck anger	13	42.85(6.87)	42(35 to 59)	41.92(6.24)	42(31 to 55)	41.92(7.14)	42(32 to 56)	0.304 (1.36,16.34) ^a	n.s.	
SDQ total difficulties	13	9.04 (5.91)	6 (1 to 21)	6.92(4.79)	7(0 to 19)	7(4.54)	6(1 to 18)	3.64 (2,24)	p=0.042*	0.56 (pre gp vs post gp & follow up)

*p<0.05 **p<0.01, n.s. = non significant, 2 tailed. ^a Greenhouse-Geisser correction for sphericity applied.

Note: Piers Harris high score = more positive, all others high score = negative

Qualitative analyses

Overall experiences of the group

Children's responses to the evaluation questions are summarised in Figure 1. For all items, mean ratings were above 3, where 3 denotes 'agree' and 4 'very much agree' (all medians = 4).

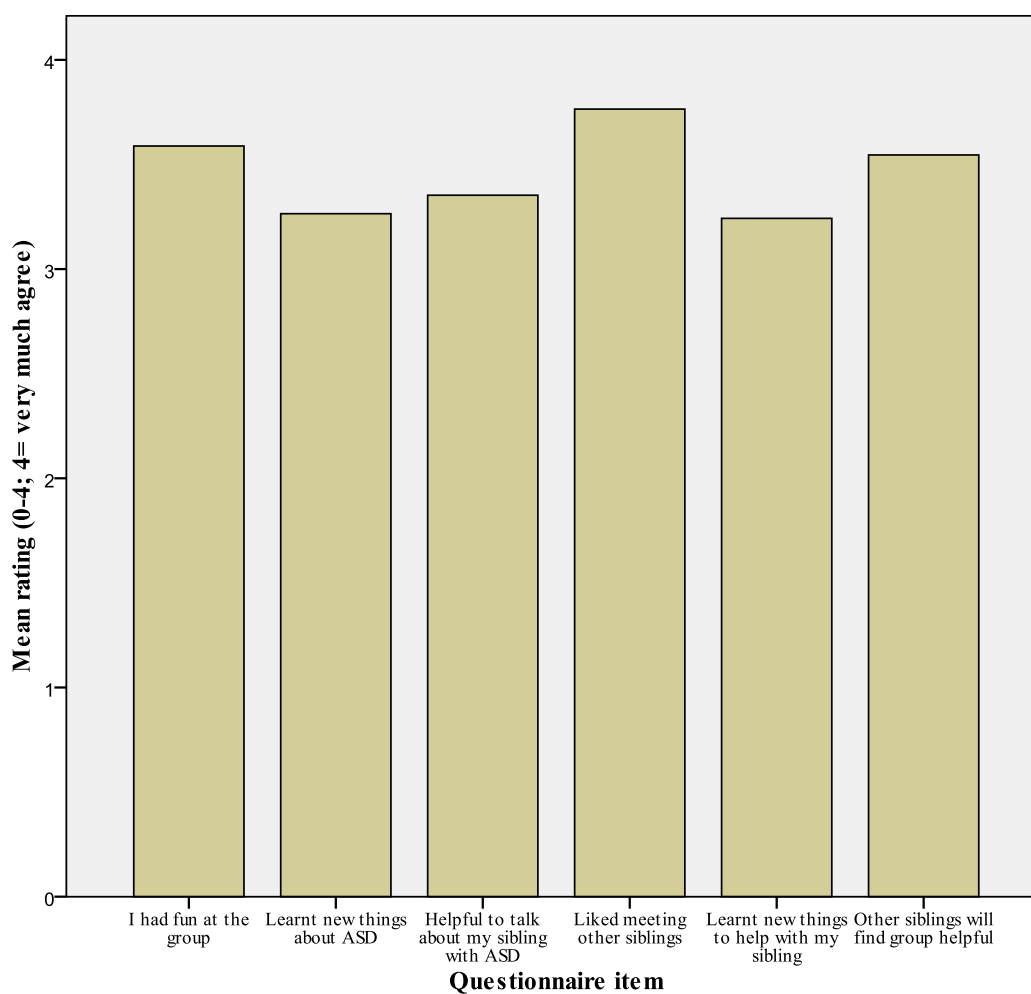


Figure 2. Mean ratings for evaluation questions (n=35)

Thematic analysis

Four broad themes emerged from the focus group and open ended questionnaire data. Identified themes and subthemes are presented below and each is illustrated by representative quotations (see appendix I for more examples).

1. Learning/new information

All participants spoke about learning new information as a result of their participation in the group. This included information about ASD/Aspergers as well as new ways of coping. According to siblings, this learning occurred via fun activities as well as question and answer sessions where children could gain answers to their own specific questions. It was clear that the children greatly valued this new learning and the learning process itself.

“Talking to Dr XX (specialist psychologist) and finding out about, well just answering our questions and the fact that we got to ask our own questions was good as well”
(Focus group Participant 1)

“To learn about my big brother (with ASD).....Because I wanted to know how to *cope with him*” (Focus group Participant 2, when asked reasons for doing the group)

“*It’s good to find out about siblings and how to cope*” (Sibling group Participant)

Children particularly valued activities where learning was combined with fun.

“*I liked it when we done ‘Mr Potato Head’ (game about sensory difficulties) and done examples of what they (siblings with ASD) do...*” (Sibling group Participant)

“*Having fun whilst learning about Autism*” (Sibling group Participant, when asked about the best parts of the group)

However a small number of children felt that they were required to do too much writing in their group and were not happy when the group environment was set up like a classroom.

“*..change the part where we have to write out*” (Sibling group Participant)

“...not set out like a classroom” (Sibling group Participant)

2. Meeting similar others

Another important aspect for siblings was the chance to make new friends and meet other children who had siblings with ASD. Children described how this gave them a chance to share feelings and experiences and normalise these.

“I really liked meeting other people who were like me and had annoying brothers and sisters. And I had fun” (Sibling group Participant)

“That I found out about other people’s experiences with their brothers” (Sibling group Participant)

“Knowing other people feel the same way I do” (Sibling group Participant)

However it was important that groups had an appropriate age mix – in a small number of cases where this was not balanced appropriately, children found this difficult;

“I felt a bit out of place as I am a bit older than the other siblings in the group” (Sibling group Participant)

3. Applying learning/impact outside the group

Children in the focus group all talked of the impact of the group on them (this was not directly addressed on the evaluation form). This included increased understanding and empathy, changed behaviours as well as the application of new ideas.

“At home I get a bit irritated by my brother cause...the way he whines, he always whines and then it’s....he’s a pain, he just doesn’t, understand sometimes aswell..... Yeah I used to be really angry at it but now I’m not really that angry. I just think ...whatever, I just ...deal with it.....I think it’s just finding out about...that there’s a reason he does it and just that he can’t help it so...there’s no need to have a go at him....” (Focus group Participant)

“I’m happier.....because I play with people now.....my friends” (Focus group Participant)

“ I learnt about my brother ...oh and if I try to do those things and that he will be more nicer...” (Focus group Participant)

4. Fun

This was one of the strongest themes and provided an overarching theme for all other themes. Whilst fun was clearly important in itself, fun activities also provided scaffolding for learning about ASD, sharing feelings and coping strategies. Food was also frequently mentioned by participants as was the opportunity to miss school;

“Having fun activities and playing games”(Sibling group Participant)

“I liked all the learning and fun and getting out of school” (Focus group Participant)

“Fantastic.Errr, you get to play....I’d say it’s really good fun and you get to learn lots about your Autism brother or sister.” (Focus group Participant)

DISCUSSION

This study evaluated the impact of an ASD specific support group intervention on 35 children with siblings with ASDs. The main hypotheses predicted more positive ratings of self concept and decreased anger and anxiety for siblings following participation in a support group. Parent-reported behavioural and emotional functioning for siblings was also expected to improve. In support of Hypothesis one, paired t-tests indicated a small but significant increase in Piers Harris 2 total self concept scores following children’s involvement in a sibling group (effect size = 0.13). Of six individual domain scores, ‘Freedom from Anxiety’ scores significantly improved. Hypothesis 2 was also supported. Siblings’ ratings of anger and anxiety on the Beck subscales were significantly lower at post group than at pre group, with medium effect sizes (effect sizes Anxiety and Anger = 0.31). These findings are strengthened by the finding of unchanged scores during the pre-intervention baseline period

when children had no group input. Follow up analyses also suggested that in the case of anxiety, scores continued to decrease 3 months following the group intervention. This indicates that group participation was associated with continued benefits for siblings in terms of reduced anxiety. Results for Hypothesis 3 were contradictory. Contrary to expectations, parent SDQ ratings of sibling behavioural and emotional difficulties remained unchanged following the sibling groups (Total SDQ and SDQ subscales, all p s >0.05). In comparison to the pre and post intervention analyses however, participants in the follow up analyses showed significantly improved parent SDQ ratings across time. Here, SDQ Total difficulties and Emotional symptoms subscale scores decreased significantly between pre and post group and between pre group and 3 month follow up.

In considering the secondary research question, responses to the evaluation questionnaire suggested siblings found the groups to be fun, helpful and informative. The qualitative analyses indicated 4 dominant themes regarding siblings' experiences of the group. Siblings valued the opportunity to meet similar others, learn new information about ASD and apply this knowledge to their own situation outside the group. Most importantly, the groups and activities were viewed as fun, which in turn enabled learning and expression/normalising of difficult feelings.

The finding of improved self concept scores support and extend the findings of Smith and Perry (2005). This study includes a larger sample size and addresses Smith and Perry's original concern that Piers Harris group means can often increase over time, regardless of treatment. As their study lacked a comparison group or any other experimental controls, it was difficult to attribute improvements to the sibling group. In the present study, the finding of unchanged Piers Harris 2 scores during the non-intervention baseline period, when compared to post intervention increases the confidence in which these findings can be

viewed. These findings are also consistent with studies of support groups for siblings with other disabilities, where improved self esteem has been demonstrated post intervention (Phillips, 1999; Williams et al., 2003).

It is interesting that despite the greater statistical power, the effect size in this study ($r=0.13$) was somewhat smaller than that found by Smith and Perry ($r=0.25$). This may reflect differences in the length of intervention in Smith and Perry's study (8 weeks) compared to the present one (ranging from 1 day to 4 weeks). Another possibility is that cultural differences between Canadian and U.K. siblings influenced the way in which Piers Harris items were completed. In the present study for example, several participants required clarification on the U.S. wording of certain Piers Harris items (e.g. item 5: 'I am smart', item 43: 'I am dumb about most things') and appeared particularly embarrassed about endorsing others (e.g. item 33: 'I have nice hair'). It is interesting to note that when used with other European children in a non-ASD specific sibling group study, Piers Harris scores were unchanged (D'Arcy et al., 2005), though the small sample size in this study may also account for this. Finally, on consideration of individual domain scales, only 'Freedom from Anxiety' reached significance. It is thus possible that the improved global self concept scores actually reflected a more specific effect of reduced anxiety following group participation. This would be supported by the comparatively larger effect size for the Freedom from Anxiety scale ($r=0.22$) and the significant decreases in Beck Anxiety scores.

The finding of decreased sibling anger and anxiety following attendance at the sibling group is encouraging. Whilst the lack of control group means that definite conclusions regarding causality are difficult, these results suggest further investigation is warranted. Phillips (1999) has also demonstrated decreased anxiety and improved behaviour for siblings of children with developmental disabilities. This followed a 15 week sibling group which met

for 2 hours each weekday. The present results suggest that it may be possible to achieve similar effects within a shorter time frame and that in the case of anxiety, these effects may continue beyond the group. This has important implications given the current NHS financial climate and need for effective, time limited interventions. The anger findings contrast with those of Smith and Perry (2005) who found no significant decreases in sibling anger and resentment post group. However, the authors recognise this may have been influenced by the choice of an unstandardised outcome measure, with only fair reliability. Thus the inclusion of a standardised measure with good psychometric properties in the present study provides a valuable contribution to the current evidence base.

It is interesting that in the majority of cases, parent SDQ ratings did not change post group. This is perhaps unsurprising: as noted earlier, previous research has noted that parent and child rated outcomes often tend to differ (Ferrari, 1984; Gold, 1993). Secondly, given the limited time frame of measures in the study, it is possible that children were more likely to notice the immediate impact of the group than their parents. This may also account for the contradictory finding of significant improvements in SDQ scores at 3 month follow up compared to immediately post group. In addition, the SDQ is a screening measure targeted towards identifying difficulties in clinical populations, whereas children's scores in the study were outside the clinical range. It is thus possible that the SDQ may be less sensitive to detecting changes in these non clinical scores over a short time period. Indeed, on an anecdotal level, many parents commented verbally on how much the group had helped their child and the changes they had noticed at home in terms of increased empathy and reduced anxiety. Thus future studies would benefit from using parent measures which are more sensitive to change in non-clinical populations.

The qualitative results support existing qualitative findings regarding sibling groups and other disabilities, as well as ASD specific groups. These studies also found that siblings enjoyed the groups and valued the opportunity to increase their knowledge, meet similar others and share experiences, feelings and coping strategies (D'Arcy et al. 2005; Dodd, 2004; Knott, 2009; Naylor and Prescott, 2004). It is encouraging that this study replicates these findings with a larger group of children. This also extends to elements siblings wished to change about the groups such as the need for groups with an age appropriate age mix (Burke and Montgomery 2001). Thus these findings support the use of the F.R.A.M.E. model (Sibs organisation) and suggest that this may enable therapeutic 'agents of change' such as installation of hope, universality and imitative behaviour (Yalom, 2005). Further, the value that children placed upon learning about ASD and questioning ASD specialists, suggests the benefit of sibling groups which are ASD specific. Whilst generic sibling groups have also been shown to be useful, the additional challenges faced by children with ASD siblings warrant focused attention. Indeed it would be interesting to compare the value of generic and specific groups in future research.

Limitations

It is important to note a number of limitations within the present pilot study. Firstly, as in Smith and Perry's (2005) study, the present study lacked a control group. This means that it is difficult to conclude whether findings are accountable to treatment effects alone or to other more generic factors. Whilst this study attempted to include a non intervention baseline period, unfortunately only limited participant data (n=8) were available for this analysis. Although difficult in the present pilot study, future sibling group research would benefit from the inclusion of a control group. This would facilitate greater inferences regarding treatment

effects and could include both no intervention and control intervention study arms in order to explore specific beneficial group elements.

A second limitation is the small sample size, particularly at follow up. Whilst the present sample size is greater than that of previous studies, a larger number of participants would enable closer analyses of potential moderators such as age, gender and birth order for example. Further, the follow up analyses were restricted to those participants (n=14) who returned measures by post, which may have added potential biases. Whilst this group did not differ in terms of demographic characteristics, they may have felt particularly motivated to return questionnaires due to positive consequences of the sibling group, for example.

Thirdly, as this study relied on a convenience sample, it included several groups across different NHS and community settings, of different lengths and formats. Whilst this may contribute to ecological validity, this brings clear implications for treatment fidelity. Thus, despite the fact that each group was based on the F.R.A.M.E. model and facilitators had completed 'Sibs' training, there were slight variations between interventions. As treatment fidelity was not assessed, the extent to which each group followed F.R.A.M.E. is also unclear. Future research should seek to evaluate sibling group interventions of the same length, which follow the same protocol.

Fourthly, as the study relies upon both parent and child self report measures, this brings inherent difficulties such as subjectivity and social desirability response biases (Stone et al., 2000). These measures also rely on children and parent's ability to read, understand and respond to specific questions. Whilst assistance was available for children who needed it, it is possible that some children were reluctant to ask for this. In order to improve reliability in future research, it may be useful to combine self report measures with additional

observational ratings collected by blinded assessors. Finally, given the genetic basis of ASD traits, it is statistically likely that some siblings may also experience some degree of developmental or learning difficulties (e.g. Ronald, Happe & Plomin 2005; Silverman et al., 2002). Despite this, cognitive and ASD measures were not collected in this study. Whilst this information may have been useful, collecting it was not deemed practically possible or ethically appropriate in the limited time span and context of this study.

Conclusions

The present pilot study extends the existing literature on support groups for children with a disabled sibling and specifically, siblings with ASDs. Despite the limitations discussed, it would appear that participating siblings enjoyed the groups and valued the opportunity to meet similar others and learn about ASD. In comparison to many earlier sibling studies, this study has combined qualitative data with quantitative data from standardised measures which have good psychometric properties. This is a particular strength and extends the existing research findings. These findings suggest that participation in an ASD-specific sibling group is associated with more positive self concept and decreased anger and anxiety in siblings. Decreases in anxiety continued at 3 month follow up. Given the short duration of the sibling groups, these results are striking and suggest that this area warrants further research. Here, a larger more controlled study with a standard sibling group protocol would be of benefit.

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Section C

Critical Appraisal

Word Count: 1999

1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

Prior to starting clinical training I had already worked within several research positions including work on multi-centre randomised controlled trials within the NHS. Through these roles I developed a sound knowledge of research methodology and range of qualitative and quantitative research skills. The present study however, has offered the opportunity to apply these skills to a piece of work I had devised personally. In contrast to earlier roles, I was directly involved through each stage of the research process. I found it immensely rewarding to develop and refine my own research idea in an area in which I have a personal interest. I also enjoyed working with other psychologists within this field and found this helped to maintain my enthusiasm during particularly challenging parts of the process.

Devising an NHS ethics application and attaining ethics and Research and Development approval was a new experience. I found this process to be rather laborious, confusing and at times repetitive. On several occasions I found myself wishing I had not chosen to conduct research within the NHS and can understand why this process may discourage many clinicians from conducting research. Indeed once I had achieved approval, I found myself feeling as if I had almost conducted the study itself! On reflection, I have learnt an immense amount regarding this part of the research process. I have learnt to write a succinct and effective ethics application and through the review process, to present my proposal clearly to a mixed audience. I feel these experiences and the knowledge I have gained will be invaluable should I decide to conduct further research.

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This was the first time I had conducted a focus group. Through reading and discussion with colleagues I decided that a moderately structured approach was most appropriate to exploring my research question regarding children's group experiences (Krueger, 1998; Morgan, 1998). I learnt to generate a series of opening, introductory, key and ending questions in order to progress discussion. However I also discovered that there can be unique challenges to conducting focus groups with younger children. For example, during the study focus group, some of the children appeared to find the tape recorder 'off-putting' and found it difficult to verbalise their experiences.

Overall, I found undertaking this study to be more challenging than previous research I have conducted. Unlike my other roles, I had to learn to balance the competing demands of collecting research data with the demands of clinical work on placement. On reflection, it was perhaps over ambitious to collect data from 7 different sibling groups in 4 different geographical locations and at 4 different time points. However, this did teach me the importance of organisation, keeping detailed records and closely monitoring data collected. A final challenge was holding a sometimes uneasy balance between my role as a clinician and that as a researcher. For example it sometimes felt difficult not to 'join in' with the group activities and to maintain a more 'separate' role. I feel that this is a dilemma I will continue to work with should I conduct future research.

2. If you were able to do this project again, what would you do differently and why?

Initially I had been keen to undertake a purely qualitative study to explore children's group experiences in greater depth. However on examination of the existing literature, it was apparent that most sibling group studies utilised qualitative or non standardised evaluation measures. In this respect, my choice of a pilot study with mixed methodology was appropriate. This design would enable an extension of the evidence base on sibling groups and potentially be more generalisable.

Ideally I would have included a control group in this study. However given the small number of groups available and that each was already established, this would have been unfeasible and unethical. As the number of U.K. ASD-specific sibling groups is now increasing, I would include a wait list control group if I were to repeat this study. This group would be offered the chance to join a sibling group once study data had been collected. The presence of a control group would strengthen the study as it would facilitate greater inferences regarding treatment effects.

Whilst this study attempted to include a non intervention baseline period, unfortunately only limited participant data (n=8) were available for this analysis. For some groups (n=2), short notice regarding the start of the group made it impossible for participants to complete baseline questionnaires. However, whilst the remaining participants were sent questionnaire packs and pre-paid envelopes 6-8 weeks before the group, there was a poor response rate. Despite this, all were keen to participate and agreed to complete questionnaires immediately prior to the group. On reflection, perhaps it was incorrect to assume that busy families with a child with ASD would find the time to complete study questionnaires via post. Perhaps it was also important that parents had the chance to first meet me face to face and

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discuss the study in person. If I were to conduct this study again, I would reconsider this part of the study and try to make it as easy as possible for families to return questionnaires. Clearly it would not be practically possible to individually meet each family 6-8 weeks before the group, particularly given the scale of this study. However I would discuss other possibilities with sibling group facilitators such as a 'pre group information session', or arranging to attend clinics to which parents may already bring their child with ASD for example. The latter may also be useful for 3 month follow up questionnaires, for which there was also a relatively poor response rate.

A final adaptation I would make to this study would be to the child focus group. As mentioned above, some of the children in the group seemed to find it difficult to verbalise their experiences. Whilst I tried to create a comfortable, flexible environment which included each child, I wondered if this was influenced by the approach I chose, which was purely question based. In order to access children's views and meanings more effectively, I would approach the focus group differently in future. For example, some researchers have suggested using a group task or activity, role play or interviews with a puppet can be helpful in children's focus groups (Gibson, 2007; Morgan, Gibbs, Maxwell & Britten, 2002).

3.Clinically, as a consequence of doing this study, would you do anything differently and why?

At the start of the study I had the opportunity to attend sibling group facilitator training with the Sibs organisation which provided numerous ideas for activities which follow the F.R.A.M.E. model (www.sibs.org.uk). During data collection, I saw how much siblings valued a short focused group intervention which included these activities. Indeed in both clinical settings in the study, there were waiting lists for sibling groups. The study findings also suggest benefits in terms of reduced anxiety, anger and improved self concept. Consequently, I would definitely consider including sibling interventions as part of my future practice. This study has highlighted the impact of ASD on the entire family system and the benefits of focused support.

More generally, I have learnt several practical considerations regarding facilitating child group interventions. Firstly, I have seen the importance of considering an appropriate age and gender mix to participants. For example in two of the groups in this study, one child was a few years older than the others in the group. This impacted on the flow of discussions and led to sometimes awkward silences. In one case the older child seemed to adopt a more 'adult' and caring role towards his younger peers. Given that group aims included discussing feelings and having a fun break from carer responsibilities, this was concerning. I will continue to consider these issues when planning groups in future. A second related point is regarding age appropriate activities. From my observations, it appeared that the F.R.A.M.E. model and related activities were particularly suited to younger participants and it is possible that older children would value adaptations. Finally, I would carefully consider the setting in which groups were held. Some children in this study seemed worried about attending a group

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at a hospital setting for example, and this heightened the initial anxiety that was already present at the first session.

Most significantly, I have seen the value of arts, creative media and playful interventions in helping children to learn and express their views and feelings. Such media can help children to express challenging psychological material at their own pace, in a way that seems safe and manageable (e.g. Geldard & Geldard, 2008; Sunderland & Engleheart, 1993; Sunderland, 2001). Since the start of this study, I have developed a real enthusiasm for creative therapeutic activities and have already attended two specialist training days within this area. These approaches have been invaluable for both individual and group therapeutic work during my child and specialist placements with looked after children and adolescents. I have used art-based materials, role plays, metaphor, puppets and therapeutic story writing to support children's self expression during clinical work, for example. I feel I will continue to use these approaches throughout my clinical career.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

As discussed earlier, I would conduct a larger, more controlled study. This would seek to answer similar questions to the present study; that is, whether ASD-specific interventions were associated with more positive self concept and decreased anger and anxiety. However, I would attempt to strengthen the existing findings by including a larger sample and a wait list control group. I would also include sibling groups which followed a standard protocol, with assessments of treatment fidelity. In this respect I would hope to generate greater inferences regarding treatment effects.

Subsequently, a related research study would seek to investigate mechanisms of change within ASD-specific sibling groups. That is, how and why does participation in an ASD-specific sibling intervention influence anxiety, anger and self concept of siblings? According to Kazdin & Knock (2003), there is a relative lack of research which explores the process of therapeutic change within child and adolescent therapy. However knowledge of change mechanisms would help to refine the sibling group protocol for optimal benefit to children. Initially, it would be useful to explore this via qualitative interviews and a grounded theory approach (Strauss & Corbin, 1998). For example, group facilitators could be asked to reflect on siblings who had and who had not benefitted from the sibling interventions. Siblings themselves and their parents could also be interviewed regarding their experiences. Transcripts could then be analysed for common themes and categories, in order to generate a model to describe potential change mechanisms in sibling groups. Indeed, other researchers have successfully used this methodology to explore factors influencing treatment outcome of Cognitive Behaviour Therapy for psychosis (McGowan, Lavender & Garety, 2005). In later studies, any potential mediators generated from this research could then be explored

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quantitatively. Here, sibling adjustment and potential mediators could be assessed on a number of occasions during the course of the sibling intervention, (rather than only before and after) (Kazdin & Knock, 2003).

Finally, it would be interesting to explore other potential support interventions for siblings. For example internet support forums may be one possible area and have been shown to be beneficial for other groups such as children with siblings with special needs and parents of cancer patients (Barak, Boniel-Nissim & Suler, 2008; Han & Belcher, 2001; Tichon & Shapiro, 2003). These may be potentially more cost effective and could widen access to siblings who do not have an available sibling group to attend. Such interventions could be studied qualitatively, or in a similar research design to the present study. Further research could compare the effectiveness of different intervention types.

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PART C: CRITICAL APPRAISAL

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Section D

Appendices

Appendix A

Literature review search strategy

Reviewed literature was identified through computer based searches of the following databases:

- Psychinfo (2000-2011)
- Web of Knowledge (2000-2011)
- Wiley Interscience (2000-2011)

Additional papers were identified through manual searches of reference sections and an internet search using 'Google Scholar'. Searches included combinations of the following terms: "sibling", "brother", "sister", or "family" combined with "illness", "autistic spectrum disorder", "asperger syndrome", "autism", "mental retardation", "learning disabilities/difficulties", "developmental disabilities", "intellectual disabilities" and "pervasive developmental disorder". All searches stipulated that these terms appeared in the abstract or key words.

The following exclusions were stipulated in each search; dissertation abstracts international, non peer-reviewed papers, encyclopedias, books and book chapters. The review focused upon literature within the past 10 years, which was written in English. Papers published earlier than this were excluded from the main review but were used to provide a context for the introductory sections.

For the first part of the review, the above key terms were combined with: "adjustment", "coping" and "relationship". This identified 104 articles. For the review of sibling group

interventions, the above key terms were combined with “intervention”, “therapy”, “group”, “support” or “treatment”. This identified 320 articles.

Identified abstracts were assessed for inclusion against the following additional criteria:

- Studies relating to emotional, social or behavioural adjustment of non-affected siblings of children with ASDs or Asperger Syndrome
- Studies relating to children aged 0-18 years

For the second part of the review:

- Group interventions aimed directly at siblings
- Intervention studies which included non-affected siblings of children with ASD or Asperger syndrome

Results

Fifteen articles were retained for inclusion in the first part of the review (social, emotional and behavioural adjustment of children with ASD siblings). Studies were based in a range of countries including the U.K (n=6), U.S.A. (n=3), Canada (n=3), Australia (n=1), Belgium (n=1) and Israel (n=1). Siblings’ ages ranged from 4 to 18 years. For the second part of the review, 9 studies were retained. This included studies from the U.K. (n=3), U.S.A. (n=4), Canada (n=1) and Ireland (n=1). Siblings’ ages ranged from 4 to 16 years.

Appendix B: Copies of outcome measures

SDQ: 2 PAGES; 99-100

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BECK QUESTIONNAIRES

2 PAGES; 101-102

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PIERS HARRIS 2 QUESTIONNAIRE

2 PAGES; 103-104 (This has been removed from the electronic copy)

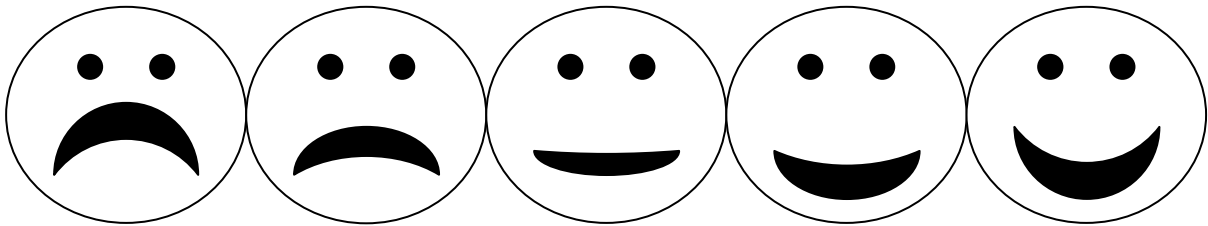
Appendix C: Copy of evaluation form

What did you think about the group today?

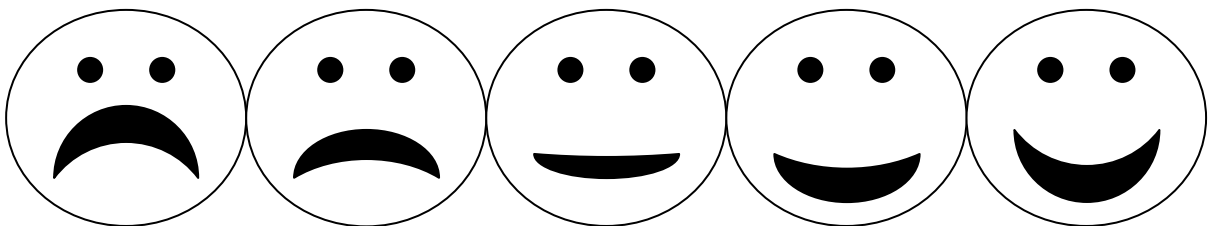


Please put a circle around the face which best matches what you thought of the group.

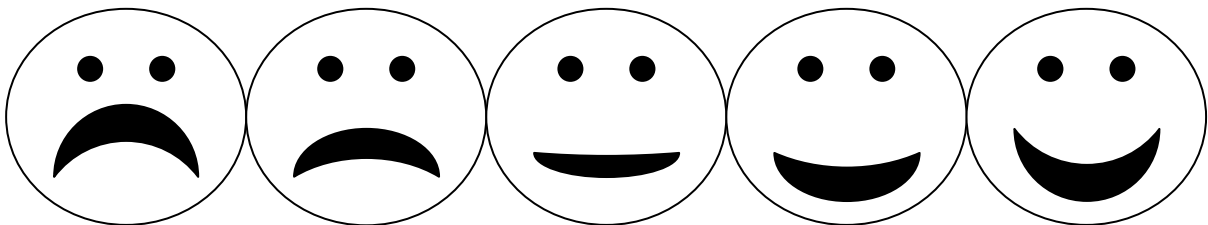
1. I had fun at the group



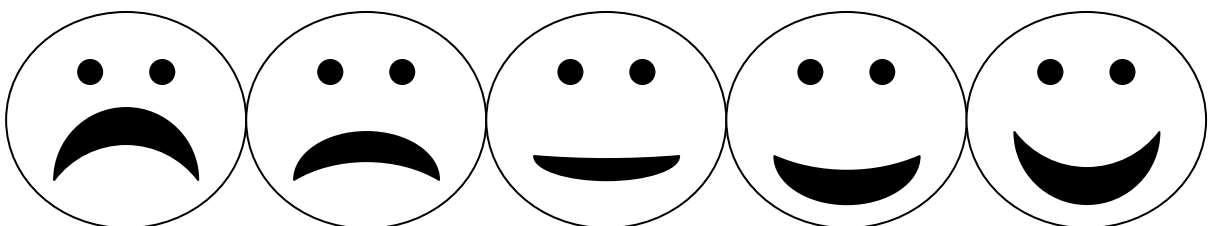
2. I learnt some new things about Autism



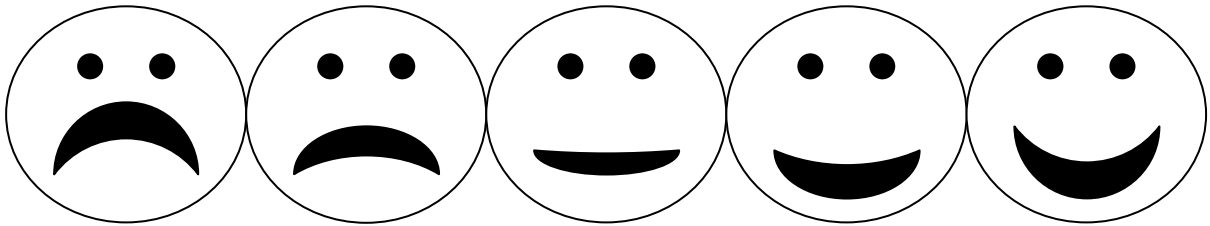
3. It was helpful to talk about my brother or sister with Autism



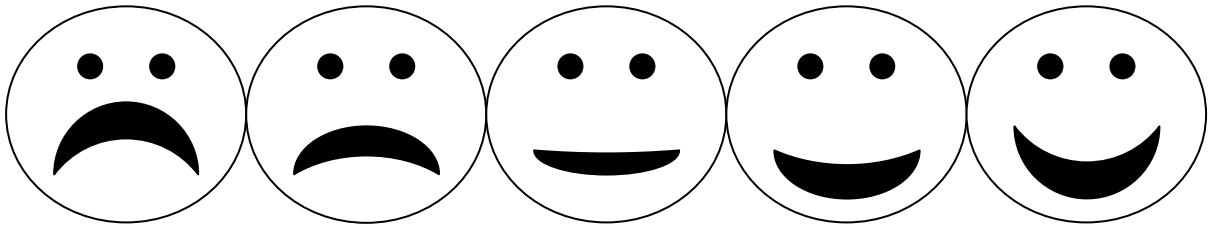
4. I liked meeting other children who have brothers and sisters with Autism



5. I learnt new things to help me with my brother/sister



6. I think other children who have brothers/sisters with Autism will find this group helpful



Please tell us what you liked best about the group

.....
.....

Please tell us anything you didn't like about the group

.....
.....

How could we make the group even better?

.....
.....

Thank you!

Appendix D: Parent demographic questionnaire

Questionnaire for parents/guardians

Please complete the following questions and return these in the envelope provided. All responses will be kept strictly confidential. Thank you.

How many adults (18 years & over) are in your household?

What is your present marital status?

(Please tick for each adult in the household) **Mother** **Father** **Other adult**

Married/civil partnership	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living with someone/cohabiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Divorced/separated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Single	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Widowed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state)			

Do you work outside the home?

Mother **Father** **Other adult**

Yes, full-time work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yes, part-time work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No not working	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please state)			

Please state your occupation (if relevant):

Mother: _____

Father: _____

Other adult: _____

How many children are in your family?

PART D: APPENDICES

Please provide the following information for your child who is participating in the sibling group:

Child's age: years months

Child's gender (please tick):

Male
Female

Please provide the following information for each of your child's brothers/sisters:

(please tick for each child)

Gender:	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7
Male	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Female	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Age in years:	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Which of these children	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7
have Autism? (please tick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you completed any home programs with your child(ren) with Autism? (e.g. Applied Behaviour Analysis, Son-Rise, TEACCH)

Yes No

If yes please specify: _____

Thank you for taking the time to complete this information

Appendix E1: NHS Ethics committee approval letter

3 PAGES: 109-111 (This has been removed from the electronic copy)

Appendix E2: Trust 1 R&D approval letter

4 PAGES: 112-115 (This has been removed from the electronic copy)

Appendix E3: Trust 2 R&D approval letter

2 PAGES: 116-117 (This has been removed from the electronic copy)

Appendix F: Information sheets: Appendix F1: Parent/guardian information sheet

INFORMATION SHEET: PARENTS OR GUARDIANS

**Support groups for siblings of children with Autistic Spectrum Disorders:
A pilot study**

Dear Parents & Guardians,

I would like to invite your son or daughter to take part in a research study which I am carrying out as part of a Doctoral qualification. It is important that you read this information about the project because your son or daughter is under 16. I will need both you and your child to agree to take part. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your child. Your child may need help to understand some parts of the study, and it is important that they do so. Please ask me if there is anything that is not clear, or if you would like more information. Take time to consider the information and decide whether or not you might be interested in taking part.

My name is Sophie Eyres and I am a trainee clinical psychologist in the Department of Applied Psychology, Canterbury Christ Church University. I am supervised by Professor Patricia Howlin (Institute of Psychiatry), Ms Celia Heneage (Canterbury Christ Church University) and Dr Rachel Hussey (Oxleas NHS Foundation Trust). All my supervisors are clinical psychologists with extensive experience of working with children with ASD's and their families.

What is the purpose of the study?

Living with a brother or sister with an Autistic Spectrum Disorder (ASD) can be difficult. However there can also be positive effects, including improved social competence, empathy and communication skills. There may also be additional challenges such as coping with difficult behaviours from their sibling, feeling isolated from peers and increased responsibility at home for example. As ASD's can often appear 'invisible' to others, children must also learn to cope with potentially negative reactions to their brother or sister from the public.

It is really important to help brothers and sisters to cope with these additional stressors and to provide them with information and support. The Department of Health have recognised this, although there are still few services for siblings in the U.K. Several organisations have set up 'sibling support groups' and many parents and children say they have been helpful. However, we do not know exactly how or why these groups have helped siblings and their families.

The aim of this research is to find out whether these groups are useful to brothers and sisters. We would like to know what, if anything, children find helpful about these groups. There has been no other research of this kind in the U.K.

It is hoped that the results of this study will provide crucial information about the best way of supporting brothers and sisters and the continuation and provision of future sibling services.

Why have I and my son/daughter been asked to take part?

Children with a brother or sister with an ASD, who are about to join a sibling support group, have been invited to take part. We are approaching all children and their parents/guardians who are taking part in groups in London and the South East.

Does my son/daughter have to take part?

No. Taking part is completely voluntary. It is up to you and your child whether you decide to participate or not.

If you think you might be interested in taking part in the study, please could you return the enclosed form to myself or your sibling group leader in the envelope provided. Please keep this information sheet for yourself. I will then contact you with further details about the study and you can decide whether or not you would like to take part. You can also contact me on the number or email below if you have any questions. If you later agree to take part, you are still free to withdraw at any time and without giving a reason.

Any decision that you make will not affect your child's participation in the sibling support group.

What will happen if we decide to take part?

If you decide to take part, I would like you to complete 2 brief questionnaires about you and your child and return these to myself or your sibling group leader in a pre-paid envelope. You will then be asked to complete one of the questionnaires on 3 more occasions; just before the first sibling group session, within 2 weeks of the end of the group and again 3 months later. On each occasion, it should take no longer than 5-10 minutes to complete the forms.

Your child will be also asked to complete 2 questionnaires to return to myself or the group leader. They will then be asked to complete these questionnaires again just before the first sibling group session, within 2 weeks of the end of the group and again 3 months later. Again, it should take no longer than 10 minutes to complete the forms on each occasion.

I will be present at the first and final sessions of the sibling group to collect the questionnaires from you and your child, and to answer any questions you may have. On the final occasion the questionnaires will be posted to you and you will be provided with a pre paid envelope in which to return them.

How might my son/daughter benefit from taking part?

This study may not help you or your child directly. However, many people like to know that they have helped with research which might help other children who have a brother or sister with an ASD and their families in the future.

Some children think that it's a fun thing to do, as they have the chance to feedback what they think about the sibling support group. Other people enjoy having a bit of time and space to think about themselves.

What are the possible disadvantages and risks of taking part?

The research involves your child answering some questions about their experiences of the support group and whether they have found it helpful. Most people don't mind this at all but for some people it bothers them. There are also some questions about how your child feels about themselves. Some people find it difficult to answer those kinds of questions or worry that they might get upset.

As the researcher, I believe that it is unlikely that your child will feel uncomfortable. I want to make every effort to avoid this situation. I and the sibling group leaders will be present at the first and final group sessions when your child completes the questionnaires. I am trained to talk to young people and manage the situation in the unlikely event that someone becomes distressed. If this were to be the case I will discuss what to do with your child, such as talking to the group leader and to yourself.

Some of the questionnaires are also used by psychologists in routine clinical practice. If your child's responses were unusual for his/her age range, I would let you know where it may be helpful to seek further advice.

For most people, there are no problems with this research.

Will our participation in this study be kept confidential?

Yes. All of the information collected about you and your child during this study will be kept strictly confidential. After the sibling groups I will take the questionnaires and consent forms away. You/your child's names will be removed from the questionnaires, and the consent forms will be stored separately so that you cannot be recognised. All the information will be kept in a locked filing cabinet and the only people that see it will be myself and my research supervisor.

What will happen afterwards?

Afterwards, I will write to you and your child to tell you what the outcome of the research is, if you choose. The results may also be submitted for publication in a journal, so that they can be used by other professionals who work with brothers or sisters of children with ASD's. If this were to be the case, your identity and any personal information will not be revealed in the results of the study.

Who is organising and conducting this study?

The lead researcher is Sophie Eyres, trainee clinical psychologist. This research forms part of my qualification for a Doctorate in Clinical Psychology at Canterbury Christ Church University.

Who has reviewed the study?

The study has been reviewed and approved by the NHS Research Ethics Committee and the Research Review Committee, Canterbury Christ Church University.

Who do I ask if I have questions or concerns?

You can contact me, Sophie Eyres, on XXXXX or XXXXXXXX. If you phone, please say that the message is for me and leave a contact number so I can call you back.

Sophie Eyres, Trainee Clinical Psychologist

Canterbury Christ Church University,
Department of Applied Psychology
Broomhill Road, Tunbridge Wells
Kent, TN3 0TG

Thank you for taking the time to read this information sheet

Appendix F2: Parent/guardian information sheet (focus group)

INFORMATION SHEET: PARENTS OR GUARDIANS (FOCUS GROUP)

**Support groups for siblings of children with Autistic Spectrum Disorders:
A pilot study**

Dear Parents & Guardians,

I would like to invite your son or daughter to take part in a research study which I am carrying out as part of a Doctoral qualification. It is important that you read this information about the project because your son or daughter is under 16. I will need both you and your child to agree to take part. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your child. Your child may need help to understand some parts of the study, and it is important that they do so. Please ask me if there is anything that is not clear, or if you would like more information. Take time to consider the information and decide whether or not you might be interested in taking part.

My name is Sophie Eyres and I am a trainee clinical psychologist in the Department of Applied Psychology, Canterbury Christ Church University. I am supervised by Professor Patricia Howlin (Institute of Psychiatry), Ms Celia Heneage (Canterbury Christ Church University) and Dr Rachel Hussey (Oxleas NHS Foundation Trust). All my supervisors are clinical psychologists with extensive experience of working with children with ASD's and their families.

What is the purpose of the study?

Living with a brother or sister with an Autistic Spectrum Disorder (ASD) can be difficult. However there can also be positive effects, including improved social competence, empathy and communication skills. There may also be additional challenges such as coping with difficult behaviours from their sibling, feeling isolated from peers and increased responsibility at home for example. As ASD's can often appear 'invisible' to others, children must also learn to cope with potentially negative reactions to their brother or sister from the public.

It is really important to help brothers and sisters to cope with these additional stressors and to provide them with information and support. The Department of Health have recognised this, although there are still few services for siblings in the U.K. Several organisations have set up 'sibling support groups' and many parents and children say they have been helpful. However, we do not know exactly how or why these groups have helped siblings and their families. The aim of this research is to find out whether these groups are useful to brothers and sisters. We would like to know what, if anything, children find helpful about these groups. There has been no other research of this kind in the U.K.

It is hoped that the results of this study will provide crucial information about the best way of supporting brothers and sisters and the continuation and provision of future sibling services.

Why have I and my son/daughter been asked to take part?

Children with a brother or sister with an ASD, who are about to join a sibling support group, have been invited to take part. We are approaching all children and their parents/guardians who are taking part in groups in London and the South East.

Does my son/daughter have to take part?

No. Taking part is completely voluntary. It is up to you and your child whether you decide to participate or not.

If you think you might be interested in taking part in the study, please could you return the enclosed form to myself or your sibling group leader in the envelope provided. Please keep this information sheet for yourself. I will then contact you with further details about the study and you can decide whether or not you would like to take part. You can also contact me on the number or email below if you have any questions. If you later agree to take part, you are still free to withdraw at any time and without giving a reason.

Any decision that you make will not affect your child's participation in the sibling support group.

What will happen if we decide to take part?

If you decide to take part, I would like you to complete 2 brief questionnaires about you and your child and return these to myself or your sibling group leader in a pre-paid envelope. You will then be asked to complete one of the questionnaires on 3 more occasions; just before the first sibling group session, within 2 weeks of the end of the group and again 3 months later. On each occasion, it should take no longer than 5-10 minutes to complete the forms.

Your child will be also asked to complete 2 questionnaires to return to myself or the group leader. They will then be asked to complete these questionnaires again just before the first sibling group session, within 2 weeks of the end of the group and again 3 months later. Again, it should take no longer than 10 minutes to complete the forms on each occasion.

After 3 months, I will ask all of the children in your child's sibling group to return for a 'focus-group'. This will be at the place where the support group was held. It should take about 1 hour. I will ask all of the children about their experiences of the group and what they found helpful/not helpful. I will audio record this meeting and type it up afterwards. After I have typed it up I will destroy the recording. I will not name your child or put any identifying details in the write up. I will look at the recording for broad themes which children found helpful about the group.

I will be present at the first and final sessions of the sibling group and at the 3 month focus group to collect the questionnaires from you and your child, and to answer any questions you

may have. On the final occasion the questionnaires will be posted to you and you will be provided with a pre paid envelope in which to return them. Alternatively you can return them to me at the focus group.

How might my son/daughter benefit from taking part?

This study may not help you or your child directly. However, many people like to know that they have helped with research which might help other children who have a brother or sister with an ASD and their families in the future.

Some children think that it's a fun thing to do, as they have the chance to feedback what they think about the sibling support group. Other people enjoy having a bit of time and space to think about themselves.

What are the possible disadvantages and risks of taking part?

The research involves your child answering some questions about their experiences of the support group and whether they have found it helpful. Most people don't mind this at all but for some people it bothers them. There are also some questions about how your child feels about themselves. Some people find it difficult to answer those kinds of questions or worry that they might get upset.

As the researcher, I believe that it is unlikely that your child will feel uncomfortable. I want to make every effort to avoid this situation. I and the sibling group leaders will be present at the first and final group sessions when your child completes the questionnaires. I am trained to talk to young people and manage the situation in the unlikely event that someone becomes distressed. If this were to be the case I will discuss what to do with your child, such as talking to the group leader and to yourself.

Some of the questionnaires are also used by psychologists in routine clinical practice. If your child's responses were unusual for his/her age range, I would let you know where it may be helpful to seek further advice.

For most people, there are no problems with this research.

Will our participation in this study be kept confidential?

Yes. All of the information collected about you and your child during this study will be kept strictly confidential. After the sibling groups I will take the questionnaires and consent forms away. You/your child's names will be removed from the questionnaires, and the consent forms will be stored separately so that you cannot be recognised. All the information will be kept in a locked filing cabinet and the only people that see it will be myself and my research supervisor.

Immediately after the focus group, I will transfer the audio-recording onto a password protected CD. After I have typed it up I will destroy the recording. I will not name your child or put any identifying details in the write up of the recording.

What will happen afterwards?

Afterwards, I will write to you and your child to tell you what the outcome of the research is, if you choose. The results may also be submitted for publication in a journal, so that they can be used by other professionals who work with brothers or sisters of children with ASD's. If this were to be the case, your identity and any personal information will not be revealed in the results of the study.

Who is organising and conducting this study?

The lead researcher is Sophie Eyres, trainee clinical psychologist. This research forms part of my qualification for a Doctorate in Clinical Psychology at Canterbury Christ Church University.

Who has reviewed the study?

The study has been reviewed and approved by the NHS Research Ethics Committee and the Research Review Committee, Canterbury Christ Church University.

Who do I ask if I have questions or concerns?

You can contact me, Sophie Eyres, on XXXXXX or XXXXXXXXXX If you phone, please say that the message is for me and leave a contact number so I can call you back.

Sophie Eyres, Trainee Clinical Psychologist

Canterbury Christ Church University,

Department of Applied Psychology

Broomhill Road, Tunbridge Wells

Kent, TN3 0TG

Thank you for taking the time to read this information sheet

Appendix F3: Child information sheet (6-8 years): 2 PAGES 125-126



INFORMATION SHEET: 6-8 year olds



An investigation of support groups for brothers and sisters of children with Autistic Spectrum Disorders

Hi I'm Sophie.

Would you like to help me with some research?

You might need to talk to your mum, dad or carers about it.

Only say yes if you really want to do it. It's up to you!

Do you go to a group because you have a brother or sister with autism?



- We would like to hear about this group!
- We want to find out what you think about the group and if you like it or not. Maybe this will help us to make the groups even better.



Do I have to take part?



- No. It is up to you!
- If you don't want to that's absolutely fine. Everything that happens to you in your group will be just the same.

What will happen if I say yes?



- If you say yes, I will ask you to answer some questions on paper. Your mum, dad or carer can help you.
- I will come and meet with you and the other children in your group.
- I will ask you some questions about what you liked or didn't like about the group.



Could anything go wrong?



- Some children could find some of the questions are about things that make them feel sad.
- If you feel a bit upset you can tell me. You can stop at any time. I will talk to you and I can ask your parent to help as well.
- For most children, there are no problems with the research.

Why should I take part?

- It could be fun and it's your chance to tell us what you think.
- It might help us to make the groups work better.



What will happen afterwards?

- We will keep all your answers safe and remove your name. We will make sure no-one knows it is you.
- When I've finished talking to everyone, I will send you a letter telling you how helpful your answers have been and what we have found out!



What if I have any worries or questions?

- Talk to your mum, dad or carer. They can get in contact with me.

What will happen now?

- You just have to think about whether you wish to take part!



Thank you!

Appendix F4: Child information sheet (6-8 years, focus group)



INFORMATION SHEET (FOCUS GROUP): 6-8 year olds



An investigation of support groups for brothers and sisters of children with Autistic Spectrum Disorders

Hi I'm Sophie.

Would you like to help me with some research?

You might need to talk to your mum, dad or carers about it.

Only say yes if you really want to do it. It's up to you!

Do you go to a group because you have a brother or sister with autism?



- We would like to hear about this group!
- We want to find out what you think about the group and if you like it or not. Maybe this will help us to make the groups even better.



Do I have to take part?



- No. It is up to you!
- If you don't want to that's absolutely fine. Everything that happens to you in your group will be just the same.

What will happen if I say yes?



- If you say yes, I will ask you to answer some questions on paper. Your mum, dad or carer can help you.
- I will come and meet with you and the other children in your group.
- I will ask you some questions about what you liked or didn't like about the group.
- After your group has finished, I will ask you and the other children in your group to come back for a meeting. I will ask you all what you liked about the group and what would make the group even better.



Could anything go wrong?



- Some children could find some of the questions are about things that make them feel sad.
- If you feel a bit upset you can tell me. You can stop at any time. I will talk to you and I can ask your parent to help as well.
- For most children, there are no problems with the research.

Why should I take part?

- It could be fun and it's your chance to tell us what you think.
- It might help us to make the groups work better.



What will happen afterwards?

- We will keep all your answers safe and remove your name. We will make sure no-one knows it is you.
- When I've finished talking to everyone, I will send you a letter telling you how helpful your answers have been and what we have found out!



What if I have any worries or questions?

- Talk to your mum, dad or carer. They can get in contact with me.

What will happen now?

- You just have to think about whether you wish to take part!



Thank you!

Appendix F5: Child information sheet (9-16 years)



INFORMATION SHEET: YOUNG PEOPLE



An investigation of support groups for brothers and sisters of children with Autistic Spectrum Disorders

My name is Sophie. I would like to invite you to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the information below carefully, and talk to your family about taking part. Don't worry if you don't understand it straightaway. Your parents have also been told about this and you can ask them to help you. Please ask me if you have any more questions or you would like some more information. Take time to think about it and decide if you want to say YES or NO to this. Thank you for reading this.

Why are we doing this?

There are lots of children growing up with a brother or sister who has autism. We know that there can be some good things about this. We also know that it can be hard sometimes too. It is normal to sometimes feel caring and protective, and sometimes to feel totally fed up or annoyed with your brother or sister. You may feel that you don't get enough time with your mum or dad, or that you are the only one with a brother or sister with autism. Sometimes you may wish you had some more information about autism or some help to cope with the difficult things that happen.



We want to know how best to help children who have a brother or sister with autism. Some people think that 'sibling support groups' (sibling is another word for brother or sister), like the group that you will be going to, might be helpful. But we don't really know yet.



That is why we are doing this project. We want to find out what you think about the group and if you like it or not. We would like to know whether these groups make a difference to you and how you feel about yourself. This is really important as it will tell us the best way to help other children who have a brother or sister with autism.

Why have I been chosen?

We would like to talk to children who have a brother or sister with autism. We have asked you because you are going to take part in a support group for brothers and sisters soon. We have asked all the other children in your group too. We are also asking children from some other sibling groups in England to take part.

Do I have to take part?



No. It is up to you and your parents to decide. If you decide you don't want to that's absolutely fine. Everything that happens to you in your group will be just the same.

If you do decide to take part, you will be given this information sheet to keep. I will also ask you to sign a form to say you understand (consent form). If you decide to take part you are still free to change your mind at any time and without giving a reason.

What will happen if I decide to take part?

Before you go to your group, I will ask you to answer some questions about you and how you feel about things. There are no right or wrong answers. This will take about 15 minutes.



I will come to your group to meet you and the other children. I will ask you some more questions and this will take about 15 minutes. At the end of the group, I will ask you what you liked and didn't like about your group.

I will ask children from different groups to answer the same questions. After I have collected the answers from all the children happy to take part in the research I will look for patterns in what they say.

Why should I take part?



Some children think that it's a fun thing to do, as they have the chance to tell us what they think of their group. Other people enjoy having a bit of time and space to think about themselves. Many children like to know that they have helped with research which might help other children who have a brother or sister with Autism and their families in the future.

Could anything go wrong?

The research involves asking you some questions about what you think about the group for brothers and sisters. Most people don't mind this at all but for some people it bothers them. There are also some questions about how you feel about yourself. Some people don't like that – for example if they are feeling sad that day, they might worry about getting upset.

I want to make sure that this will not happen. I want you to feel safe and happy doing the research. I am trained to talk to young people and think of ways to help them if they feel unhappy, and I can ask your parent or group leader to help you as well.

For most people, there are no problems with this research. However, if these are the type of things that bother you, you might want to have an extra think about whether to take part. If you take part and you do feel a bit upset, you can tell me. You can ask to stop the research. If I get worried that you seem a bit upset, I will ask you, and I will see if someone else can help if necessary. The idea is to make sure you feel comfortable doing the research.

What will happen afterwards?

After your group I will take the questionnaires and forms away. None of the pieces of paper with information on them will show your name. All the information will be kept in a locked cupboard and the only people that see it will be the people doing the research.



Afterwards, I will write to you to tell you what the research can tell us. I would also like to publish the results in a journal, so that other people who work with brothers and sisters can know about it. If this happens, you will not be named in the article.

Who do I ask if I have any questions or worries?



Please talk to your parent or guardian about the project. If you have any other questions, you or your parent/guardian can contact me, Sophie Eyres, on XXXXX, or XXXXXX. If you phone, please say that the message is for me and leave a number so I can call you back.

Sophie Eyres, Trainee Clinical Psychologist

Canterbury Christ Church University

Department of Applied Psychology

Broomhill Road

Tunbridge Wells

Kent, TN3 0TG

What will happen now?



You just have to think about whether you would like to take part! Talk to your family about it. When you have decided if you want to say YES or NO, please sign the consent form. It tells us that you understand what the research is about, what will happen and that you want to take part. There is also a form for your parent or guardian to sign as well.

Thank you!!

Appendix F6: Child information sheet (9-16 years, focus group)



INFORMATION SHEET: CHILDREN (FOCUS GROUP)



**Support groups for siblings of children with Autistic Spectrum Disorders:
A pilot study**

My name is Sophie. I would like to invite you to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the information below carefully, and talk to your family about taking part. Don't worry if you don't understand it straightaway. Your parents have also been told about this and you can ask them to help you. Please ask me if you have any more questions or you would like some more information. Take time to think about it and decide if you want to say YES or NO to this. Thank you for reading this.

Why are we doing this?

There are lots of children growing up with a brother or sister who has autism.

We know that there can be some good things about this. We also know that it can be hard sometimes too. It is normal to sometimes feel caring and protective, and sometimes to feel totally fed up or annoyed with your brother or sister. You may feel that you don't get enough time



with your mum or dad, or that you are the only one with a brother or sister with autism. Sometimes you may wish you had some more information about autism or some help to cope with the difficult things that happen.

We want to know how best to help children who have a brother or sister with autism. Some people think that 'sibling support groups' (sibling is another word for brother or sister), like the group that you will be going to, might be helpful. But we don't really know yet.



That is why we are doing this project. We want to find out what you think about the group and if you like it or not. We would like to know whether these groups make a difference to you and how you feel about yourself. This is really important as it will tell us the best way to help other children who have a brother or sister with autism.

Why have I been chosen?

We would like to talk to children who have a brother or sister with autism. We have asked you because you are going to take part in a support group for brothers and sisters soon. We have asked all the other children in your group too. We are also asking children from some other sibling groups in England to take part.

Do I have to take part?



No. It is up to you and your parents to decide. If you decide you don't want to that's absolutely fine. Everything that happens to you in your group will be just the same.

If you do decide to take part, you will be given this information sheet to keep. I will also ask you to sign a form to say you understand (consent form). If you decide to take part you are still free to change your mind at any time and without giving a reason.

What will happen if I decide to take part?

Before you go to your group, I will ask you to answer some questions about you and how you feel about things. There are no right or wrong answers. This will take about 15 minutes.



I will come to your group to meet you and the other children. I will ask you some more questions and this will take about 15 minutes. At the end of the group, I will ask you what you liked and didn't like about your group. I will ask children from different groups to answer the same questions.

After your group has finished, I will ask you and other children in your group to come back for a meeting. This will take about an hour. I will ask you all about what you thought about the group, what you liked and disliked, and what would make the group even better. I will make a recording of what everybody says, so I can write it out later. I won't put your name when I do this.

After I have collected the answers from all the children happy to take part in the research I will look for patterns in what they say.

Why should I take part?



Some children think that it's a fun thing to do, as they have the chance tell us what they think of their group. Other people enjoy having a bit of time and space to think about themselves. Many children like to know that they have helped with research which might help other children who have a brother or sister with Autism and their families in the future.

Could anything go wrong?

The research involves asking you some questions about what you think about the group for brothers and sisters. Most people don't mind this at all but for some people it bothers them. There are also some questions about how you feel about yourself. Some people don't like that – for example if they are feeling sad that day, they might worry about getting upset.

I want to make sure that this will not happen. I want you to feel safe and happy doing the research. I am trained to talk to young people and think of ways to help them if they feel unhappy, and I can ask your parent or group leader to help you as well.

For most people, there are no problems with this research. However, if these are the type of things that bother you, you might want to have an extra think about whether to take part. If you take part and you do feel a bit upset, you can tell me. You can ask to stop the research. If I get worried that you seem a bit upset, I will ask you, and I will see if someone else can help if necessary. The idea is to make sure you feel comfortable doing the research.

What will happen afterwards?

After your group I will take the questionnaires, forms and recording away. None of the pieces of paper with information on them, or the write up of the recording will show your name. All the information will be kept in a locked cupboard and the only people that see it will be the people doing the research.



Afterwards, I will write to you to tell you what the research can tell us. I would also like to publish the results in a journal, so that other people who work with brothers and sisters can know about it. If this happens, you will not be named in the article.

Who do I ask if I have any questions or worries?



Please talk to your parent or guardian about the project. If you have any other questions, you or your parent/guardian can contact me, Sophie Eyres, on XXXXXX, or XXXXXX. If you phone, please say that the message is for me and leave a number so I can call you back.

Sophie Eyres, Trainee Clinical Psychologist

Canterbury Christ Church University
Department of Applied Psychology
Broomhill Road
Tunbridge Wells
Kent, TN3 0TG

What will happen now?



You just have to think about whether you would like to take part! Talk to your family about it. When you have decided if you want to say YES or NO, please sign the consent form. It tells us that you understand what the research is about, what will happen and that you want to take part. There is also a form for your parent or guardian to sign as well.

Thank you!!

Appendix G: Consent forms: Appendix G1: Parent/guardian consent form

CONSENT FORM: PARENT/GUARDIAN

**Support groups for siblings of children with Autistic Spectrum Disorders:
A pilot study**

Please tick the boxes next to each statement, to show that you understand and agree to them. Then please sign your name at the bottom, and put the date.

Please initial box

- | | |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to ask questions and I have had my questions answered | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I/my child are free to withdraw at any time, without giving any reason. | <input type="checkbox"/> |
| 4. I understand that the results may be published in a journal | <input type="checkbox"/> |
| 5. I agree to take part in the above study with my child. | <input type="checkbox"/> |

_____	_____	_____
Name of Parent/guardian	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

Appendix G2: Child assent form

CONSENT FORM: CHILDREN

**Support groups for siblings of children with Autistic Spectrum Disorders:
A pilot study**

Please tick the boxes next to each statement, to show that you understand and agree to them. Then please sign your name at the bottom, and put the date.

Please initial box

1. I have read the information sheet and I understand what it says

2. I have had the chance to ask questions and I have had my questions answered.

3. I know that I can decide to stop if I change my mind.

4. I agree to take part in this research.

Name of person taking part

Date

Signature

Name of Researcher

Date

Signature

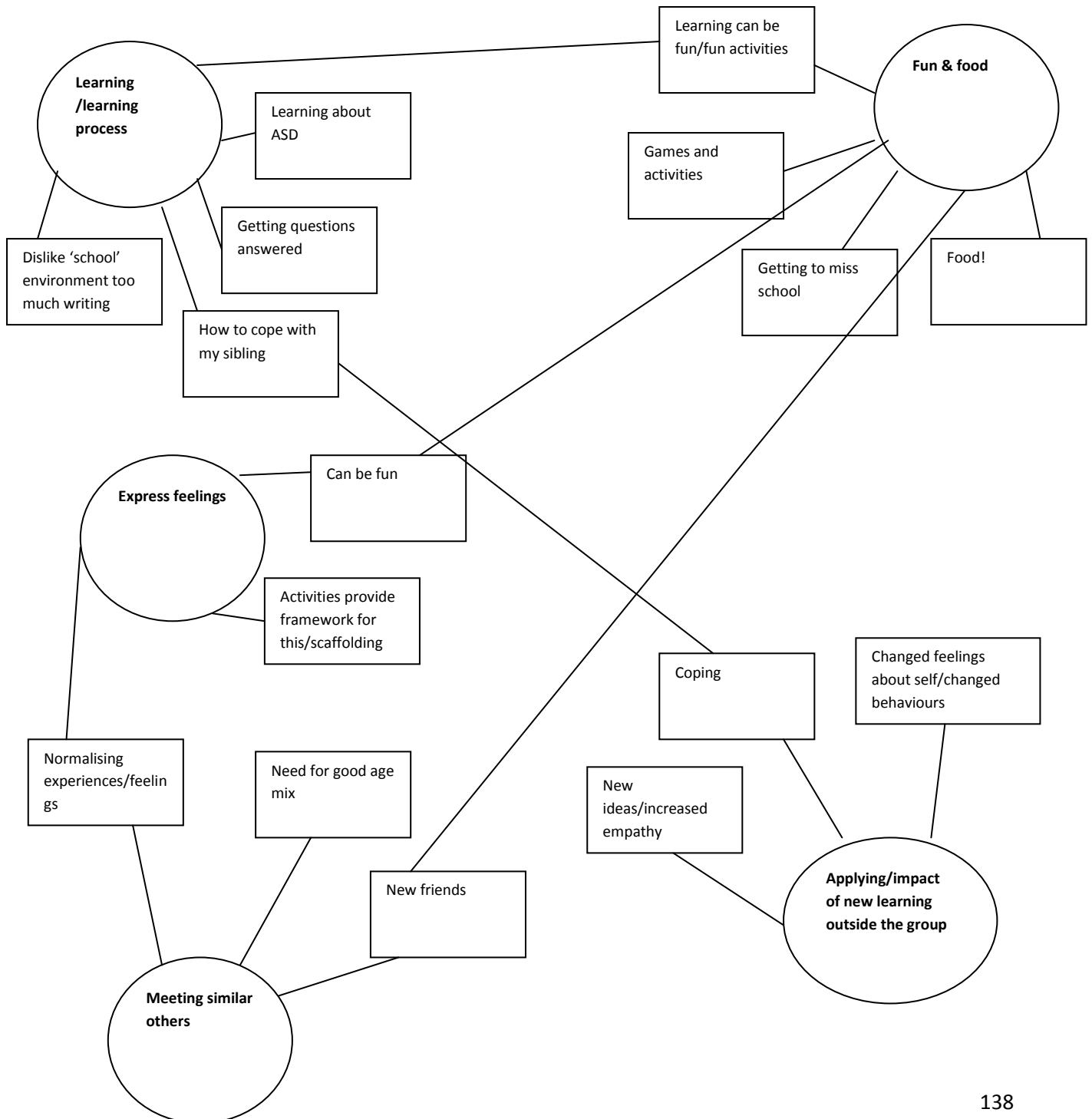
Appendix H: Study poster

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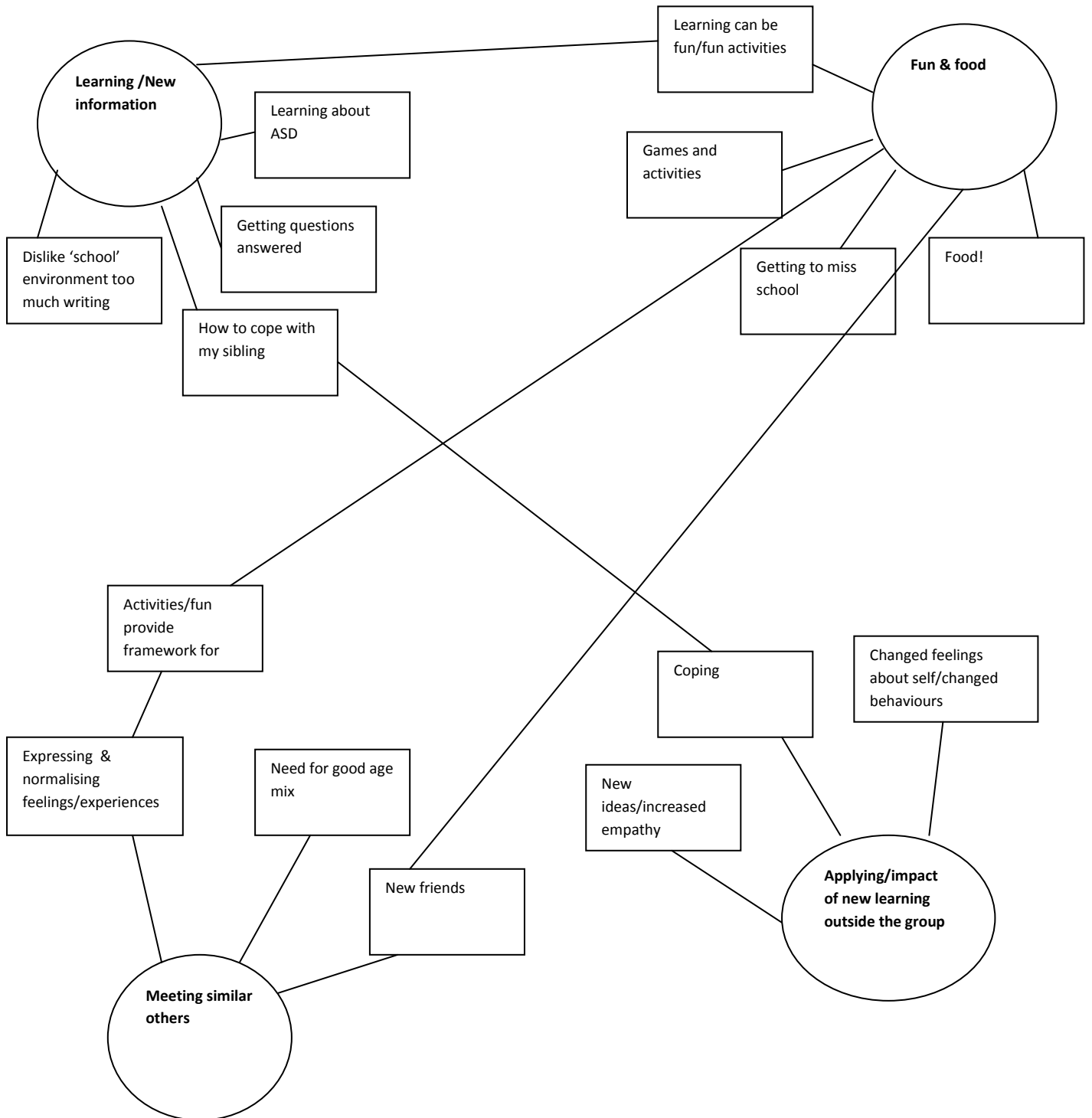
Appendix I: Thematic analyses

Appendix I1: Thematic maps

Appendix I1: Initial thematic map



Appendix I1: Final thematic map



Appendix I2: Example section of annotated focus group transcript

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Appendix I3: Additional example quotes for themes

1. LEARNING/LEARNING PROCESS

F. Why are you pleased that you did this group?"

L. "So I can learn about my sister."

M. "To learn about asperger's yeah..."

F. OK, and what kind of things have you learnt?

A. That it's not possible to go away and it is possible for it to get worse.

M. How to cope with it and how to make it so it doesn't get worse.

L. How you get it.

A. "Because it's fun and I can learn about my brother".

M.I was saying that when we learned about how to cope with it, our questions got answered by Dr xxxx erm, that was a good bit...

M. "It's good to find out about siblings and how to cope"

M. .I'd tell my friends that it's quite fun and it's good to learn about, how to cope and how it gets worse and all about Autism".

A. I'd say it's really good fun and you get to learn lots about your Autism brother or sister.

F. OK. And what kind of things do you get to know?

A. How to cope with them.

(Questionnaire responses to the best thing about the group):

"knowing the science behind autism"

"when we talked to dr xxxxx and learnt the answers to our questions about Autism"

"playing games, learning about aspergers and asking questions"

"learning about xxxx (my brother with aspergers)"

"The fact you learn then go somewhere fun"

"The learning and the outing and the hot chocolate (thanks)"

"having fun whilst learning about Autism"

"That it is fun and helps me"

"Having fun and the washing line (game re expressing difficult feelings)"

"I liked all the learning and fun and getting out of school"

Responses to things wish to change

M. Filling in the forms. Too many forms.

L. Filling in forms definitely. Hate filling in forms.

M. Some of the questions on the forms were a bit personal and some I didn't know how to answer.

"work"

"having to write"

"Not set out like a classroom"

2. MEETING SIMILAR OTHERS

“That I could make friends and help me”

“We have so much fun and I met lots more friends”

“A possible change; more people”

“Meeting others who also have brother/sister with Autism or other”

“That I found out about other peoples experiences with their brothers”

“Meeting people who have had the same experience as me”

“Because its good to spend time with other people who have autism brothers/sisters, for them to come”

“I liked it that we played games, had fun and that with our brothers and sisters we are in the same situation”

Sharing feelings

“talking about my feelings”

“More group talking”

“Knowing other people feel the same way I do”

“They were not shy about speaking up”

Age mix

M. Well it’s a bit babyish for me, because I’m quite a bit older. So that’s all really.

“Age group too varied/slightly awkward”

“I felt a bit out of place as I am a bit older than the other siblings in the group”

“...maybe make sure everyone has someone of a similar age to them”

3. APPLING NEW LEARNING/IMPACT OUTSIDE THE GROUP

A. That I learnt about my brother ...oh and(can’t hear this part)...if I try to do those things and that he will be more nicer...

F. OK, what kind of things can you try and do

A. Maybe I can do, try and do what he’s just said, play with lego...then see if when he’s at school I can quickly sneak on his Xbox to play (halo breach?) and try and get the hang of it and then I....when he’s being nice I’ll ask if I can play and then if he’s used that already then...he’ll start playing with me a lot of the time

M. I’ll just remember, just remember how to cope with it and that he can’t help it.

L. Yep!..... That I’m happier..because I play with people now..... My friends. (quiet voice)

M. When we’re at home they’ve noticed I’m a little less aggressive but at school it doesn’t make much difference.

4. FUN

“I’d say it’s really good fun and you get to learn lots about your Autism brother or sister.”

“L. That....I had fun...and....I got food.

F. That you had fun and you got food?

L. Yeah. (Giggles)”

M. I missed maths

F. You missed maths?

M. Yeah, (smiling)

L: And it needs to go on for longer.....L & A. Yeah! It needs to go on forever!!!

(Questionnaire responses to the best thing about the group):

“make it longer - forever!”

“Going on carts and on the wall”

“new things”

“Playing on the go karts”

“Having fun activities and playing games.”

“cooking, lunch, playing games”

“parachute game”

“activities and kind adults”

“I liked playing games”

“pirate ship”

“More games”

“I liked all the learning and fun and getting out of school”

Appendix J1: End of study report to ethics and R&D boards

Support groups for siblings of children with Autistic Spectrum Disorders: A pilot study

Final summary report

Introduction

Living with a brother or sister with an Autistic Spectrum Disorder (ASD) can have a notable impact on non-affected siblings. Whilst there can be positive effects, these children may experience challenges such as reduced parental attention, increased responsibility at home, isolation from peers and coping with difficult sibling behaviours. It is crucial to help siblings to cope with these additional stressors and to provide them with information and support. This is especially important as there can be an increased risk of psychological and behavioural difficulties in these children, when compared to other siblings (e.g. Dodd, 2004; Ross & Cuskelly, 2006). Several organisations have established ‘sibling support groups’ and many families say they have been helpful. A Canadian research study has reported improved knowledge of Autism and a more positive self concept following sibling involvement in an ASD-specific support group (Smith & Perry, 2005). However, despite positive anecdotal reports, U.K research within this area is limited (Knott, 2009; Cooke & Semmens, 2010).

Aims

The current pilot study aimed to investigate the utility of support groups for U.K. siblings of children with ASDs, from the perspective of siblings and their parents. It was hypothesised that participation in an ASD-specific support group would lead to an increased in positive ratings of self concept, decreased anger and anxiety and improved behavioural and emotional functioning in siblings.

Methods

A within group, mixed methods design was used with a pre-intervention baseline. Participants were 35 children aged 7-15 years with an ASD sibling who were attending ASD-specific sibling group interventions across London and the South East of England (mean age =9.6 years, female = 17). Groups were held in one of 4 community or NHS settings and were delivered in a variety of formats including 4 weekly 2 hour sessions, 1 full day session and 3 full day sessions. 49% of participants attended day long groups (n=17) and the remainder attended groups lasting more than a day (n=18, 51%). All groups followed the F.R.A.M.E. approach adopted by the Sibs organisation, whereby groups were designed to be ‘Fun’, ‘reduce isolation’, ‘Acknowledge feelings’, ‘Model coping strategies’ and ‘Enhance knowledge of ASD’ (www.sibs.org.uk).

Sibling rated measures of self-concept, anxiety and anger and parent rated measures of emotional difficulties were collected before and after the groups and at 3 months follow up. All completed evaluation questionnaires and children from one group also participated in a focus group, which explored their group experiences.

Results

Results indicated significant improvements in sibling self concept and significant decreases in anger and anxiety ratings following participation in an ASD-specific sibling group. Anxiety continued to decrease at 3 month follow up. Parent rated sibling emotional difficulties did not change following the groups. All siblings valued the groups. Four main themes were identified from focus group and open ended questionnaire data: Siblings valued the opportunity to meet similar others, have fun, learn new information about ASD and apply this knowledge to their own situation.

Conclusions

The present pilot study extends existing literature on ASD-specific sibling groups. This is one of the first sibling studies to combine qualitative data with standardised outcome measures which have good psychometric properties. These findings suggest that participation in an ASD-specific support group may be associated with more positive self concept and decreased anger and anxiety. It is important to note that the lack of a control group means that definite conclusions regarding causality are difficult. However given the short duration of these sibling groups, these results are striking and suggest that this area warrants further research. Here a larger, more controlled investigation with a standard sibling group protocol would be of benefit.

Dissemination

This study was completed as part of the requirements for the researchers' Doctorate in Clinical Psychology (DClinpsy). It is planned to submit these findings for publication in a peer-reviewed journal. A brief summary will also be posted to participating families and sibling group leaders.

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- Cooke, J. & Semmens, C. (2010). The development and evaluation of a support group for siblings of children on the autistic spectrum. *Good Autism Practice* 11, 23-29.
- Knott, F. (2009). Sibshops: Supporting siblings of children on the Autistic Spectrum. *Good Autism Practice* 10, 18-26
- Dodd, L.W. (2004). Supporting the siblings of young children with disabilities. *British Journal of Special Education*, 31, 41-49.
- Ross, P. & Cuskelly, M. (2006) Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, 31, 77-86.
- Sibs Organisation (n.d.). The F.R.A.M.E. model. Retrieved on 4th November 2009 from http://www.sibs.org.uk/group_aims/
- Smith, T., & Perry, A. (2005). A sibling support group for brothers and sisters of children with autism. *Journal on Developmental Disabilities*, 11, 77-88.

Appendix J2: Ethics NRES end of study form

(This has been removed from the electronic copy)

Appendix J3: End of study report to participants

Dear parent or guardian,

RE: An investigation of support groups for siblings of children with Autistic Spectrum Disorders

A huge thank you for all your support with the above study.
The study is now complete and I am writing to let you know the results!

Background

We know that living with a brother or sister with an Autistic Spectrum Disorder (ASD) can be difficult. Whilst there can be positive effects, there may also be challenges such as coping with difficult behaviours from their sibling, feeling isolated from peers and increased responsibility at home for example. As ASDs can often appear 'invisible' to others, children must also learn to cope with potentially negative reactions to their brother or sister from the public.

It is really important to help brothers and sisters to cope with these additional stressors and to provide them with information and support. The Department of Health have recognised this, although there are still few services for siblings in the U.K. Several organisations have set up 'sibling support groups' and many parents and children say they have been helpful. However, it is unknown exactly how or why these groups have helped siblings and their families.

Aims

The aim of this research was to find out whether sibling groups (like the one your child attended) are useful to brothers and sisters. We wanted to know what, if anything, children find helpful about these groups. There has been no other research of this kind in the U.K.

We collected data from 7 sibling groups for ASD across London and the South East

In total, 35 children aged 7-15 years with an ASD sibling (and their families) took part! Siblings completed questionnaires before, after and 3 months after each sibling group. The questions asked how your child feels about themselves, including whether they have had any angry or anxious feelings. We also asked some questions about their experiences of the group and what they thought of it. Parents completed a questionnaire which asked about their child's strengths and any difficulties they may have. Thank you both so much for doing this. We asked you to

complete the same questions several times, because we wanted to know whether these feelings might change after participating in the sibling group.

What we found

After participating in a sibling group, we found that children showed improved self concept, or thought about themselves more positively. Children's ratings of anger and anxiety also decreased. Feelings of anxiety continued to decrease 3 months after the group had ended. Parent ratings of sibling emotional difficulties did not change.

Children said that they liked the groups. In particular, children valued the opportunity to have fun, meet other siblings, learn new information about ASD and apply this knowledge to their own situation.

Conclusions

This study has made an important contribution to the existing research on ASD-specific sibling groups. This is one of the first U.K. sibling studies to combine focus group and anecdotal data with standardised questionnaires. These findings suggest that participation in an ASD-specific support group may be associated with more positive self concept and decreased anger and anxiety. Given the short duration of these sibling groups, these results are striking! This suggests that this area warrants further research. In particular, a more controlled investigation with a larger number of siblings would be useful.

Thank you so much for your help with this valuable study!!!

If you have any further questions please do not hesitate to get in touch at the address above.

Kind wishes

Sophie

Sophie Eyres
Trainee Clinical Psychologist
Canterbury Christ Church University

Appendix J3: End of study report to participants (child)



**An investigation of support groups for brothers and sisters of children with
Autistic Spectrum Disorders**

Dear

Thank you so much for helping me with the research at the sibling group!

I know you worked very hard to answer all the questions.

I would like you to tell you what we found out

- Children from 7 different groups answered the same questions as you did
 - That's 35 children altogether!



We wanted to find out how you felt after going to the sibling group

- We found that after the group you felt better about yourself
- You felt less worried and less angry about things

You told us that you liked the group

- You liked having fun
- You liked meeting other children who have brothers and sisters with Autism
- You liked finding out about Autism
- You said this helped when you were at home with your brother or sister with Autism



Thank you again for your help!

Kind wishes

Sophie

Appendix K: Submission guidelines for Journal to submit section B

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