

# The development and evaluation of a support group for siblings of children on the autism spectrum

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## Editorial comment

Parents often express concern about the effects on their other children of having a brother or sister with autism or Asperger syndrome. The literature suggests that there are positive effects (as evidenced in the two articles which appeared in the October 2009 issue of the GAP Journal). There are also potential difficulties for them in terms of getting their fair share of their parents' attention and in having their play and life disrupted. There is a growing literature on how to support siblings but still not enough initiatives offered by services or schools for these children. This paper is therefore welcomed as it provides ideas on how to work with siblings who may not know one another but who have a common bond in having a brother or sister on the autism spectrum. The workshop sessions described provide a forum for enhancing their knowledge of autism, discussing their feelings and developing strategies to manage some of the situations they face.

## Introduction

The siblings of children on the autism spectrum may have increased care responsibilities, less parental attention, decreased self esteem and feel socially isolated (Wolf, Fisman, Ellison and Freeman, 1998; Williams, 1997). Further to this, outside of their families, siblings may experience limited access to information about the child's condition, negative peer reactions and disruption in social activities (Blue-Langer, 1996 in Lobato and Kao, 2002). Badger (1988 in Evans et al, 2009) described that siblings of children with learning disabilities are susceptible to feelings of guilt and resentment and are at risk of developing psychological problems, behaviour difficulties and are more vulnerable to illness. The siblings of children on the autism spectrum confront unique challenges. They are likely to encounter negative reactions from the public due to the repetitive and unpredictable behaviour of their sibling, who may appear as a typically developing child, as well as having to cope with the uneven profile of skills and the difficult behaviours of the child (Margan, 1998 and Royers and Mycke, 1995 in Smith and Perry, 2005).

Consequently support for the siblings of children on the autism spectrum is needed yet is often overlooked. This need to provide for brothers and sisters is identified in the guidance and regulation of the Children Act 1989. With reference to disabled children, it states that:

*'... the needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability.'*

Also the Government review *Aiming High for Disabled Children: better support for families*, launched in May 2007, reviews services for disabled children and their families. It recommends:

*'Focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help improve outcomes for all.' (p 9)*

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There is much evidence that sibling support groups are able to encourage the emotional and social development of siblings of children with disabilities. Evans and colleagues (2001) evaluated the efficacy of sibling support groups designed to help brothers and sisters discuss and explore their relationships with their sibling with learning difficulties. They found that the siblings had increased self esteem, greater knowledge of their sibling's needs, and better coping strategies and emotional adjustment. The charity Sibs reports that there are common themes indicated by siblings who have attended groups across the country, as well as their parents. The immediate short-term themes include increased confidence, improved family dynamics, increased understanding of the disability, increase in play between the sibling and the disabled child, increase in siblings talking about issues with their parents and use of coping strategies at home. The long-term themes include prevention of mental health problems, prevention of behaviour problems and improved academic performance (see [www.sibs.org.uk](http://www.sibs.org.uk)).

Many studies of sibling support groups evaluate the effectiveness of the group. For example, Evans et al (2009), using the Family Relations Test (Bone and Anthony, 1985) identified that the siblings in their study had greater involvement with their sibling with a disability. Further, using the Culture Free Self Esteem test (Battle, 1981), it was demonstrated that the siblings' self esteem increased post-group. D'Arcy et al (2005) studied 16 siblings of children with disabilities who had attended a sibling support group (Sibshops). They used semi-structured interviews and the Piers-Harris Children's Self-Concept Scale (Piers, 1986) and found that there was a dramatic increase in the siblings' reported discussions around their feelings and they had improved coping strategies. While these studies describe the methodology of their research, the aims of the groups and some of the content of the workshops, they do not provide enough detail to replicate the sibling support group for those wishing to develop their own.

An aim of this study was to provide a detailed model for a support group for siblings of children on the autism spectrum, which may act as a guide for those seeking to set up their own sibling support group. Another aim was to evaluate the effectiveness of the group by measuring any changes in the siblings' knowledge of the autism spectrum, as well as parental feedback.

## **NORSACA Sibling Support Group Model**

The sibling support group model used in this study was originally developed by Professor Elizabeth Newson and Julie Davies (Davies, 1994). The concept of the model was to explore both the positive and negative aspects of having a sibling on the autism spectrum, how to cope and where to go for additional support and advice. Newson and Davies devised a workshop manual which combines a mixture of small group work, whole group discussions, games, presentations and drama. The model forms the basis of a sibling support group which is delivered annually by NORSACA (Nottinghamshire Regional Society for Adults and Children with Autism) (a regional autism charity) and funding is received from charitable trusts. The group is run by assistant psychologists and supervised by senior staff within NORSACA. Prior to the start of the group the assistant psychologists attended safeguarding training, which is critical, given the nature of the group and potential disclosures. Evaluation questionnaires are sent to parents and children who attend the group every year, and on the basis of this evaluation, the model has been refined slightly.

## **Sibling Support Group 2009**

To recruit participants for the group, leaflets and posters advertising the group were sent to local organisations involved in the lives of children on the autism spectrum and their families. Parents who contacted NORSACA expressing an interest were asked to complete a questionnaire. Fifteen questionnaires were returned and 12 siblings were chosen to take part in the group. The decision process was based on the perceptions of need and the composition of the group.

The sample consisted of 12 children (eight girls and four boys), all of whom had a sibling on the autism spectrum. There were nine sets of parents. In three cases, two siblings from the same family participated, one set of these siblings were twins. The siblings ranged in age from 8–12 years. Eight of the 12 siblings had a younger sibling on the autism spectrum and for the remaining four children, their sibling was older. The children on the autism spectrum (seven boys, two girls) ranged in age from 4–14 years and were diagnosed with either autism or Asperger syndrome.

## **Methods**

Prior to the start of the workshops, consent was gained from parents of all 12 siblings. The parents

also completed a detailed questionnaire to provide the group leaders with information about the sibling and his/her family, as well as emergency contact details. The questionnaire posed questions about areas such as the understanding and expressive abilities of the child on the autism spectrum, any materials previously used by the parents to explain autism, any issues that concerned the parents about the sibling's adjustment to their brother/sister's difficulties, parents' reasons for encouraging their child to participate in the workshops and any doubts or concerns that parents had regarding the workshops.

The children attended the group for eight weeks between 6.30 and 8.30 pm, covering each topic detailed in the workshop outline (see *Table 1*). There was a 30-minute break during the session. The group was held at one of the NORSACA school sites. The venue was ideal because it had a large area for group discussions, games and small group/paired work. There was also a garden outside with play equipment for use during break times and a separate meeting room which was used by parents who stayed for the session. This gave the parents an opportunity to meet other parents and relax.

**Table 1: Workshop outline**

|                   |  |
|-------------------|--|
| <b>Workshop 1</b> | Getting to know each other   |
| <b>Workshop 2</b> | Difficult times with our brothers and sisters.<br>Enjoying ourselves with our brothers and sisters |
| <b>Workshop 3</b> | What it is like to have Autism/Asperger syndrome   |
| <b>Workshop 4</b> | Explaining to others   |
| <b>Workshop 5</b> | Being treated differently  |
| <b>Workshop 6</b> | Feelings about our brothers and sisters  |
| <b>Workshop 7</b> | Thinking about the future  |
| <b>Workshop 8</b> | An outing – eg bowling, ice skating  |

At the first (pre-test) and seventh (post-test) workshop all siblings completed a sibling knowledge poster (see *Table 2*). Parents were sent a parental evaluation questionnaire one week after the workshops had finished and eight of the nine of these were returned (see *Appendix 1*).

**Table 2: Workshop 1: Knowing me knowing you posters**

- Ask the siblings to bring a photograph of themselves and their sibling to the group.
- Make posters using these photographs and ask the siblings to write about themselves and their siblings, including their likes and dislikes and their siblings.
- Ask the siblings to then share these with the rest of the group.
- This gives the group an opportunity to learn something about their fellow group members and their siblings.

## Measures

### Knowledge of autism and their sibling

The children were asked to make a poster detailing everything they knew about autism or/and Asperger syndrome. They were told they could write and draw on their poster and were provided with large coloured paper, felt tipped pens, stickers and glitter glue. They were given approximately 20 minutes to complete their poster. All children completed the posters independently, although some siblings asked for help to spell particular words. The siblings were told to write 'I don't know' on their posters if, after thinking about the topic, they did not have anything to write. For two other activities used within workshops, see *Tables 3 to 6*).

### Parental evaluation

The parental evaluation is a 12-item questionnaire developed by NORSACA. It combines closed and open questions, referring to the practicalities and content of the group. It has been used to evaluate the group in previous years and the results have been sent to the group funders to demonstrate its value.

## Results and discussion

### Knowledge of the autism spectrum

To evaluate the siblings' knowledge of the autism spectrum, their pre-test and post-test posters were compared. On the pre-test posters, seven siblings wrote what they knew about autism, four siblings wrote 'I don't know' and one child decorated a picture of his brother. For the post-test poster, 11 children wrote what they knew about autism and one child described their sibling. Eleven children showed an increased knowledge.. The child that described their sibling in the post-test poster rather than indicating what they knew about autism, had written several points about autism in the pre-test poster. Therefore it was unclear whether this child showed an increased knowledge of autism.

**Table 3: Activity in Workshop 2: Spider's web and 'super flies'**

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Discuss the concept with the children that having a difficult time with their sibling can feel like being stuck in a spider's web with nowhere to go. Give each child a bug template and ask them to write a difficult time on the bug and then decorate it. Once the siblings have finished, asked them to attach their bugs to a spider's web (made from string glued onto a large piece of card). Discuss the sibling's difficult times. Then perhaps after a break, introduce various coping strategies that could be used during difficult times (eg ignore, distract, bargain, avoid it, ask mum/dad). These could be explained to the siblings as Super Flies who can rescue them when they are in need.

**Siblings' response:**

The siblings identified difficulties such as:

*'When it's bed time my sister never lets me sleep.'*

*'At school when he starts shouting, swearing and hitting his teacher because it makes me feel really bad when he gets held down.'*

The siblings seemed to relate very well to this activity and seemed to find reassurance in sharing difficulties with each other. The siblings reported that they had tried using the 'super flies' to help them manage situations at home after this session. Following this activity the siblings identified positive times with their siblings such as:

*'When we went swimming.'*

*'When we play on the trampoline together.'*

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**Table 4: Activity in Workshop 3: The rules game**

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The aim of this game is to help the children understand how it may feel for their siblings if they don't understand social rules.

For this game:

- One person is asked to leave the room and wait while the rest of the group make up a rule.
- The person then joins the group again, without knowing the rule.
- The person then has to try and guess the rule that had been created.

Some examples of rules were:

- touch your legs only while you are walking
- touch something electrical
- only touch things that are red

The person who does not know the rule feels excluded and confused because they don't understand what is going on and this helps them to appreciate how their sibling might be feeling.

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**Table 5: Activity in Workshop 4: Aunt Blabby**

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Ask the siblings to write a letter to an Agony Aunt (Aunt Blaby) about a time when they had to explain autism to someone. Group leaders then reply to these letters with ideas about ways to explain autism and give these to the siblings in the following session.

**Siblings' response:**

The siblings seemed to enjoy the opportunity to honestly share their irritations. The siblings raised issues such as:

*'When friends are at my house and my brother takes his clothes off.'*

*'When he gets mardy at KFC.'*

*'My sister keeps screaming in shops and everybody stares at her.'*

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**Table 6: Activity in Workshop 6: Feelings Fish**

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Write a feeling on a fish template, and decorate it. Put the fish into a 'pond' and ask each sibling in turn to use a magnetic rod to catch the feelings fish. Then ask the sibling to talk to the group about a time then they felt the feeling written on the fish they caught.

**Siblings' response:**

Siblings were able to think of good and bad feelings but found it more difficult to discuss times when they felt that feeling.

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Listed below are comparisons of pre-test and post-test posters from three siblings.

### **Sarah (name has been changed)**

For her pre-test poster she wrote, '*Autism is something that makes people not understand as well as others*' and drew a picture of her sibling. For the post-test poster, she split the poster into two sections, labelling them, Autism and Asperger's. On each side she drew a triangle and labelled the three points 'social', 'rigid' and 'language' to indicate the triad of impairments found in children with autism and Asperger syndrome. She then described both autism and Asperger syndrome. Examples are listed below:

#### **Autism**

'*People are born with autism.*'

'*Makes people not understand as well as others.*'

'*You may not tell they have autism until they're 1–2 years old.*'

#### **Asperger syndrome**

'*Asperger's means you have one or two special talents.*'

'*Asperger's is like autism.*'

'*You can't catch autism.*'

#### **Jessica**

Jessica wrote 'I don't know' on the pre-test poster and drew a picture of their family. On the post-test poster, she listed the coping strategies that had been taught in the second workshop; 'bargain, nip it in the bud, ignore, ask mum and dad and distract'. Further to this, she wrote:

'*Autism is you don't understand a lot of things.*'

'*Trouble learning.*'

'*Trouble talking and making friends.*'

'*Repetitive.*'

'*You need a lot of time to get it in your head.*'

#### **Samantha**

Samantha wrote 'has difficulty playing' and 'can't talk' on her pre-test poster. On her post-test poster she drew a triangle and labelled it with 'social', 'rigid' and 'speech' and wrote beside it 'three main points to autism'. The sibling also wrote:

*'Autism is when a child struggles to speak in the early ages. Also they don't mix in groups as well as we do. My brother likes sensory things. Rigid means they like to repeat things lot of times.'*

### **Parental Evaluation**

#### **Practicalities**

All parents felt that the group was held at a convenient time of the year and at an appropriate day and time. One parent commented that they would have liked the duration to be longer, the rest were satisfied with the number of sessions.

#### **Content**

Parents were asked to indicate their expectations of the group and whether they were satisfied that these had been met. All but one indicated that their expectations had been met. Some examples of parent expectations are listed below:

*'To understand that other children are going through similar lives to us. To help her express how she feels without me being there.'*

*'To learn more about autism, how it manifests and why their sister does the things she does.'*

*'I wanted her to express her inner feelings that she perhaps couldn't tell us (fears) and to realise other children have similar experiences.'*

All parents felt that their child/children enjoyed the workshops. One respondent wrote, '*She couldn't wait to go each week!*' All parents indicated that there had been positive outcomes from the group and none felt there were any negative outcomes. Two sisters from the group joined another siblings group (at the school that their sister attends) shortly after the last workshop. Some examples of positive outcomes are listed below:

*'She has more patience with her brother now.'*

*'He knows his brother is like other autistic people.'*

*'She understands why she has been treated differently.'*

Parents were also given space to write any additional comments:

*'Incredibly worthwhile.'*

*'It was nice for me to meet and sit at times with the other parents and chat, whilst the children were in the group.'*

*'She got some really positive ideas to take away with her as well as making new friends.'*

## **Discussion**

Comparisons of the pre-test and post-test knowledge of the autism spectrum posters indicated that 11 of the siblings showed an increase in knowledge. All parents were satisfied with the practical elements of the group. There were common themes in the parents' expectations of the group, these included: meeting other children with similar experiences, sharing their feelings and learning more about the autism spectrum. There were also common themes in parental report of positive outcomes of the group; increased understanding of autism, increased patience with their sibling and increased understanding of why they may be treated differently.

The aims of this study were to describe a model for a sibling support group in order to encourage and guide other individuals and organisations to develop their own. A further aim was to evaluate the effectiveness of the group by measuring knowledge of autism. The robustness of this measure is limited somewhat by not having a control group. However, the siblings did show greater knowledge of autism and parental evaluations indicated that the group had been a valuable experience for the siblings and they had enjoyed it very much. The siblings were able to share their experiences, express their feelings, learn about autism in a supportive environment, advise each other in problem-solving and to have fun.

## **Considerations for future practice**

Although the sibling group model described has successfully shown its value for siblings and their parents, there are some changes to the model which could be considered. During the workshops, many siblings reported that they wanted the group to continue past eight weeks, indicating that they enjoyed attending and found it helpful. In addition, discussions with group leaders indicated that they found that the workshop in which they focused on increasing children's understanding of autism was quite rushed. They said the siblings appeared to become tired quickly due to the amount of information they were given. Therefore, it may be useful to increase the workshop duration to ten weeks, so that the information about autism could be divided between two workshops. A further issue raised by the group leaders which they had foreseen to such an extend related to behavioural difficulties within the group. The group leaders felt that setting clear boundaries and rules for the group was very important as well as referring back to these regularly.

## **Size of the group**

A further consideration relates to the size of the sibling group. It is important to have a large enough group to be able to split up to work in smaller groups or have the opportunity to have team games. However, it is important that the group are able to have group discussions in which everyone is concentrating and listening to each other. A large group can make this aim more difficult to achieve. The NORSACA sibling group model suggests a group size of eight to twelve. After discussions with group leaders, it was felt that ten as a maximum group size would allow for successful whole group discussions, as well as smaller group work.

## **Composition of the group**

It is important to consider carefully the selection of the children at the outset, in particular, the age and gender of the children as well as the age of the sibling on the autism spectrum and their diagnostic profile. The most successful group may be where the children have most in common, for example, the siblings on the autism spectrum being closer in age. The problems and difficulties encountered by the children are likely to be markedly different if their sibling is under five or an adolescent, for example. This may make it more difficult for the group to relate to each other's experiences. Further, children with younger siblings may not be emotionally ready to think about future challenges that their sibling, themselves and their family might face as their brother or sister gets older. There did seem to be a group divide between the younger and older members of the group, which was sometimes difficult as there were activities that appealed to the younger group more than the older group and vice versa. The younger group for example, had more difficulty writing their Aunt Blabby letters.

## **Concluding comments**

As the literature demonstrates, siblings of children on the autism spectrum are likely to develop psychological problems and behavioural difficulties (Badger, 1988 in Evans et al, 2009). Therefore while the support group demonstrated positive outcomes, in order to ensure the effects of the group are maintained and developed in the long term, further support is needed. A future development of the model may be to offer the siblings post workshop support, such as an Internet forum. By using this, the siblings could continue to share their experiences, work together to overcome challenges and maintain their friendships. For siblings/parents and anyone else interested in this area, the authors would like to refer to the sibs website ([www.sibs.org.uk](http://www.sibs.org.uk)).

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## **Appendix 1: Parental evaluation questionnaire**

### **FINAL EVALUATION**

The following questionnaire aims to give you the opportunity to express your thoughts and feelings about the siblings group. We encourage honest replies as we hope to use your suggestions to improve future siblings groups. The questionnaire is completely confidential so you can feel free to say exactly what you think.

#### **Practicalities**

The following questions are related to the practical aspects of the group. Please circle either **Yes** or **No** where this choice is provided. We also encourage you to use the spaces provided to add any comments you wish to make.

- |   |        |
|---|--------|
| 1 Was the Siblings Group held at a convenient time of the year for you?         | YES NO |
| 2 The Siblings Group was held on a Wednesday, was this day appropriate for you? | YES NO |
| 3 The group was held between 6.30pm and 8.30pm, did you find this convenient?   | YES NO |
| 4 How satisfied were you with the length of the sessions (2 hours)?             |        |
| 5 How satisfied were you with the duration of the groups (8 weeks)?             |        |
| 6 Do you have any other comments regarding the practical aspects of the group?  |        |

Please use this space, and overleaf if necessary, to comment.

#### **Content Evaluation**

The following questions are related to the content of the workshops.

- |  |        |
|--|--------|
| 7 How did you expect your child to benefit from attending the group? (eg learn more about sibling's difficulties, make friends, help him/her talk more about feelings towards their sibling etc). Please give details: |        |
| 8 How satisfied were you that your expectations were met?  |        |
| 9 Did you feel that your child enjoyed attending the siblings group?   | YES NO |
| 10 Have there been any positive outcomes which you think have been a result of your child attending the group?   | YES NO |
| 11 Have there been any negative outcomes which you think have been a result of your child attending the group?   | YES NO |
| 12 Do you have any other comments you would like to make about the group?  |        |