

## PRELIMINARY INVESTIGATION OF A QUALITATIVE METHOD OF EXAMINING SIBLINGS' EXPERIENCES OF LIVING WITH A CHILD WITH ASD

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### Introduction

Siblings of children with disabilities can be affected by the presence of the disabled child in the family in both positive and negative ways. Positive effects include having a warmer and less conflicted relationship with the disabled sibling than is the norm between pairs of typically developing (TD) siblings (Fisman *et al.*, 1996; Lobato *et al.*, 1991). Negative effects include behavioural difficulties (Fisman, *et al.*, 1996; Lobato *et al.*, 1987; Nixon and Cummings, 1999; Rodrigue *et al.*, 1993), higher levels of depression (Gold, 1993; Lobato *et al.*, 1987; McHale and Gamble, 1989), and lower self-esteem (McHale and Gamble, 1989).

Studies of TD siblings of children with autism have produced mixed results. Regarding the quality of the sibling relationship, TD siblings have given positive accounts of the relationship with the sibling with autism in some studies (McHale *et al.*, 1986; Rivers and Stoneman, 2003). Kaminsky and Dewey

(2002), however, found that although siblings of both children with autism and Down syndrome (DS) reported greater admiration by their siblings and less competitiveness and quarrelling in their relationship than a control group, siblings of children with autism reported lower levels of intimacy, prosocial behaviour, and nurturance by their siblings compared to the other two groups. Findings on the behavioural adjustment and behavioural outcomes of TD children with a brother or sister with autism are similarly mixed. Several studies report mainly positive findings on a range of measures, including measures of self-concept, self-esteem, academic achievement, levels of loneliness, depression, and behavioural problems (see for example Mates, 1990; Kaminsky and Dewey, 2002). Other studies using similar measures have produced more negative findings (see for example Gold, 1993; Rodrigue *et al.*, 1993; Fisman *et al.*, 1996; Hastings, 2003a).

The above findings illustrate that the presence of a child with autism in the family

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can have varied effects on TD siblings: the relationship between the TD and the sibling with autism can be affected in both positive and negative ways; adjustment problems can arise, but this is not always the case. It is important, therefore, to ask why this variation occurs, because it may be the case that intervention can help to ensure that positive rather than negative effects occur.

It is clear from the studies referred to above that the effects of the child with autism on the TD sibling are mediated by a number of factors. Several of these factors relate to the TD child's family environment, such as the number of siblings in the family (Kaminsky and Dewey, 2002), marital stress and the availability of social support (Hastings, 2003b; Rivers and Stoneman, 2003). In addition to evidence for mediating factors in the child's environment, there is some evidence that factors internal to the child also influence adjustment and behavioural outcomes. So, for example, TD children and their mothers in McHale *et al.*'s study (1986) described the sibling relationship as being more positive when future concerns, feelings of rejection, and parental favouritism were perceived as minimal by the TD child; when the TD child saw the child with disability as reacted to positively by parents and peers; and when she/he felt able to cope with their brother or sister's disability.

Of the mediating factors identified above, family size is not an appropriate issue for intervention, and marital stress may not easily be alleviated. Social support from family and friends may also be difficult to influence. Practitioner support for the child with autism has, however, been shown to have indirect beneficial consequences for TD siblings (Hastings, 2003b). Moreover, the results of McHale *et al.*'s study suggest that it may be beneficial to work directly with TD siblings to allow

them to explore, and possibly to modify, their thoughts and feelings about their sibling with autism and the effect their sibling has on their experiences within the family. This suggestion is supported by findings from a study by Gold (1993) who found that siblings of boys with autism scored higher on depression than the control group, and it was those siblings who had no one to talk to about having a brother or sister with autism who were most vulnerable to depression.

Subjective perceptions and feelings can to some extent be assessed using formal assessment procedures such as rating scales or questionnaires, as in some of the studies referred to above. However, formal assessment procedures necessarily constrain the range of responses the respondent can give, and they do not in general elicit qualitative data such as gives the true flavour of subjective experience. Moreover, a pencil and paper assessment may elicit a 'standard' or 'expected' response, rather than eliciting a more accurate report of what may be complex and half-hidden feelings.

To date there have been no studies exploring the subjective experiences and feelings of typically developing siblings with a brother or sister with autism using a method specifically designed to encourage the participants to talk openly about their own emotions and thoughts about their sibling with autism, and about how having a sibling with autism affects their lives. The aim of the study reported here was to pilot such a method, and to assess its practical usefulness in identifying those aspects of having a sibling with autism which individual children find rewarding and special, and also those aspects which they find painful and difficult to cope with. In providing for the needs of typically developing children living in families with a child with autism, extending and

reinforcing the positive experiences, and targeting advice and support towards the painful and difficult experiences, should help to mitigate any adverse effects on adjustment and behavioural outcomes.

The investigative method was developed with the following subsidiary aims in mind. First, we wanted each child to feel free to talk truthfully, in a situation with no pressure to give the 'right' or 'expected' response. Each participant was therefore interviewed alone, and the examiner was someone they had met before but whom they did not expect to meet again. They were assured that anything they said would be treated confidentially. Participants were seen at home, to avoid any connotations of a clinical interview or school-related assessment. Second, the questions around which the interview was based were designed to elicit both positive, as well as any negative experiences and feelings. Third, we wanted to elicit full responses, including concrete examples from the participants illustrating any general points they made in their responses: i.e. we were specifically interested in eliciting qualitative data. Questions were therefore designed to be fairly open, no time limits were imposed, and prompts were built into the protocol to minimise the chances of cursory responses.

## **Method**

### *Participants*

Fourteen siblings were recruited from 11 families in which there was a child with a diagnosis of either autism or Asperger's syndrome. Specifically, five children were diagnosed with moderate to low functioning autism, three with high functioning autism and three with Asperger's syndrome. In all cases the initial

diagnosis had been made by qualified and experienced practitioners, and was confirmed in the children's Statements of Educational Need. All of the children/teenagers had some to many behavioural difficulties. Families were recruited via an advertisement in the Newsletter of the West Midlands Autistic Society, UK, a large and active family support group. The ages of the children/teenagers with an ASD ranged from 7 to 20 years with a mean age of 10.58 years (SD=3.63).

All of the siblings of the children/teenagers with an ASD who were willing to participate were recruited into the study (only one sibling declined to take part). Written consent was obtained from both the parents and the sibling(s) of the child with the ASD. The children/teenagers with the ASD who were able to understand the purpose of the study were informed of it, although since they did not participate in it they were not asked to provide their consent. The group of 14 siblings consisted of 10 females and 4 males, with a mean age of 14.73 years (SD=2.25; range 11.0 to 18.0 years). Twelve were older siblings and two were younger siblings of the child/teenager with an ASD.

### *Material*

A semi-structured interview format was developed as a means of eliciting responses relating to the participant's family situation in general, and their thoughts and feelings about their brother or sister with autism in particular. The questions used in the interview are shown in TABLE I. Interviews lasted between 20 and 30 minutes, and were audio taped and subsequently transcribed.

**TABLE I**  
**Questions on Specific Issues Related to Having a Brother/Sister with an ASD**

1. What's the most difficult part of being .....’s brother/sister?
2. What's the best part of being .....’s brother/sister? Are there some good things as well as difficult things? (*the second question is asked if the child/teenager does not respond at the first one*).
3. How much time do you spend with your brother/sister?
4. What kind of activities do you do together?
5. Can you remember a difficult/unpleasant incident about your brother/sister?
6. Can you remember a really fun memory of your brother/sister?
7. Have you ever discussed with your parents the problems your brother/sister has?
8. Do you ever think about the future when it comes to your brother/sister? Do you worry about it?

### *Procedure*

The semi-structured interview was carried out during a home visit lasting between 60 and 90 minutes. The remainder of the visit was taken up with completion of a set of questionnaires relating to other research questions.

### **Results**

Verbatim transcripts of the interview data were made, and a content analysis was performed on these data (Poweney and Watts, 1987). This involved examination of the raw data to identify an exhaustive set of categories into which all the participants’ responses could be allocated. Responses to each of the 8 questions were assigned to the categories identified by the content analysis, and the frequency with which responses within each category were reported was calculated, question by question. Participants sometimes gave responses to a single question which fell into more than one of the identified categories. The summed frequencies of

responses to any one question therefore total more than the total number of participants (14) in some instances.

The results are reported below, in the order in which questions are listed in TABLE I. Examples are given where the nature of any response category is not immediately obvious.

#### *Qu. 1: The most Difficult Part of Having a Sibling with an ASD*

When children/teenagers were asked about the most difficult part of having a sibling with an ASD, their most frequent answer related to the sibling’s aggression (6), e.g. “You try to play with her and she doesn’t like it, and then she gets in a mood cos she doesn’t get it. She gets angry with herself. And she gets angry with everybody else.” The embarrassment often caused by the sibling was also mentioned (3), e.g. “If you have a guest he won’t take that into account. He’ll just carry on shouting. It’s quite embarrassing really. Quite often you don’t want to have people around, ‘cos when he’s near, you just don’t know what will happen.” as well as other behavioural problems (3), e.g. “Most of the time he

wants you to do what he wants to do. If I could do something he doesn't like, like play sports or read, it would be all right. But he wants everything the way he likes it. If he's not interested in something I have to stop it." Finally, other people's attitudes (3), e.g. "I think trying to explain to other people what his problem is, cos he looks quiet normal." and the responsibility of having a sibling with an ASD were also reported (2), e.g. "The responsibility that comes with it probably, cos because he's autistic I have to help my mum more than I probably might have to otherwise."

*Qu. 2. The Best Part of Having a Sibling with an ASD*

When TD siblings were asked what is the best part of having a sibling with an ASD, six mentioned the good nature of the sibling with autism (fun, loving, humour), six mentioned playing and having fun together, one mentioned that she felt she had grown more mature and understanding, and finally, four children/teenagers could think of nothing.

*Qu. 3. Time Spent with the Sibling with an ASD and Qu. 4. Activities Undertaken with the Sibling with an ASD*

Seven TD children/teenagers reported spending a lot of time with their siblings, three some time, two a little time and finally, two no time. Regarding the activities TD children/teenagers undertake with their siblings, the most common one is playing (6), followed by watching TV (3), and spending time outside the house (3). Only two reported looking after the sibling with autism (2).

*Qu. 5. Difficult/unpleasant Incident Involving the Sibling with an ASD and Qu. 6. Pleasant/Fun Incident Involving the Sibling with an ASD*

TD children/teenagers reported as

the most difficult/unpleasant incident involving the sibling with autism: incidents of aggressive behaviour (4), embarrassing events (4), incidents involving other behavioural difficulties (6), and finally, problems with regard to the sibling's welfare (2), e.g. "When he was little, when he was poorly, when he was ill and he stopped babbling. He wouldn't bubble any more." Pleasant/fun incidents with the sibling with an ASD involved playing/having fun (8), sibling being happy (2), and sibling's good nature (1), whilst four children/teenagers could not remember anything.

*Qu. 7. Discussion with Parents and Qu. 8. Future Concerns.*

Responses to this question showed that most of the participants had discussed with their parents the problems their sibling experienced, and the reasons for his/her behaviour. Specifically, only four participants reported talking about those issues with their parents very rarely or not at all. Some of the participants also explained how knowing that the brother or sister had an ASD helped them deal with difficult experiences: e.g. "My parents spent a lot time telling me about it. It made it a lot easier to live with him when we knew there was a problem. It's still hard to live with him, but it made it a lot easier to understand why."

Five of the TD children/teenagers reported being quite concerned about the future, whilst three reported thinking about it without being too concerned, and six said that they very rarely think about it. Specific concerns mentioned included the child/teenager's welfare, school placement, or future employment, e.g. "I get scared cos when he'll go to an older school he's going to get bullied and stuff and that scares me. But, I will always be there for him." Of the participants who stated feeling at

least some concern about the future, six mentioned their own responsibilities.

## **Practical Application**

The main aim of the study reported here was to pilot a quick and easy method of obtaining information about the subjective experiences and feelings of typically developing siblings with a brother or sister with autism, for use in future research, and/or for use by practitioners concerned with the support needs of TD siblings. With regard to the theoretical need for such a procedure, we suggested in the Introduction that factors internal to the child/teenager are likely to influence psychological adjustment and behavioural outcomes, and that there is therefore a need for an appropriate method of eliciting data concerning subjective experiences. Regarding the practical uses of the method piloted, we suggested that identifying those aspects of having a sibling with autism which individual children/teenagers find rewarding and special, as well as those aspects which they find painful and difficult to cope with, is important for targeting support to individual needs, thus reducing the known risks of adverse reactions to living in unusual family circumstances. This suggestion is supported by the findings of Moes and Frea (2002) who showed that consideration of issues specific to the family environment in the assessment and intervention planning process can contribute to the stability and durability of reductions in challenging behaviour of children/teenagers with ASDs.

## **Discussion**

### *The Method*

Details of the method used (seeing the child/teenager at home, the relative impersonality of the relationship between interlocutor and child/teenager, the quasi-conversational format based on a prepared set of open-ended questions, the assurance of confidentiality) were specifically designed to encourage each child/teenager to feel free to talk openly and truthfully, in a situation with no pressure to give the 'right' or 'expected' responses. We have no way of directly validating the truthfulness of the participants' responses, i.e. the extent to which the responses accurately reflected each participant's true thoughts and feelings. However, none of the participants denied that they had some negative experiences (see Results for Questions 2 and 7). Moreover, some of the participants denied that there were any positive aspects of having a sibling with autism (Questions 3 and 8). The above results provide indirect evidence that at least a proportion of the group, and possibly all the participants, felt free to express themselves truthfully and openly in the situation we established. The children's/teenagers' individualistic and detailed responses to the questions tend to confirm this argument.

Moreover, although the validity of the responses was not assessed by means of comparing the siblings' responses to the views of the parents, it was the subjective thoughts and feelings of the informants that we were interested in and not a more objective account of the family life. That is, even in cases where parents might think that siblings are adjusting well to possible difficulties in family life, in a situation where children/teenagers can freely express their thoughts and emotions a different picture might unfold. It can

be concluded, therefore, that the method used is appropriate for use by researchers, as well as by those concerned with the practical support needs of TD siblings of children/teenagers with autism.

### *The Data*

The pilot study reported here was not designed to obtain data amenable to statistical analysis; as mentioned above, the target group was small, and control groups were not included. However, one of the aims of the study was to collect preliminary data regarding the subjective experiences of TD siblings, such as might help to shape subsequent studies of ways in which a child's/teenager's reactions to living in unusual family circumstances may influence their psychological adjustment and behaviour, as well as indicating likely support needs.

The majority of the 14 participants reported at least some positive aspects of experiences relating directly to the child/teenager with autism (see responses to Questions 3 and 8). The range of responses was narrow, however, most commonly referring simply to 'playing' or 'having fun with' the affected sibling. This no doubt reflects the difficulty of interacting with a brother or sister with an ASD. From the practical point of view of 'reinforcing the positive', it may be possible to extend these positive experiences by helping TD siblings, who are interested, participate in their siblings therapy programme through generalisation of trained abilities in the every day environment. For example, Colletti and Harris (1977) have shown that siblings of children/teenagers with ASD can learn to behaviourally modify the behaviour of their brother or sister, whilst Celiberti and Harris (1993) have shown that they can use behavioural skills to

engage their brother or sister in play. It is suggested that showing TD siblings how to best enhance their siblings' abilities could boost their self-esteem, help them form a stronger relationship with their brother or sister, and ameliorate any negative feelings of exclusion.

Although the majority of the participants reported at least some positive experiences directly relating to their brother or sister with autism, four participants reported nothing positive. Certain negative aspects of living with a sibling with an ASD stood out particularly clearly (see responses to Questions 1, 2, 6, and 7). Most prominent were the *aggression* and *bad temper* of the affected sibling. Acts of aggression, tantrums, excessive anger and explosiveness, were mentioned by 12 of the participants as being a serious problem affecting their lives in one way or another. Only two participants made no mention of such incidents. The other negative aspect which was frequently mentioned was *embarrassment* caused by the sibling. Only four of the participants did not mention being bothered by the attitudes of other people, or having experienced feelings of embarrassment when their friends met their siblings, or when siblings had tantrums and behaved inappropriately in public. Thus in at least some cases, the uncontrolled or aggressive behaviour of the child/teenager with autism causes the feelings of embarrassment.

Behaviours, such as aggressiveness, impulsiveness and temper tantrums, are described in the Diagnostic and Statistical Manual of Mental Disorders (4th Edition) of the American Psychiatric Association (1994) as associated descriptive features of the autistic disorder, whilst other behavioural problems, such as self-injurious behaviour, sleep disturbance and excessive anxiety, have also been reported as frequent symptoms of the ASD (Klinger

*et al.*, 2003). It could therefore be argued that a significant majority of negative experiences mentioned by the informants are features often characteristic of the ASD, which is not always the case of other learning disabilities. By contrast, there was only occasional mention of negative experiences likely to be shared by all TD siblings with a disabled brother or sister, such as lack of privacy, inability to have friends over, restrictions on holidays, interference with personal life, and the demands made on the parents' time. A tentative conclusion from this study is, therefore, that behavioural problems often related to the ASD, and especially aggression and uncontrolled anger, cause a variety of negative emotions in TD siblings. This is confirmed by studies which show that behavioural disturbances in a disabled brother or sister can have adverse effects on the psychological adjustment of typically developing children/teenagers within the family (Lardieri *et al.*, 2000). It could also explain why previous research has shown that growing up with a sibling with autism can have more detrimental effects than having a sibling with, for example, Down syndrome, or other disorders less likely to be characterised by behavioural disturbance (Fisman *et al.* 1996; Rodrigue *et al.* 1993). If confirmed, these findings would also have clear implications for the support-needs of siblings of children/teenagers with an ASD. Specifically, an intervention directed towards helping both parents and siblings to establish effective ways of handling aggressive and other uncontrolled behaviours could significantly lessen the detrimental effects the child/teenager with autism has on other children in the family.

### *Limitations of the study*

Some of the limitations of the study have been mentioned already, in particular the small size of the sample and the fact that we did not include a control group. It is important to point out, also, that the fact that the 6 of the participants came from 3 families in which there was a child/teenager with autism and two TD siblings, both of whom took part in the study, entails that the participants' experiences were not independent in all cases. In addition, the majority of the participants were older than their sibling with autism (in 12 out of 14 cases), and there was a preponderance of girls in the group (10 compared to 4 boys). Our participants were not, therefore, fully representative of the broader population of TD siblings in families with a child/teenager with an ASD. None of the above limitations is germane to the central aim of piloting a practical and effective method of eliciting the children's thoughts and feelings about living with a sibling with autism. However, the limitations of the study do entail that the data reported should be viewed as suggestive and preliminary only. Moreover, many factors were unexplored, e.g. the effects of relative age, gender, family structure, the affected child's/teenager's place on the spectrum etc. etc., which it would be of interest to investigate in future research.

### **Summary**

The aim of the study reported here was to pilot a method of eliciting data concerning the subjective experiences, thoughts and feelings of typically developing (TD) children/teenagers living in families including a child/teenager with autism. A semi-structured interview was

used, and piloted with 14 TD children/teenagers from 11 families in which there was a child/teenager with autism. We aimed to elicit reports of both positive and negative experiences such as might contribute to an understanding of internal factors influencing the behavioural adjustment of TD siblings of children with autism; and which might also be useful in identifying the support needs of TD siblings. The semi-structured interview was successful in eliciting what, from internal evidence, we judged to be truthful and accurate reports of children/teenager's thoughts and feelings. The data obtained were not amenable to statistical analysis, and findings can be considered preliminary only. However, the data strongly suggest that having a brother or sister with autism has positive aspects for the majority (but not all) TD siblings; but that negative reactions are quite evident and are largely related to the affected sibling's aggressive or uncontrolled behaviour, and the embarrassment caused by such behaviour or by other autism-associated behaviours. The potential implications of these preliminary findings for research into the psychological well-being of TD siblings of children with autism, and their support needs are briefly discussed, plus a critique of the methodological limitations of the pilot study.

## Acknowledgements

We are grateful to the young people who took part in the study and to their parents; also to the West Midlands Autistic Association, Birmingham UK, for putting us in touch with the families.

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