

AN AUTISTIC CHILD IN THE FAMILY

These notes focus upon the experiences of siblings of children with autism and their interactions with parents; and upon the cognitive coping strategies that may be adopted by mothers when facing the demands of bringing up a child with autism. Factors associated with positive and negative adjustment in the siblings are described, along with the "redefining" strategy observed in mothers.

Sibling Experiences

A range of studies has shown that having a brother or sister with a developmental delay or disability will have significance for the progress and well being of both the normally developing child and the child with the disability. The presence of a child with a condition such as autism carries potentially both positive and negative effects for the sibling(s), but the outcomes will be influenced by other family factors notably the management style of the parents.

For example, birth order, sibling gender, severity of the disability, and the socio-economic status of the family can directly impact upon the sibling relationships; and Simeonsson and McHale (1981) described how an emphasis in parental time and attention towards the child with the disability may arouse feelings of jealousy or resentment among other children of the family or increase existing feelings... thus exacerbating general familial stress.

Other studies, such as that of Powell and Ogle (1985), have shown that the presence of a child with special needs may frequently involve siblings in direct care-giving activities and in their devoting time to supervising or entertaining their brother or sister.

The work of Powell and Gallagher (1993) explored the common concerns and anxieties of the siblings of children with special needs, including autism, and six general categories were identified:

- Concerns for the child - such as the cause of the disability; the availability of appropriate provision; the longer term future.
- Concerns related to parents - including the perceived differential expectations upon their behaviour and that of the sibling; communication with the parents; anxiety about the pressure upon parents' time.
- Their own feelings - concern over the relationship with the disabled child; their own health.
- Worries about peer attitudes - how to deal with teasing; informing their friends about their sibling's needs; anxieties about gaining boy or girl friends.

- Community issues - such as being able to get on at school; acceptance within the wider neighbourhood.
- Future problems as adults - having to take financial responsibility or guardianship; having to liaise with support services.

A review of research and survey findings completed by Miller (2001) showed that very high, even excessively high, expectations upon normally-developing children was a further source of stress. This appeared to apply particularly to boys. Meanwhile, girls could also experience heightened pressure as they frequently were cast wittingly or unwittingly in the role of parent-surrogate.

As increased demands in respect of child care were experienced, there may be increased conflict between the siblings and the child with special needs, reflected in anger and resentment, but also in guilt.

Meanwhile, parents have been found commonly to believe that the normally-developing children are coping much better than the children themselves believe to be the case : and

siblings were more depressed and showed a lower self esteem when they were dissatisfied about the way their parents were treating them relative to other family members. One study enabled parents to realise that they had been largely ignoring other children in favour of the disabled sibling.

Miller has not identified much research specifically concerned with the brothers and sisters

of children with autism, but does quote from *one* such study completed by Harris (1994).

She found that there were a number of specific concerns among her sample:

- The need for information about the nature of autism
- The need for respect - to be treated as individuals as opposed to being identified as the brother or sister of the autistic child
- The need to learn specific social and communication skills in order to be able to increase the amount and quality of interaction with their autistic sibling
- The desirability of having opportunities to share feelings and experiences with other children and young people who have a sibling with autism

Miller's own piece of research was designed to tap the experience of a sample of children with a sibling with autistic spectrum disorder. The particular areas of interest were their reports of involvement in day to day activities with the autistic child; difficulties in the

interactions between them and compensatory strategies; and parental management and style.

A total of 24 children between the ages of 10 and 16 were interviewed. 8 had a younger brother or sister attending a specialist school for children with autism; 8 had a sibling with learning difficulties; and 8 had normally developing siblings. Each group of 8 comprised 4 boys and 4 girls.

The interviews included general discussion of routine activities, and the use of a questionnaire specifically investigating attitudes and perceptions. (In addition, the mothers all completed a questionnaire by which to rate the behaviour of the target child towards sibling[s] - acceptance, hostility, support, and embarrassment).

The results of the maternal reports suggested that sibling relationships were uniformly positive, with few or no feelings of jealousy or rivalry.

Comparisons between groups showed that children with an autistic sibling tended to take part in activities that were care-giving rather than play-based, and this applied particularly when the autistic child was a girl.

More concern was expressed about the future of boys with autism (or learning difficulty) than girls with either disability.

Concerns about having a sibling with ASD related to perceived parental favouritism and concern about what would happen in the future.

Miller's discussion picked up the unequal anxiety about boys and girls with a disability; and he also noted that family size can be significant for maintaining self esteem or avoiding resentment, etc., in that there appears less embarrassment (and less responsibilities for any one sibling) when the child with autism is one of a larger family.

The type of activities shared appear to differ among normally developing groups of siblings and groups containing a child with autism or learning difficulty. The latter were more task-oriented (care-giving and helping) rather than play-based interactions. Girls spent more time than boys in caregiving activities with siblings with ASD or learning difficulty.

Miller also argues that there is a need for young children directly to be taught interactive skills in order more easily to share play-based activities with their brother or sister with autism.

Further, he acknowledges the continuing problem whereby the specific demands placed on the parents in looking after a child with autism may lead to *some* feeling that a fair share of their time and attention is not available to other children in the family. However, it was encouraging that the results of this present survey did not reveal any jealousy or rivalry towards the autistic sibling (in contrast to the findings of previous studies which

have shown, for example, that the behavioural allowances afforded by the parents to the child in question may give rise to negative attitudes and resentment).

The final comment relates to the need for effective communication about the nature of autism to normally developing siblings. This should be an ongoing provision, sensitive to the changing course or expression of autism and to the changing needs within the sibling relationship over time.

Psychosocial Adjustment in the Siblings of Children with Autism

The study of Kaminsky and Dewey (2002) begins with a recognition of the frequency with which children with autism may engage in behaviours which appear aggressive or impulsive or obsessive and which can have disruptive effect upon family life. The difficulties with communication, and the anxiety surrounding public contact and family outings, may present further challenges not only to the parents but to the siblings of a child with autism.

The authors review what few studies already exist concerning the adjustment of siblings and report how some evidence suggests that they are at an increased risk for externalising and internalising adjustment problems. For example, Gold (1993) found higher levels of self-reported depression in siblings of boys with autism.

On the other hand, they cite studies which have shown how siblings are well adjusted and show positive self esteem and scholastic progress.

It is speculated that the inconsistent results may reflect the small numbers involved in the various samples (or the variation in ages of both the children with autism and of the siblings across the study samples ?).

Inconsistent findings also apply to the social skills and the peer relationships of siblings of children with autism. Some studies have found entirely satisfactory levels of social competence while others have reported that these children and young people are at an enhanced risk for loneliness and problems with peers. This latter finding is seen as significant because such experiences may underlie more serious adjustment problems as the individuals get older.

The present study of Kaminsky and Dewey (2002) set out to investigate whether siblings of children with autism have greater difficulties in psychosocial adjustment than siblings of children with Down Syndrome or siblings of normally developing children. The sample of Down Syndrome children was selected as a comparison group because they represent a relatively homogenous group of individuals with recognised learning needs but fewer social/communication problems than those associated with autism.

The second purpose was to determine whether feelings of loneliness or of social support were related to psychosocial adjustment (and whether adjustment is influenced by such factors as gender or family size).

The participants were 90 normally developing children and young people between the ages of 8 and 18 years with an average of 11 to 12. Three groups were formed according to the presence of a sibling with autism or with Down syndrome or with no known problem. The groups were matched for gender, birth order, and approximate age. The majority of the reference siblings (i.e. the child with autism or Down Syndrome or no disability) were younger than the participants.

Measures used included a behaviour checklist; a social support scale; and a loneliness or social dissatisfaction scale.

Parents completed a short adaptive behaviour questionnaire; and information was gathered about family size, birth order, presence of any other children with disabilities, parental education and occupation, and type of family (2-parent, single parent, re-married, etc.).

The results indicated that siblings of children with autism are *not* at some greater risk for adjustment difficulties or loneliness.

The authors speculated that this discrepancy with the findings from some earlier studies may be explained in terms of the large number of participants' families who attended support groups. The siblings are, therefore, more likely to have enhanced knowledge about autism and its implications, and to interact more frequently with other families of children with autism. The social support attached to group participation may facilitate healthy adjustment.

It was also found that the perceptions of social support held by the siblings of children with autism did not differ from those of the other groups of participants; but it was also noted that there was some pattern whereby the better social adjustment was linked to having the greater number of siblings in the family.

This latter finding may be a matter of some diffusing of responsibility for the sibling with autism along with less embarrassment; and the presence of other normally-developing brothers and sisters would be an important source of social support.

Limitations of this study were acknowledged. Firstly, the majority of siblings were older than the child with autism. Different interaction patterns and experiences may operate when the child with autism is older than the sibling(s) so the findings from this study may not fully apply to such families.

Secondly, the higher rate of autism among boys means that many more participants reported on a relationship with a brother than with a sister and it may be that future

investigations may reveal different adjustment or relationship patterns according to the gender of the child with autism and of the sibling(s).

Nevertheless, the overall results from this study are encouragingly positive but with implications for the need for a high level of social support to remain available for the siblings for children with autism from parents, other family members, and friends.

Characteristics Associated with Successful Maternal Coping

As an introduction to this section, it is suggested by Tunali and Power (2002) that a major challenge and source of stress arise from seeking to cope with demands which are actually outside one's control. As in any "cognitive dissonance" situation, if one cannot reduce the stress by some specific coping strategy, it may be necessary to change one's perceptions of the situation or somehow accommodate to the way things are i.e. adopt a *cognitive* strategy in terms, for example, of re-appraisal or acceptance, etc..

Although one might use Maslow's hierarchy of needs as a general guide to how individuals will act, it is still difficult to predict precise reactions or strategies in a given situation.

However, there is converging evidence that the families of children with developmental disabilities may be subject to high levels of stress. According to McCubbin et al (1982), the source of stress may be financial, a matter of strained emotional relationships, necessarily limited family activities and reduced career aspirations, reduced opportunities for social and leisure pursuits, problems of fitting to treatment demands and appointments, educational disadvantages, and the ongoing difficulty in coming to terms with the disability.

On the other hand, more recent studies (e.g. Dyson 1997) have suggested that there are no reliable differences in the psychological or marital adjustment of children with and without developmental disabilities.

Accordingly, Tunali and Power (opp.cit) tested a number of specific hypotheses about the (cognitive) coping strategies of mothers of children with autism. Their study involved 29 mothers of children with autism and a similar number of mothers of normally-developing children (or, at least, non-autistic). In each group of children, there were 22 boys and 7 girls. Their age range was from 5 to 14, with a mean of 9+. With only few exceptions, the families were intact and perceived as middle class with both parents likely to have had some higher education, and fathers (and mothers with outside jobs) to be in professional or technical occupations.

The results demonstrated that mothers of children with autism

- Placed less emphasis on career success and were more likely to believe that mothers of young children should not work outside the home.
- Spent more leisure time with the extended family
- Were less concerned about others' opinions of their child's behaviour
- Emphasised their partner's support and parental role
- Did have difficulty in understanding their child's behaviours
- Were more tolerant of ambiguity (concerning prognosis, child abilities, etc.).

The authors held that the findings supported the general prediction that mothers respond to the demands of looking after a child with autism by redefining what is important, with the mothers who showed the greater satisfaction being those who made the clearest redefinitions and who were most willing to follow alternative ways of gaining self fulfilment.

They noted that not only did the prescriptions for certain behaviour apply to the mothers themselves but were applied more widely e.g. there was the feeling that mothers of children with autism should stay home, and that mothers of young children should, as a general rule, stay home too.

The "redefinitions" were illustrated by the common emphasis upon the parental role and the importance of being a good mother; and by the greater socialisation with extended family than with non-family friends albeit with reported levels of satisfaction with leisure opportunities similar to those of mothers of children without autism.

While the pattern of findings does fit to a cognitive dissonance model, the authors acknowledge that the findings could be interpreted in an alternative way, viz, that the differences between the two groups of mothers follow actual differences in experiences. Do the mothers of autistic children spend more leisure time with other family members because a consequence of having a child with autism is that of seeking or being offered more time in general from others in the extended family? Is the support of the father more salient because the very experience of having a child with autism leads to a greater involvement on his part in care-giving or enabling the mother to focus upon the child?

It was held probable that the redefinitions and the differential experiences are complementary. For example, as more and more time is spent with members of the extended family, so more positive attitudes are developed towards these interactions.

The authors acknowledge that these data are preliminary and that more evidence is needed before one can be more definite about the operation of a redefinition process underlying efforts to manage the demands of providing for a child with a developmental

disability. Ideally, one would need an insight into attitudes and beliefs that pertained before the need to adjust to the presence of a child with autism.

(The present writer MJC - would also express some concern lest, if the kind of cognitive shifts described above are an important element of psychosocial adjustment, there are inferred problems for those mothers who find it very hard to match these views and day by day styles. What if a mother cannot adopt these redefinitions or adapt to particular routines? It is also noted that the mothers in this above study were described as sharing stable relationships and as having access to extended family support. One might speculate about the enhanced pressures and tensions in the case of those mothers who happen not to enjoy these circumstances or who, for example, have no realistic choice whether or not to seek paid employment??).

M.J.Connor August 2002

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