Living with impairment: the effects on children of having an autistic sibling

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Summary Although children of impaired siblings are generally believed to be at risk of suffering from a variety of problems themselves, research studies indicate that living with impairment is not necessarily a harmful experience. This report reviews studies in this area, with particular emphasis on those involving autistic sibships. Although often lacking adequate experimental controls, the current literature suggests various factors that are likely to influence the risks on siblings. Possible ways of minimizing such risk factors are discussed.

'You're a naughty girl!' said Tom severely 'and I'm sorry I bought you the fish line. I don't love you ....Last holidays you licked the paint off my lozenge box, and the holidays before that you let the boat drag my fish-line down when I'd set you to watch it, and you pushed your head through my kite, all for nothing. And you're a naughty girl and you shan't go fishing with me tomorrow.'

With this terrible conclusion, Tom ran away from Maggie towards the mill

The main focus of George Eliot's *The Mill on the Floss* lies in the complexities of the relationship between brother and sister: the rapid swings back and forth from love and tenderness and idolization to misery and bitterness and quarrelsome recriminations. It is quoted here to serve as a reminder that even for normal siblings, growing up together is not an easy process, a fact that needs to be kept in mind when looking at the relationships between disabled children and their siblings.

Judy Dunn's (1984) book *Sisters and Brothers* also examines the intricacies of sibling relationships. It is well worth reading by any parent of an impaired child in order to place family difficulties into perspective. Amongst the many different aspects of family life explored, the book illustrates the feelings of resentment and jealousy experienced by children on the birth of a younger child. Such emotional turmoil is often manifested by an increase in problem behaviours, temper-tantrums and rituals, and by regression in sleeping, toileting and self-help skills. The book discusses the aggressiveness and quarrels which are so much a part of daily family life and the onerous role of caretaker sometimes imposed on older children in large families. On the other hand, there are also strong feelings of affection and comradeship and intense emotional ties. The importance of individual differences is also stressed, and the ways in which these affect parental responses and handling, as well as the relationships between children, which add further to the complexities of family functioning.

THE EFFECTS ON SIBLINGS OF HAVING AN AUTISTIC CHILD IN THE FAMILY

Although there have been a number of studies on the effects of having an impaired child in the family, the conclusions of these investigations need to be treated with some caution. Many of the reported findings are anecdotal in nature and whilst these may be illuminating they are no substitute for objectively collected facts. Secondly, the majority of such studies have failed to use any comparison or control groups in their assessments. As already noted, families of normal

children have considerable problems to contend with and unless this fact is taken into account there is a danger of exaggerating the impaired child's role in 'causing' problems. Thirdly, there are very few studies of specifically autistic sibships. Therefore, for this article, it has been necessary to combine findings from studies of children with different impairments, and these of course may not be entirely appropriate for the families of autistic children. Many parents in this group, for example, fear that their normal children may be at particular risk of developing problems because of the autistic child's lack of social and communicative skills and their often very severe behaviour problems.

Bearing these caveats in mind, what is the risk of children with an autistic sibling suffering from increased rates of problems themselves?

Much of the evidence stems from work with children suffering from a variety of different conditions. Studies of Down's syndrome children (Gath & Gumley 1987), those with spina bifida (Tew *et al.* 1974), the chronically ill or disabled (Lavigne & Ryan 1979), or those with cerebral palsy (Breslau 1983) have all reported higher rates of behaviour problems in their siblings than in the control groups studied. Increases in behaviour problems have also been noted in many studies where control groups have not been used, although these results must be treated with caution, for the reasons noted above (see Simeonsson & McHale 1981).

However, other studies of siblings have failed to find increased rates of problem behaviour (McHale *et al.* 1984). DeMyer (1979), for example, in one of the few comparative investigations of autistic children, studied 59 brothers and sisters of autistic children and 67 siblings of normal controls. She found remarkably few major differences between the two groups, and very similar numbers (nine in each group) were described as being emotionally disturbed. Nevertheless, more children in the autistic group (30%) reported feelings of being neglected; 18% reported worries and anxieties associated with the condition; and 15% of parents reported problems of toileting and eating which they believed were attributable to the effects of the autistic child. Other difficulties, such as problems of teasing or jealousy were also noted; two children ran away from home and one became school phobic. However, such problems also occurred in the non-autistic group and it remained unclear whether or not they had anything to do with the presence of the autistic child.

A higher incidence of learning problems in siblings has also been noted in certain studies (August *et al.* 1983). Again, it is not always clear whether these are related to the stresses of living with impairment, or whether they are in some way related more directly to the handicapping condition. In certain disorders siblings may be at the far end of a continuum of disabilities, which means that they, too, may be affected by some of the problems exhibited more evidently by the impaired child. In a proportion of families with an autistic child, for example, this certainly seems to be the case. Rates of language-related problems, such as early speech delays, or later reading and spelling problems, are significantly higher in the siblings of autistic children than in other families, such as those with a Down's syndrome child. Genetic factors seem to play an important role in this increased rate of learning and developmental problems in the siblings of autistic children. Whether or not the somewhat higher than normal rates in the Down's families is caused by genetic or environmental factors remains unclear.

Amongst other types of difficulties reported in normal siblings are feelings of guilt and fears that they might, in some way, be responsible for the condition. Identity problems have also been noted, with the normal child perhaps harbouring secret fears that he or she, too, might be affected

in some way. Many children feel that they have not received the same amount of attention from their parents as has the impaired child, and some express feelings of unfair treatment, with their sibling being able to 'get away with' much more than they could ever do. There are also difficulties associated with being expected to do more household tasks, having to care physically for their sibling, or to carry out other chores because of the greater amount of time and attention required by the disabled child (see McHale *et al.* 1984, 1986). Nevertheless, it should also be noted that recent studies have indicated that concerns about excessive housework are no greater in children in these families than they are in their peers (McConichie & Domb 1983). Dupont (1980) also found that although the presence of a disabled child very much increases the amount of work to be done in the home, almost all of this was done by mothers.

Psychological stress, too, is reported more frequently. Siblings may feel the need to over-achieve or 'make up for' the limitations of the impaired child. They may feel under pressure to provide extra emotional support to their parents, or to provide for the physical needs of their sibling as parents grow older.

Not surprisingly, such demands, whether they be real or imaginary, can result in at least transitory feelings of resentment or hostility on the part of siblings. However, many studies also show that, far from being harmed by their experiences, siblings of impaired children are often remarkably well-adjusted, and frequently show greater maturity and responsibility than their peers. They have been reported as having positive self-concepts and as being more altruistic and tolerant generally. Many also tend to go into the 'caring professions' when they grow older (Cantwell & Baker 1984). Feelings of shame and embarrassment or problems of teasing do not seem to be particularly severe, and on the whole the children's social contacts are not unduly affected (McHale *et al.* 1984, 1986). In addition to siblings' self-reports of their feelings, parents frequently confirm that the impaired child is loved and accepted within the family and that most of the problems that do develop are resolvable (Simeonsson & McHale 1981).

In a recent study of 90 children (McHale *et al.* 1984, 1986), the authors found that, as a group, siblings of autistic and mentally impaired children were significantly less hostile, less embarrassed, more accepting and more supportive than siblings of normal children. However, it was also apparent that there was much wider variation in the attitudes of the siblings of impaired children than amongst the normal group. Thus, whereas many children were extremely positive, there were also some who reported much more negative attitudes.

FACTORS RELATING TO PROBLEMS IN SIBLINGS

Although some of the contradictory findings from studies in this area may result from the failure to use adequate control groups, it is apparent that the effects on siblings are variable, and that individual children respond in very different ways. Consequently, recent research has concentrated on the factors that are likely to reduce or increase the burden on siblings (McHale *et al.* 1984).

In families of autistic and other impaired children the risks to siblings tend to be greatest in small families, particularly those where there is just the impaired child and one other and where the age gap between the two is small (a gap of 10 years or more seems to reduce the problems). In larger families the burden can be more easily shared and attention from other siblings can also help to compensate for any reduction in parental attention. Similarly, parents' disappointment and grief at having an impaired child can be reduced to some extent by experiencing their other children growing up successfully.

Siblings who are younger than the impaired child also tend to suffer more than those who are older, presumably because they 'miss-out' to some extent on the exclusive caretaking usually reserved for the youngest child. Again, risks of disturbance tend to be higher if the age gap between the impaired child and younger sibling is small. Some studies report that problems tend to be greater when the affected child is male and others have found sisters to be more at risk than brothers. This seems to be because. the 'burden of care' falls more heavily on girls than boys, although Gath (personal communication) suggests that this sexual distinction may be declining. However, she quotes several cases of girls who have shouldered considerable responsibility until the age of about 13 years and have then totally rejected their caring role.

The nature of the impairment also influences the frequency of behaviour problems exhibited by siblings. In the study by Gath & Gumley (1987) on the families of Down's syndrome children and retarded controls, behavioural problems in both groups were related to the severity of problems shown by the impaired child. Other studies have also reported a higher incidence of behaviour problems in siblings when the impairment suffered is a severe one. The situation is further complicated by the 'visibility' of the handicapping condition. Siblings of children with 'vague' or ill-defined problems are more likely to suffer than when the condition is well-defined or very obvious. One possible explanation for this is what Gath (personal communication) refers to as the 'Sainsbury's syndrome'. For instance, if a Down's syndrome child behaves badly at the supermarket check-out his family are likely to be treated with considerable sympathy and sent to the top of the queue. If a less obviously impaired autistic child behaves equally badly his family are unlikely to be served at all. In addition, of course, families in which the impairment is apparent from birth have greater opportunities to discuss and to come to terms with the problem from a much earlier stage and this, too, may help to make adaptation easier for the other children.

The extent to which siblings are affected depends also on many other factors. Poor family relationships, marital discord, depression or other psychiatric illness in the parents, all increase the risk of disturbance in both normal and impaired children. Warm, harmonious family relationships, on the other hand, have a protective effect, even when the impairment is severe (McHale *et al.* 1984).

Economic and social factors may also exert important influences. The financial implications of having to care for a disabled child are considerable, and, in addition to this, it is often impossible for mothers to go out to work because of the need to look after the child. Financial strains can add greatly to the other burdens on families, thereby increasing the risk of difficulties. In more affluent middle or upper class families, however, different conflicts may arise because of their higher expectations and the inevitable discrepancy between their aspirations and the level the impaired child will actually achieve.

One of the most powerful influences on siblings' adjustment appears to be the ability of parents to convey positive attitudes about the impaired child. Several studies have shown that, providing the 'burden of care 'is not too great, if parents demonstrate their acceptance of the impaired child, siblings tend to react similarly (Grossman 1972). More positive parental attitudes may be fostered if the amount of support offered to families is adequate. Religious beliefs, too, may be important for certain families.

Finally, the extent and openness of parental communication about the child's impairment appears to be a major factor in promoting siblings' understanding of and, hence, adjustment to the condition (Simeonsson & McHale 1981).

PRACTICAL WAYS OF MINIMIZING THE EFFECTS ON SIBLINGS

As well as highlighting the risks faced by siblings, studies of the effects of impairment offer some guidance on possible ways of minimizing these. Obviously, nothing can be done about the age or ordinal position or type of impairment of the affected child, but other factors may be more susceptible to modification. Intervention with the parents of autistic children suggests a number of ways in which the burden on these families may be alleviated (Howlin & Rutter 1987a).

Increasing other family interactions

The demands of caring for a child with a severe impairment, such as autism, inevitably affect parents' interactions with their other children and it is clear that younger siblings in particular are likely to be adversely affected by this and may, understandably, resent it. Deliberately setting aside a short period each day (or weekly if this is not possible) for the exclusive benefit of other children can be of great help. Obviously, this is not always an easy task to achieve, and it may mean that the autistic child has to be less than optimally stimulated at such times. Some parents manage to fit in time with their other children when the autistic child is still travelling home from school or when he is settled in bed (if this can be achieved early enough). Others split the time between the two parents, so that one can spend time with the normal children whilst the other keeps an eye on the autistic child. Other families make use of helpful grandparents whenever possible, and, although some parents may find it hard to believe, willing baby sitters can often be found if one searches long and hard enough. Even though the difficulties of making such arrangements may be considerable, they are usually well worth it, both in decreasing parents' feelings of guilt and other children's feelings of resentment. Once such a system is in operation it is important to ensure that this precious time together is not eroded.

As the autistic child grows older, one of the best ways of increasing the opportunities for the rest of the family to interact together is to demand and make use of respite care. Again, this is not always easy to find and many parents feel guilty about seeking such help. However, if respite care can be achieved on a regular (instead of the more usual crisis) basis the autistic child usually comes to accept this without too much resistance. As well as this making it possible for parents and their other children to spend more time together it can also offer the opportunity for parents to have the occasional break by themselves. 'Recharging batteries' in this way then provides the strength needed for continuing with the many demands of daily life. The use of planned respite care also means that if a crisis does arise on a future occasion, the autistic child has somewhere familiar to go. It can also pave the way for future residential placement should this be necessary or desirable.

Meeting the social and educational needs of the other children

As normal children grow older their lives become more complicated and as well as needing their parents' attention they have to meet the varying demands of their school and their peers. Disruption of social and educational activities has been found to be a risk for siblings of autistic and other impaired children but there are ways of reducing this. Privacy can be of vital importance both for entertaining friends, keeping valuables safe and doing homework, and a simple lock on the bedroom door can often prove an effective solution.

Some parents find that schools offering special educational provision which stagger their holidays, and therefore do not overlap entirely with the regular school vacations, provide a welcome opportunity for them to spend more time alone with both the autistic and the normal

children. However, this may not suit all parents, especially those whose own holidays are limited.

Organizations such as 'Buckets and Spades', which offer holidays for impaired children can also be a valuable source of relief for families, especially during the long summer vacation (although booking needs to be done well in advance). Again, too, such facilities offer the opportunity for the autistic child to experience separation from the family under pleasurable rather than stressful circumstances.

Finally, especially with the onset of adolescence, the demands of the normal and autistic children often become more disparate, resulting in new conflicts. Although placement at a day school is usually preferable for younger children, this situation can change as families grow older. Residential placement may be able to offer more to both the autistic child and the rest of the family as children grow older, and although not the choice of all families it is an option that should not be entirely neglected.

Avoiding undue physical and emotional pressures on siblings

The feeling of being required to offer more physical and emotional support to parents than their peers has been reported by many siblings of impaired children. Ann Gath's, work with the families of Down's syndrome children suggests that these feelings may not always be justified, but they are, nevertheless, a source of some resentment. Girls appear most likely to be at risk here and hence it is important for parents to ensure that they do not rely too much on support from their other children, particularly their daughters. However, there may be difficulties in some cases in stopping children from attempting to shoulder too much of the burden. Several parents have reported on the 'over-involvement' of other children, who do all they can to cosset their handicapped sibling. For example, daughters especially may be described as being 'old before their time', or 'like a 15-year-old in a 7-year-old body when she is with him'. Obviously, altruistic feelings should not be discouraged but in some cases it is important to try to develop outside interests as much as possible and to ensure that the emotional involvement does not become excessive.

When children are young it is also important to try to avoid feelings of 'unfairness' because the autistic child is allowed to 'get away with' behaviours that are not tolerated in the rest of the family. Obviously, some allowances do need to be made for the autistic child but it is essential to explain the reasons for these to the other children. It is also necessary to have certain rules of behaviour for the autistic child as well as the others and to ensure that these are kept to as far as p05sible. It can also help if the autistic child is seen to help out with. some routine chores, no matter how simple these may be, in the interests of equality'.

Later on, in the case of more capable autistic children, this position may be reversed with the autistic individual complaining more about the 'unfairness' of life than his siblings. For example, he or she may well resent not being allowed to do the same things, or go to the same school, or on the same outings as their normal brothers and sisters. Clearly, dealing with this situation, too, requires considerable skill and sensitivity on the part of parents.

As families grow older, concerns about future placement and provision begin to increase. Plans for finding suitable residential placement should commence long before parents become too old or infirm to cope, and planned short-stay visits can be very helpful in getting the whole family accustomed to these separations. Although parents may have difficulty in accepting the need for

residential placement, especially if the child has never lived away from home, it is essential not to expect other family members to take over their role as caretakers. Involving the other children in decisions and plans for later care is important, but they should never feel under any obligation to take over this care themselves. Financial aspects of later care also need to be carefully planned, and again the setting up of Trust funds, etc. helps to reduce the economic pressures on other family members (Fromberg 1984).

Explaining and discussing the nature of autism

Feelings of confusion about the nature of autism or even guilt that they may in some way be responsible are common reactions amongst siblings and unless there is the opportunity to discuss such issues much unnecessary anguish can result. Le Couteur (personal communication), in her study of autistic twins, reports one twin who was convinced. that her sister's autism had resulted from the time she had hit her on the head with a book. Throughout her childhood she had been too terrified to tell anyone of her fears and had lived with this guilt for years.

Providing simple explanations to the other children from the very earliest years and encouraging them to talk openly about their fears and confusions can help to resolve many difficulties. Such strategies also help them to cope better socially by enabling them to deal more effectively with their peers' curiosity. Unfortunately, explaining the reasons for autism is more complicated than explaining the reasons for some other conditions. Ann Gath, again, (also quoted in Judy Dunn's book) provides the story of a little girl whose peers were making fun of her Down's syndrome sister.

'Your sister's daft', came the mocking comment.

'Not as bloody daft as you'd be with an extra chromosome', was the crushing reply.

Such opportunities for wit may not be available to the siblings of autistic children, but helping them to deal in a straightforward way with the queries and comments of their peers is of considerable value. Simple advice about ways of handling day-to-day problems is also much appreciated by siblings. Fromberg (1984), for example, gives a moving account of the years spent with his autistic brother. He notes how much that basic information about autism, and about ways of dealing with difficult behaviours, would have helped in reducing his own feelings of upset and anger and in increasing his sense of competence and understanding.

Children may also need help to come to terms with their own, often confused and ambivalent, feelings of love, protection, guilt and anger, and they need to be reassured that such feelings are both natural and understandable, not a reason to be ashamed. In some cases outside help may be needed to work through these difficulties and counselling groups have been reported as being helpful for some children (Carr 1985, McHale *et al.* 1984).

As noted above, one of the most important variables affecting siblings' responses is the attitude of their own parents. Many studies have found that positive attitudes on the part of parents are reflected in the feelings of siblings, and encouraging them to value the assets of the handicapped child is all-important. Fortunately, the good points do not have to be of outstanding merit; even very trivial behaviours can come to be appreciated. Judy Dunn describes one 7-year-old who disliked being separated from his handicapped brother 'because I miss him snoring which stops me having bad dreams'.

Involving the other children in treatment

Several studies have reported the use of siblings as therapists for autistic children. They have proved effective both, in reducing disruptive behaviours and increasing skills, and their involvement in therapy is clearly beneficial for all concerned (Lobato 1983, McHale *et al.* 1984). Providing that care is taken not to place increased pressures on siblings by involving them in this way, they can become very successful at changing behaviours, sometimes even better than parents (DeMyer 1979). As well as this benefiting the autistic child it also helps to boost the siblings' self-esteem. With guidance, brothers and sisters may also become very adept at encouraging social behaviours and this is important since autistic children, in particular, rarely have the opportunity of interacting with other normal children (James & Egel 1986).

In families with a more able autistic child the process does not have to be entirely one way. Interests or skills, however obsessional, in arithmetic, spelling, geography, history, computing or general know-ledge can be of great benefit to other children especially at homework time and their value should never be underestimated. In one family, for example, the older autistic brother is currently giving his 16-year-old sister extra coaching for her maths 'A' levels; in return she is helping to desensitize him to his dog phobia.

Parents, too, may benefit from such 'two-way' schemes in that the behavioural management techniques that prove useful with the autistic child can also be used effectively to cope with problem behaviour shown by their normal offspring.

Other risks for siblings

Finally, particularly in the case of families with an autistic child, it is important to be aware of possible risks to the other children in terms of problems with language-related or learning skills. These are clearly much less serious than the problems of the autistic child, but statistically the chances of their suffering more problems than average in these areas are considerably raised (August *et al.* 1983). It is possible for such problems to be overlooked because of the overwhelming concerns over the autistic child, or for the difficulties to be blamed indirectly on the pressures of coping with severe impairment. However, it is important to take them seriously, in their own right, and to ensure that remedial help is available from the earliest stages. Even relatively mild problems of language development can have a deleterious effect on many other areas of functioning, including social and emotional development. Similarly, unresolved difficulties in reading or spelling can affect academic attainments, leading to many difficulties. Awareness of the possible risks, and rapid intervention if necessary, can help to minimize difficulties and reduce the risks of unnecessary, secondary problems (Howlin & Rutter 1987b).

A FINAL WORD OF ADVICE

Perhaps the most important fact for the parents of any impaired child to remember is that 'normal' family life is by no means problem free. Quarrels, violent battles, temporary enmities, are all part of the day-to-day interactions between brothers and sisters. The presence of an autistic child is most unlikely to be the sole cause of such problems, although, of course, it may exacerbate difficulties from time to time.

It is also important to be aware that, on the whole, normal children are remarkably resilient to many early adversities. Follow-up studies of children brought up in care, or suffering from other forms of deprivation, indicate that, although some show lasting problems, most show surprisingly few major after-effects (Rutter 1981). Such difficulties are a great deal worse than

those which generally face the siblings of an autistic child. Thus, with help and guidance, open discussion and sensitive (not necessarily always perfect) handling, the childhood of normal siblings is unlikely to be adversely affected to any great extent. Indeed, for many, as Judy Dunn points out, 'The intimacy and emotional power of this relationship can foster remarkable capabilities in....young children'.

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