SIBLINGS OF CHILDREN WITH DISABILITIES

an extract from
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The sibling bond is unique among family relationships in that siblings usually share a common genetic, cultural, and experiential heritage (Pruchno et al. 1996). Despite changes in individual circumstances, sibling relationships have the potential to be the most enduring of all relationships. Whereas parents sometimes leave a family and families can leave friends, sibling relationships usually endure throughout life, and to a greater age than has been the case in the past. Given that divorce is increasing and geographical moves are common, siblings can be the only source of an ongoing, stable relationship in families. In addition, families now have fewer children and the children are closer together in age, making the sibling relationship more intense. Therefore, there is potential for sibling relationships where one of the siblings has a disability to have long standing influence on the lives of both siblings.

In any family, sibling relationships are complex, with mixed emotions and, sometimes, less than positive long-term relationship outcomes. This mixed picture is also true when the family has a child with a disability.

RESPONSES OF SIBLINGS

Siblings of children with disabilities can have their own additional needs. Meeting these needs is in their interests, as well as those of their brother or sister with a disability. Having a brother or a sister with a disability may have a positive, neutral or negative effect on siblings, depending on a range factors (Harry et al. 1998; Hannah & Midlarsky 1999). Some studies report that siblings experience high levels of stress; others suggest no differences in self-esteem, positive feelings about their lives, or stress when compared with children whose brothers and sisters do not have disabilities (Hannah & Midlarsky 1999). Thus, the picture of sibling responses is complex, influenced among other things, by the severity and type of the child's disability, the children's ages, birth order, family size and parental influences.

Characteristics of the disability

The characteristics of the sibling who has a disability are believed to have various outcomes for the sibling relationship. The first aspect is the type of disability. For example, a complex disability such as autism may be more confusing for a sibling than a more straightforward diagnosis. Some disabilities will be visible and may attract more stigma – although, on the other hand, the unusual behaviour of a child with no outward signs of a disability can cause more embarrassment for siblings than when the child's disability is visible and hence explains the aberrant behaviour.

The competence level and communication ability of the sibling with the disability is likely to have a profound effect on interactions (Heller et al. 1999). In the case of deaf-blindness the children may have difficulties communicating

with each other and may need to use alternative or augmentative communication systems (Heller et al. 1999).

The second aspect to affect siblings' reactions is the severity of their brother or sister's disability. A child with more severe disabilities may require more caretaking, which can stress the parents – and, in turn, the siblings – and place pressure on siblings to act as substitute carers. On the other hand, the significant factor may not be how much time the child with a disability requires, but how he or she *behaves* when being cared for (Seligman & Darling 1997).

Ages of the children

The sibling relationship where one child has a disability often centres around caretaking, rather than shared play. The level of responsibility that siblings feel as a result can be related to the birth order and gender of siblings, with elder sisters often shouldering most responsibility. Acting as substitute caretaker takes skill and patience and may limit siblings' opportunities to engage in age-appropriate activities and peer relationships (Hannah & Midlarsky 1999).

Wider spacing between children is reported to lead to less parental stress and, with it, less sibling stress. While children of the same gender who are close together in age can feel more companionship, their greater closeness may provide an opportunity for more conflict and embarrassment (Powell & Gallagher 1993).

Siblings who are younger than the child with the disability are particularly prone to misunderstanding the disability and its cause (Lobato 1990), especially if the disability has no visible signs. Younger siblings are also more likely to believe that they will catch the disability, or that they have caused it. They are also in more need themselves of a high degree of nurturing and so they can suffer more than older siblings if that is not available from parents who are busy caring for the child with additional needs. Younger children can expect their older brothers and sisters to be more able than them, and may become embarrassed when displays of immature behaviour demonstrate that this is not so. Moreover, once the younger child's development surpasses the older disabled child's, the younger sibling may feel guilty about being more capable than an older sister or brother.

On the other hand, youngest children have grown up with their disabled brother or sister and so may see him or her as 'normal' because that is how their family has always been. They can therefore be very accepting.

The family's circumstances

The sibling bond is likely to be influenced by the family's particular circumstances. For example, siblings' perceptions of their parents' attitudes regarding the child with a disability can be a powerful influence on their own adjustment (Caldwell & Guze 1960). It seems important for both parents to share the same positive attitude, too, rather than just one parent feeling positive.

Parental and family expectations for siblings to take care of or have responsibility for children with disabilities will also affect the siblings' wellbeing. Although it may be the case that older girls often shoulder this

responsibility, the characteristics of other family members and the cultural background of the family is likely to affect this. It may be that siblings respect and welcome their (sometimes lifelong) responsibility for their brothers or sisters with disabilities as this is a traditional cultural practice. This is particularly the case where families have hierarchical structures and the child with the disability is one of the younger siblings (Harry et al. 1998).

In response to their differing needs, many families treat their disabled and nondisabled children differently. Nevertheless, the nondisabled children may not be dissatisfied with that, when they see that is necessary or fair. However, evidence that one child is unfairly favoured or is given preferential treatment can lead to ill-will and conflict between them (Powell & Gallagher 1993).

Children from larger families can be better adjusted than children from smaller families (Powell & Gallagher 1993). This may come about because a larger number of children can share extra caretaking tasks and share the pressures to achieve in compensation for the sibling's disability. Further, if there is another nondisabled sibling with whom to share confidences, each sibling is better adjusted than when a sibling has only his or her parents on whom to rely (Lobato 1990).

Size of the family influences its socioeconomic status (SES), however, which in turn influences the experience of siblings. Families of low SES and larger families may have fewer resources to meet all the caretaking and medical needs of the child, possibly placing more pressure on the family as a whole and increasing the caretaking responsibility of siblings (Hannah & Midlarsky 1999).

Parents from high socioeconomic levels may have difficulty lowering their expectations for a child with a disability, a reaction which siblings might copy. On the other hand, middle-class families often have the funds to pay for outside help, such as a cleaner or housekeeper. This means that parents are freed up to spend more time with the children and can place fewer caretaking demands on their children (Stoneman et al. 1988, in Powell & Gallagher 1993). A higher family income also allows siblings to spend more time in activities away from home, providing friendships and an outlet for their feelings as well as some respite from the demands of home.

SIBLINGS' EMOTIONAL RESPONSES

Children are likely to experience a range of emotions in response to their brother or sister's disability. Emotional issues, of course, can be found in siblings in any families (Powell & Gallagher 1993). However, their intensity may be greater with a sibling who has a disability and the feelings themselves might be more persistent, and so the disabled child's brother or sister may need some support to express them.

Fears

Young children may be fearful of 'catching' the disability; older children may experience concern about the disabled child's future, at possible exploitation of their brother or sister, about the reaction of their own friends, and fear of having their own children.

Isolation

Many siblings feel that they are different from their peers and that their family is different from others. This can generate a sense of being special, or it may have negative effects on self-esteem and wellbeing (Hannah & Midlarsky 1999). Siblings may feel isolated from other family members. When another family member is so obviously in need, siblings may be reluctant to ask for their needs to be met.

Anger

Anger may result from feeling unappreciated and ignored and may be directed towards the disabled brother or sister, parents, society or even God. Children may also feel angry if their mother bears a burden of care without the father's help. They may also feel angry at the parents for not protecting the child from becoming disabled, whether or not they could have prevented it in fact. It is also common for siblings to get angry at peers who mistreat the child with the disability. The extent to which siblings harbour anger depends on a number of factors: how responsible the sibling is for the child with a disability, whether the disabled child manipulates or takes advantage of the sibling, how restricted the sibling's social life becomes, how much parental attention that the child with the disability requires, whether the family can cope financially, and family size (Seligman & Darling 1997).

Guilt

Siblings may also be angry when their brother or sister is teased and bullied, but may be too intimidated themselves in these situations to offer the protection they would wish. Guilt can result from being unable to put a stop to the teasing, even though achieving this is beyond the capabilities of the child's years. If the child's friends are doing the teasing, then loyalty to them can also engender confusion.

Resentment

Siblings may resent the amount of parental time that the child with the disability calls on, resent curtailment of family activities that the disability may provoke, and may resent that parental expectations are different for them compared to their disabled brother or sister. Jealousy and resentment can also arise when their disabled brother or sister's achievements are met with great enthusiasm, whereas their own attainments, appearing to be easier to achieve, are met with a lukewarm response from their parents. Similarly, nondisabled children may resent the amount of schoolwork that they have to do compared with what seems to be more enjoyable learning tasks for the child who has a disability. Jealousy can also lead to guilt for feeling negatively about their sibling, for wanting to have their own needs met and for placing demands on their parents (for 'bothering' them).

Embarrassment

Siblings may be embarrassed at the unsightly equipment that their brother or sister uses or might feel embarrassment when his or her inappropriate

behaviour attracts attention in public. They sometimes are embarrassed when friends meet their brother or sister for the first time. This can be especially acute, as already mentioned, when the child with the disability is older but does not act it. Sometimes, siblings may not be embarrassed at the reactions of others, but are watchful nevertheless:

> Friends came to our house to play, and I watched to see how they would play with him. As we got older, I tested out the boys I dated to see how they treated Bob. Lots of them just didn't make the cut, because they treated him differently.
>
> Cramer et al. (1997: 46)

Confusion

Siblings may also be confused about their roles in the family, about the complex feelings that they experience towards their sibling, about treatment priorities for the disabled child, and about parents' different opinions about ways to treat the child. Confusion may be especially felt when the sibling's condition has no known cause and yet results in displays of inappropriate behaviour (such as with autism).

Pressure

Finally, siblings can feel pressure to achieve at high levels to compensate their parents for the sibling's disability, and eldest girls in particular tend to feel pressure to care for and attend to the disabled sibling both now and in the future.

Conclusion: Siblings' emotional reactions

These negative feelings that can be associated with a brother or sister's disability are similar to those experienced by parents. These feelings are natural and healthy. It is important that siblings are not forced to deny or try to change them as, like any emotions, they will be transient and are more likely to be resolved if they are accepted as a natural part of life.

POSITIVE ASPECTS OF SIBLING RELATIONSHIPS

Having listed siblings' negative feelings, it is important to acknowledge that many also report potent benefits of having a disabled child in the family (Meyer 1993; O'Halloran 1993; Schulz 1993). The differences in children with disabilities are often celebrated by their families (Schulz 1993). These feelings often flow from the parents' and other family members' positive attitudes. The most commonly reported positive outcome is that a child's disability can bring the family closer together.

In terms of their own personal growth, some siblings report that having a child with additional needs in the family taught them to accept individual differences (Meyer 1993; Schulz 1993). Positive feelings include strong love and protection, excitement, and joy at their siblings' hard-won achievements. Siblings report that they develop 'greater understanding of people in general and handicaps in particular, more compassion, more sensitivity to prejudice, and more appreciation of their own good health and intelligence' (Grossman 1972, in Lobato 1983: 349; see also Meyer 1993).

Siblings can informally teach their disabled brother or sister skills which the child would not copy from his or her parents. While often feeling pressured to act as a substitute parent or teacher, siblings can also feel some pride and increase in status for taking on these duties. They can gain immense satisfaction from their successes as a 'teacher' and from the hard-won achievements of the brother or sister. Watching a child struggling to learn something that is easy for themselves can teach nondisabled siblings great respect for their disabled sister or brother and can teach them how to overcome difficulties in their own lives.

Children who are actively involved in caring for the child with a disability tend to be well adjusted despite the added responsibilities (Seligman & Darling 1997). Perhaps positive adjustment in siblings is more likely in those families who work as a united team, whereas poor adjustment may be more likely in families where individual siblings feel that they are carrying responsibility *instead of* the parents rather than as an adjunct to them.

Many siblings turn their special sensitivities developed during childhood into a caring career. This is fine, as long as it is not motivated by guilt (Seligman & Darling 1997). Berry (1988) cautions against developing a 'helpaholic' lifestyle where one is addicted to helping others at excessive cost to oneself.

In terms of the relationship between the siblings, Powell and Gallagher (1993) report that even when siblings feel stress or are frustrated with their disabled brothers or sisters, siblings tend not to take out these feelings on their sibling but, if anything are kind and positive towards them. This restraint may help family functioning and may ensure that the child with the disability feels accepted, but the siblings' feelings will also need an outlet so that their frustration does not become unbearable for them.

The siblings can receive an outlet in their relationships with friends when it is accepted that the child with the disability may be left out of some play. When the child with the disability is mainly included in siblings' activities, all family members seem to accept those other occasions when siblings need some time to themselves (Harry et al. 1998). A child's occasional lack of involvement is not seen as a rejection but simply an acknowledgment that he or she is not able to participate.

Interviews with siblings (aged 9-13 years) of younger children with severe disabilities revealed that the children's responses were predominantly 'positively toned' (Wilson et al. 1989). These children had a high level of day-to-day involvement with their siblings, were aware of their siblings' special needs and felt strong feelings of responsibility towards their siblings. In addition, siblings also acknowledged sadness, anxiety and anger associated with their siblings and more than half of the children indicated that they would like to participate in some sort of support groups for siblings of children with disabilities.

IMPLICATIONS FOR PROFESSIONALS

It is clear from the above discussion that, although siblings tend to be personally well adjusted and the sibling relationship can be close when a child in the family has a disability, nevertheless, siblings experience different challenges and sometimes more intense emotions – and from a younger age

– than usual. Therefore, it can be helpful when those around them are sensitive to these extra challenges.

Siblings of children with disabilities want information about disabilities, opportunities to talk about feelings, time to hear about the experiences of other siblings, opportunities to meet with people with whom they can share their feelings of pride and joy and strategies to plan for the future (Cramer et al. 1997).

Table 1: Emotional reactions of children whose sibling has a disability

	Younger children	Older children
Fears	Of catching the disability Of having caused the disability	About having children themselves About the future
Isolation	From distracted parents	Because of reluctance to ask to Have their needs met
Anger	At parental unresponsiveness	At mother's work load At parents, for not protecting the sibling from the disability At peers who mistreat their sibling At restrictions on their social life At extra responsibilities
Guilt	About being more capable than their older sibling About their negative feelings	At not being able to protect their sibling from teasing
Resentment	Of differing parental expectations Of receiving lukewarm praise for their own accomplishments, compared with sibling	Of curtailment of family activities
Embarrassment	At special equipment That older sibling does not act more maturely	About anticipated reactions of friends At sibling's inappropriate behaviour About attracting attention in public
Confusion	About the disability (especially complex conditions and behaviours) About the cause of the disability	At the complexity of their own feelings About sibling's treatment priorities About parents' differing opinions on how to treat the child About the child's educational needs
Pressure	To care for their sibling To include the sibling in their activities	To achieve highly as compensation To take care of the sibling To repress their emotions

At the same time, we need to remember that all siblings experience ups and downs in their relationships and that maladjustment of a child may have nothing to do with the disability of another child in the family. Professionals must also keep in mind that if we somehow encourage (often unwittingly) the child with the disability to be the main focus of the parents, we will inevitably affect others within the family, including siblings.

Information

Siblings need information about the cause of the disability, its prognosis, and special services their sister or brother will need – both now and in the future. They need to know also whether they themselves are vulnerable to the disability in any way, through genetics or by infection. The information needs to be balanced and honest (Powell & Gallagher 1993). It will need embellishment as the child grows older (Cramer et al. 1997). Seligman and Darling (1997) report that, for instance, children aged between six and nine years want to know what their brother or sister can and cannot do, and they what to know about speech and motor development; while older children (aged 10 to 12 years) tend to want information about the disabled child's future and their own chances of having a child with a disability.

Siblings may not ask questions of their parents in order to protect them from talking about the disability or to protect the family from tension that arises when it is discussed. Therefore, it is important for parents to raise the topic with siblings to explain the child's disability and respond to the siblings' questions and fears.

Siblings will have private explanations of the causes of their brother or sister's disability; therefore, adults need to ask the children what their understanding is (Seligman & Darling 1997). This allows misunderstandings to be replaced by facts, and guilt about being the cause (often arising from young children's magical thinking) to be addressed. Parents can help children to cope with their sibling's disability by giving them some words to use to describe it and explain it to friends (Roe 1988).

Finally, siblings need information about how to deal with uncomfortable feelings about their sister or brother with the disability. It is also important that siblings are told that they do not have to look after other people all the time.

Throughout their lives, siblings will require frequent updates of information. Adults will need to check that the children understand what they have been told, and encourage them to talk and ask questions about the disability at any time.

Opportunities to talk

Although parents can help their children by accepting the children's feelings – even the 'ugly' ones – at times, parents will feel emotionally unavailable as a result of already having so many demands on them. In that case, it can help if they can organise someone else for their children to talk to, such as a family friend or relative.

Siblings benefit from the opportunity to talk about their feelings because doing so reduces the negative emotions and resentment that may obstruct their relationships with their siblings. With an opportunity to express the full

range of emotions, the siblings can achieve four things (Powell & Gallagher 1993):

- They can come to a greater understanding of emotions – such as anxiety – and the causes of their feelings.
- They can be guided to develop skills for coping and adjusting and to handle their feelings constructively. They can develop skills for handling conflicts that arise concerning the sibling's disability.
- They can receive permission to pursue their own growth and to have their own needs met. Younger siblings can have permission not to act as if they were older than the disabled child.
- With acceptance of their ambivalent feelings towards their disabled brother or sister, siblings will be freed up to act on the positive feelings that they experience, with the result that the sibling relationship can grow stronger. If the siblings are denied their 'negative' feelings, they will resent that fact and could come to resent the sibling.

Sibling support groups

Miller (1985, in Powell & Gallagher 1993) reports that siblings need to meet together so that their feelings do not hurt their parents and are not criticised. Siblings do not need to hear the benefits of having a child with a disability in their family – because they already appreciate those benefits – but they need time out to speak about the personal costs with other people who can truly understand.

This is illustrated in a question and answer activity reported by Cramer and colleagues (1997). When one child asked whether it was normal to feel embarrassed and want to run and hide when her sister had a seizure in public, other children whose own brothers or sisters had disabilities were able to reassure her that her feelings were natural and that it was okay to feel as she did.

Education

Many siblings want information about their siblings' disability and want to learn how to teach or respond to the behaviour of their sister or brother. This was demonstrated in a study of sibling interaction where siblings would have benefited from knowledge about how to communicate and modify activities to facilitate their play with their deaf-blind brothers and sisters (Heller et al. 1999).

Siblings may benefit from attending some planning sessions with the professionals who are involved in their sister or brother's care. Like fathers of children with disabilities, siblings often lack this contact with professionals and so lack the opportunity to ask their own questions in this safe context.

It is well established that parents do not necessarily want to act as their child's teacher or therapist; the same is true of siblings. Therefore, while the care and education of family members with disabilities can be a family affair, it is probably useful to proceed with caution if planning to involve siblings formally in the delivery of an aspect of their brother's or sister's remedial program.

Counselling

For most siblings, informal supports from the family will be enough for them to receive the support they need. For a few others, professional counselling might be beneficial. For this reason, Powell and Gallagher (1993) list some questions that professionals can ask siblings:

- How did you become aware of your sibling's disability?
- Has it meant extra responsibilities for you? If so, did you take these on voluntarily, or are you required to help?
- Do you think that family life has changed because of the sibling's disability?
- Do other people react differently to you when they learn you have a sister or brother with a disability?
- Has having a sibling with a disability affected your social life, friendships, future plans?
- Have you been included in plans made for your sibling?

Professionals can also help siblings to contemplate the future and to ask themselves how obliged they should feel to look after their disabled brother or sister (Seligman & Darling 1997). For some children, this will be a central issue so that they can grow up free of anxiety about their responsibility for their sibling and without guilt if they cannot meet the high expectations that are placed on them, either by their family or themselves. They might need encouragement to stay in balance and to let themselves appreciate their own childhood and cater to their own needs.

Family support from community services

A further important way to help siblings is to arrange regular respite care for the child with the disability, so that the family can participate in those activities that otherwise they cannot do. Respite care alleviates some of the parents' workload, allows them to relax, gives them a chance to attend to their own needs, and allows them to focus on the needs of the siblings. In turn, siblings who worry about their parents will be relieved to see that the parents are looking after themselves and, in turn, will be able to relax.

Siblings in the classroom

If you have a student in your class who is the sibling of a child with a disability, you will need to consider whether that child has additional needs as a result. Developmentally, it is common for the sibling to have a similar disability to another family member's but for that to go undetected when it is less severe. For example, the siblings of children with autism often themselves have disordered or impaired language skills; as this seems minor compared to autism, it may not be detected.

Emotionally, the child may be preoccupied at times with the range of emotions and added responsibilities described here. It is important that teachers do not add to these challenges, especially when the siblings attend the same school. For example, siblings might be relied upon to relay

messages to parents concerning the disabled brother or sister, or to attend to the child's needs at playtime. These responsibilities can be exacerbated when the family is of a non-English speaking background, and the nondisabled child in the family takes on the role of translating for teachers and parents at case conferences about his brother or sister. As these can be a frequent event, the burden on the young child can be overwhelming.

IMPLICATIONS FOR PARENTS

Parents aim to consider the needs of all children in the family. This was evident in the study by McKenzie (1996) where parents mentioned their efforts to ensure that the child with the disability did not become the total focus of the family and that the needs of all children were met. Although a focus on the child with the disability is natural at times, particularly during medical crises or transitions between services, many parents try to limit the impact of this on their other children (McKenzie 1996). For example, parents may ensure that they do not discuss the disabled child's difficulties in the hearing of siblings and make an effort to provide nondisabled siblings with extra attention to ensure they do not feel neglected because of any additional attention that their sibling receives. Professionals can assist parents in this task by being aware of sibling needs and allowing siblings' time out of home to be a respite from any additional responsibilities that they experience.

If parents need siblings to contribute to caring for their brother or sister with a disability, the parents still need to retain executive control of their family. They must decide what tasks need doing, and ask the brother or sister to help out, rather than expecting a child to become responsible for deciding what needs to be done.

CONCLUSION

While research tells us much about sibling relationships when one member has a disability, our information is still formative. Therefore, when working with families, we need to approach all family members – including siblings – with a listening ear, rather than having preconceived notions about what they may be experiencing.

Lobato (1990) cautions us against attributing a sibling's difficulties to being raised with a sister or brother who has a disability, as the difficulties may have occurred anyway. While it is easy to blame the obvious – a child's disability – for the difficulties that family members are experiencing, individuals are more complex than this and their emotions have many influences (Hayes 1998).

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