

## Information for parents

### Siblings of children with disabilities

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Being the brother or sister of a child with a disability can be a challenging experience. All siblings experience friendship, love, acceptance, jealousy, rejection, loneliness, anger, sadness, humour and a range of other emotions as a result of their interactions with their brothers and sisters, but when the brother or sister has a disability these experiences can be magnified and experienced very intensely. Just imagine some of the possible experiences a child may encounter with a brother or sister with a disability:

- Embarrassment: "I don't want to be part of this"- particularly in public with friends.
- Anger: "Why me!"-for example in relation to a disabled sibling who is destructive.
- Sadness: A sense of isolation, or loneliness: at the 'loss' of the brother or sister the child 'might have had'.
- Frustration: at not being able to play with the disabled sibling, or at having to miss out on specific events or experiences because of the needs of the disabled sibling.
- Jealousy: at the amount of time and affection the sibling with a disability may have to receive, and thereby take from the other children.
- Guilt: "Why didn't it happen to me?"- or at not being able to do sufficient to help.
- Injustice: "It's not fair!"- at having to miss out, or having to be a 'third parent', or at seeing a sibling receive preferential treatment.
- Over-protectiveness: towards their brother or sister that may interfere with their school and leisure activities, and their relationships with peers and friends.

On the positive side, siblings of children with disabilities often grow up to have a more mature and caring attitude towards people with disabilities than would otherwise be the case. They may develop a more tolerant attitude in general to

people who are 'different', and may develop skills and values that would be unusual in other children their age. Two issues often arise for siblings of children with disabilities:

1. Their experiences of disability often parallel their parents' experiences.
2. Siblings of children with disabilities usually receive less personal support than their parents in coming to terms with a brother or sister with a disability.

#### What to do ...

What to do about Isolation, loneliness and loss:

- Help the child to maintain social contacts with friends from school and sporting teams etc.
- Arrange to have 'special time' put aside for the child, so that he/she can feel special. Respite care is a wonderful way to assist in making this possible.

What to do about over-identification:

- Reassure the child that nothing is going to happen to him or her.
- Ensure that the child is enjoying a rich and varied life, and avoid undue reference to the disabling condition that the sibling may have.
- Provide the child with accurate and age-appropriate information so that when he or she asks questions about their disabled sibling, or the specific disability, you can answer them honestly and accurately.

What to do about resentment:

- This is often similar to feelings of isolation and loss.
- Again, arrange 'special times' for the child so that he or she does not feel left out or neglected. Ensure that specific achievements are acknowledged and praised publicly.



- Explain the reasons for the differential 'treatment' being given to the disabled sibling.
- Negotiate the specific roles and responsibilities that arise from having a child with a disability in the family.

What to do about embarrassment:

- Acknowledge the child's embarrassment, and give them 'space'.
- In other words, let them be embarrassed. But teach appropriate ways and places to be embarrassed.

What to do about guilt:

- Acknowledge the child's feelings of guilt. Talk with the child about his or her feelings.
- Allow opportunities for the child to 'work through' the conflicting feelings that generally accompany guilt.
- Provide accurate and age appropriate information so that the child can understand the situation more clearly.
- Answer the child's questions as accurately and honestly as you can.

### Siblings Groups

Every now and again, but far too infrequently, a disability organisation or group will offer a 'Siblings Workshop', or a 'Siblings Group'. These are semi-formal opportunities for the siblings of children with disabilities to come together and share their experiences. They are chances to explore their reactions to their situation knowing that other children are experiencing similar things. Siblings support groups usually include most of the following elements:

- A period of time for the group to come together and 'bond'. This is usually achieved through specific activities that encourage trust and group cohesion.
- Activities and discussions which allow the children to express their experiences, both positive and negative, about being the sibling of a child with a disability.
- Then there are opportunities for the participants to reflect upon their experiences and develop new insights into their feelings and reactions.
- Hopefully there is personal growth through these experiences, and the opportunity to make new friends who share similar experiences.

Siblings groups and workshops are usually conducted by professionals who work in the field of disability. Some parents also become involved as they realise the benefits that flow from these groups. There are no organisations that are specifically funded or exist only to run siblings groups. These groups are additional roles that professionals and organisations take on when they have the time, funding, and motivation. The importance of siblings groups cannot be underestimated, and it is a pity that so little opportunity exists to provide this outlet for the brothers and sisters of children with disabilities.

### For more Information

If you require further information please contact:

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