



BROTHERS & SISTERS: SIBLING ISSUES

by Dr Avril Brereton

Sibling relationships are important. The emotional ties between siblings are often described as second only to the ties between children and parents (Rivers & Stoneman, 2003). Sibling relationships are often longer than any other relationships within the family, and it is here that brothers and sisters develop self-identity, social skills, companionship and mutual support.

There has been increasing research into the impact upon children of having a sibling with a disability. Whilst some studies suggest that having a sibling with a disability has negative effects on children's adjustment, others suggest positive impacts. Others find no differences at all. It is important to view the research in the light of what we understand about normal sibling relationships which are characterized by shifts in feelings of resentment, jealousy, embarrassment, pride, affection, comradeship.

When the research focuses on siblings of children with autism, the findings are also inconsistent. The core features of autism, including impaired communication, social skills and repetitive and restricted behaviours lead us to expect that the sibling relationship will be affected. There is some evidence that there may be an increased risk of negative outcomes when compared with control groups, including siblings of children with other disabilities. In particular, findings indicate more peer problems, more overall adjustment problems, and lower levels of prosocial behaviour (Hastings, 2003).

The extent to which siblings are affected appears to depend on a number of factors. An increase in disturbance in both typically developing and disabled children is noted when there are poor family relationships, marital discord, depression or other psychiatric illnesses in the parents. On the other hand, warm, harmonious family relationships have a protective effect, even when the impairment of autism is severe (McHale et al 1984).

McHale et al (1986) reported that siblings viewed their relationship with their sibling with autism more positively when:

- They accepted the child's role as a member of the family
- They perceived minimal parental favoritism
- They were not worried about the future of the child with autism
- They were from a larger family
- They were older than their sibling with autism
- When there was a large age difference between siblings

Whilst parents can't minimize the effects of having a sibling with autism by changing birth order or age difference, there are other factors that can be influenced. Positive relationships between siblings are encouraged by:

- Parent well-being
- Family cohesion
- Well developed coping abilities
- Understanding of their sibling's disability - open communication
- Positive attitudes from parents and peers towards their sibling with autism
- Appropriate resources and support for the family
- Cultural & community attitudes - inclusive communities

It is also important to be aware of possible risks to siblings in relation to language and developmental problems. It is possible to overlook these issues because of the overriding concern for the child with autism, but some research indicates an increased risk of learning difficulties for their siblings, particularly language impairment. Genetic factors probably account for this increased rate of developmental problems in the siblings of children with autism (August et al, 1983).

Finally, it is important to keep this in perspective. All sibling relationships include jealousy, bickering, squabbling, and sometimes battles. They all involve conflicting feelings of resentment and affection, embarrassment and pride, jealousy and companionship. Having a child with autism in the family is unlikely to be the sole cause of negative outcomes, although it may exacerbate problems at times. Many brothers and sisters talk about the benefits of having a sibling with a disability. They talk about being more tolerant, more compassionate and that they have found inspiration through their sibling. Kaminsky and Dewey (2001) highlighted some of the positive influences of having a sibling with autism including:

- Greater admiration by their siblings
- Less competitiveness
- Less quarrelling

Talking to your other children about autism

Research tells us that it is better for siblings to understand what is wrong with their brother or sister who has autism. Name the condition, describe how it affects their brother or sister and keep explanations simple and appropriate to the sibling's developmental level.

Pre- and primary schoolers:

Preschool aged children are egocentric (I'm important, the world revolves around ME!), and they may be worried that they will "catch" autism too or have thoughts that they have caused their brother or sister to have autism in some way. Feelings of fear, anger and jealousy are common in young children and these feelings may be focussed on their sibling with autism. For example, children may be concerned about unusual behaviors that may frighten or puzzle them. Young children can very quickly become frightened of an older sibling with autism who has aggressive or unpredictable behaviour. These behaviours might be explained as being part of the way that a child with autism communicates his/her feelings and needs because he/she can't talk, but young children also need a strong message from parents that they will be protected from aggression and harm. Feelings of anger may arise when the younger child blames a brother or sister with autism for limiting family outing opportunities, toys and play things have been broken or taken, or social experiences with friends disrupted. Children need to have their problems and grievances listened to and know that their feelings are important to parents.

Pre- and primary schoolers may also have strong feelings of jealousy and may perceive that they get little attention from parents or that the sibling with autism gets more than they do. Attention should be divided as evenly as possible and younger children need to know that they have their own special time with parents. However, for this age group, explanations need to be kept simple. The key to successful communication about autism with young children is to remember to adjust what you say to the child's age and level of understanding.

Teenagers:

Older siblings usually have different worries. (What will my friends think of him/her? How can I invite my friends home from school if my brother can't talk to them?). Some siblings get upset when other people are unkind or judgmental about their brother or sister with autism and they are left feeling angry or have a sense of unfairness about the whole situation. For the adolescent sibling, concerns about their brother or sister with autism may shift from the immediate daily concerns to worries about the future and what long term care may be involved (Will I be looking after him/her when Mum and Dad are gone? Where will he live?). Some older adolescents and young adults also start to have thoughts about whether or not their own children might have autism. They begin to ask questions about the inheritance of autism. If you do not know how to answer these questions it can be a good idea to consult a Genetic counselor who will be able to give accurate information to the whole family and also provide an opportunity for you to discuss these issues as a family. At this stage, being able to listen to your other children's concerns is important even if you do not have all the answers they are seeking.

We recommend the book "Siblings of Children with Autism: A Guide for Families" by Sandra Harris (1994). This book looks at sibling issues in a number of ways. First, Harris (1994) discussed relationships between typically developing siblings and their relationships across a lifetime. Next, the need to explain autism to siblings and how this might be managed according to their age and level of understanding is introduced. Suggestions are given for helping children discuss their feelings and thoughts by talking together as a family, emphasizing that effective parenting involves the ability of family members to communicate well. Communication skills such as being able to listen, give children the message that you have understood what they are saying to you and acknowledge what they are saying (techniques called feedback and affirmation) (Harris, 1994, p. 65), and how to be open about your own feelings and also acknowledge your children's feelings are discussed.

Harris (1994) also suggested some buffers to help families and carers adapt to the special needs of the child with autism. These include:

- parent training to teach families the kinds of management procedures that will enable them to understand and control their child's disruptive behaviours and increase parental abilities to help their child master new adaptive, play communication and social skills.
- a support group that enables members to share their feelings, emotional responses, and enlarge their social networks to include other families who can help when things are tough is very helpful. Support groups can also be a focus for ongoing educational programmes and social activities for the family. A support group that helps parents to learn how to utilize community resources and advocate on behalf of themselves is also important.
- Sibling support groups can be helpful in exploring the issues confronted by brothers and sisters of the child with autism. Not all sibling responses are negative. For example, teaching siblings the skills to enable them to play with their brother or sister can be beneficial for the whole family. Some siblings report that caring for a brother or sister with autism has helped increase their self esteem, sense of empathy and interpersonal skills. Siblings should not be expected to take over parenting roles or responsibilities but the sibling support group can provide the opportunity for older siblings to learn some basic management skills. Issues such as understanding what autism is and why the child with autism behaves as he/she does, feelings of jealousy because of the attention that the child with autism receives, anger about rejection by their peers and worry about the "inheritance" of autism can be discussed in a sibling support group.

References

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McHale, S.M., Sloan, J., & Simeonsson, R.J. (1986). Sibling relationships of children with autistic, mentally retarded, and non-handicapped brothers and sisters. *Journal of Autism & Developmental Disorders*, *16*, 399-413

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support and support coping. *Journal of Autism and Developmental Disorders*, *33*, 383-394.

Useful Websites:

As with every other topic you surf the net to find information about, search engines for sibling issues will bring up sites that contain not only unhelpful information, but also inaccurate and misleading information. Some sites have links to miracle cures, herbal remedies etc. that are quite bewildering and would not be helpful if you have older children who are looking for information to help them understand their siblings with autism.

The sites below are noteworthy for their accurate, informative and helpful information. Most also have links to other quality sites.

<http://www.autism-society.org/site/PageServer?pagename=livingsiblings> (Autism Society of America)

<http://www.autism.org/sibling/sibneeds.html> (Centre for the study of Autism. Bethesda Hospital USA)

<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=124&a=2624> (National Autistic Society, UK)

http://www.bbbautism.com/siblings_contents.htm (BBB Autism Support Network)

http://www.siblingsaustralia.org.au/young_frameset.html (Siblings Australia Inc., not autism specific)

Further Reading:

Association for Children with a Disability (2003). *Supporting Siblings*. ACD, Armadale, Victoria

Celiberti, D. R., & Harris, S. L. (1993). Behavioural intervention for siblings of children with autism: A focus on skills to enhance play. *Behaviour Therapy*, 24 (4), 573-599.

Klein, S. D., & Schleifer, M. J. (Eds.). (1993). *It isn't fair! Siblings of children with disabilities*. Wesport: Bergian & Garvey Press.

Meyer, D., & Vadasy, P. (1996). *Living with a brother or sister with special needs: A book for sibs (2nd ed.)*. Seattle: University of Washington Press.

Siegal, B., & Silverstein, S. C. (1994). *What about me? Growing up with a developmentally disabled sibling*. New York: Plenum Publishing Corporation.

Stoneman, L., & Berman, P. (1993). *The effects of mental retardation, disability and illness on sibling relationships*. Baltimore: Paul H. Brookes Publishing Company.

Amenta, S. (1992). *Russell is extra special: A book about autism for children*. New York: Magination Press.

Band, E. B., & Hecht, E. (2001). *Autism through a sister's eyes: A young girls view of her brother's autism*. Arlington: Future Horizons, Inc.

Bleach, F. (2001). *Everybody is different: A book for young people who have brothers or sisters with autism*. Shawnee Mission: Autism Asperger Publishing Company.

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