

5. Siblings

A number of issues have been identified in relation to the brothers and sisters of children who have a physical disability. Information for this section comes from two main sources, the siblings Australia website¹ and the book "*Brothers and Sisters: a Special Part of Exceptional Families*"².

1. Interpersonal, family and sibling dynamics

Siblings Australia have identified a number of these issues from authors, parents and siblings, for all children with a sibling with special needs, they are summarised below, from their website.³

Feelings of isolation from those around them and unable to interact in a normal way with the brother or sister with a disability.

Lack of information may lead them to believe they are the cause of the disability and may be unsure how to explain it to others.

Difficulties in relation to the brother or sister with a disability, including potential disappointment, guilt, fear, and perhaps sorrow at what the brother or sister has to go through.

Attention. Believing that their feelings do not matter and that only those of the brother or sister with a disability do.

Relationship issues between the primary caregiver and the child with a disability resulting in the other child lacking confidence.

Pressure to be perfect. Siblings may feel they have to be perfect to gain attention or avoid giving their parent's any more distress.

Anger and resentment following on from the disruption to family routines and the disproportionate amount of time and energy directed to the child with a disability.

Other difficult feelings. There could be embarrassment about the behaviour or appearance of the sibling with a disability, the need to perform tasks not required of their peers who don't have a sibling with a disability. Also perhaps "survivor guilt" because they don't have to deal with the everyday struggles their sibling has to. Sometimes shame about how they feel towards the sibling.

Grief. For a variety of reasons, including loss and longing for a "normal" sibling.

Care giving and responsibility. Inappropriate caring responsibilities may be expected of siblings. They may feel they have no option, or are attempting to ease their own guilt, or want to take some of the load off the parents. Also, there

¹ http://www.siblingsaustralia.org.au/parents_frameset.html

² Powell, T., & Gallagher, P., (1993) *Brothers and Sisters: A special part of exceptional families*. (2nd ed.). Baltimore: Paul H. Brookes Publishing Co.

³ http://www.siblingsaustralia.org.au/parents_frameset.html

may not be the time or resources to do other activities for themselves because of the caring responsibilities for the child with a disability. There may also be considerable conflict between their feelings for the sibling and resentment on missing out on activities for themselves.

Independence. Independence issues of adolescence may be complicated by the family dynamics resulting from having a child with a disability in the family.

The Future. Siblings may be concerned about their own future, and that of their brother or sister with a disability, e.g. what will become of the child with a disability in the longer term?

2. Less parental time and energy for the children without a disability, and jealousy related to this, may become an issue for siblings;

In *“Special Children, Challenged parents”* Robert Naseef also refers to siblings wanting a “fair share” of attention without the pressure of being “the star” in the family. He also writes about how one woman said *“I would want to be treated as an individual and I would absolutely hate it if my parents always reminded me how lucky I was.”* (p 183.)

Some recent West Australian research⁴ about young sibling carers, notes how:

A strong message from the parents and young carers is **that they want to spend time together** [emphasis in original]. The parents talked about a need to re-connect with their children without the disabled child present. The young carers want respite not for themselves but for their brother or sister so that they could have time with their parent(s) or even a family holiday. (p. 67.)

At the 2002 Annual conference of the U.S. *Parent Project Muscular Dystrophy*, Suzanne Burger⁵ suggested to support siblings by:

- Making 1:1 time for the other children
- Acknowledging their feelings
 - Sadness,
 - Fear,
 - Anger,
 - Jealousy,
 - Guilt,
 - Embarrassment
- Answering questions.

⁴ Morrow, R., (2005) [A profile of young known carers and identification and snapshot of the ones who are hidden](http://www.carerswa.asn.au/news.asp?article=96). Carers WA/Curtin University. [Retrieved from <http://www.carerswa.asn.au/news.asp?article=96> 1st June 2006]

⁵ Burger, S., (2002, June). [DMD From Tattered Dreams to Patchwork Quilts: How Families can Love and Grow with Illness](#). Presentation at the Parent Project Muscular Dystrophy, Annual Conference, Pittsburgh: PA

3. Division of responsibility for physical care needs may also be an issue;

Research⁶ has shown that siblings of children with disabilities, who have major childcare responsibilities, may have more behaviour problems, e.g. anxiety, and less positive interactions with their siblings, and greater conflict with their siblings.

Therefore, it is advisable to, (as far as possible) avoid giving children the responsibility of childcare for their brother or sister with a disability.

The same West Australian research referred to above, notes that based on the reports of child carer's versus that of their parents, the parents underestimate the impact of caring on the child carer. Another major observation of this research is the consistent feedback about the:

...lack [of] participation in after school activities. [For the young sibling carers.] A number of reasons were given including financial, time restraints and having to be home to fulfil responsibilities related to the role of caring." (p.66.)

Robert Naseef also refers to how children sometimes feel they need to help their exhausted parents, at the expense of the child's own time with friends.

4. Limited financial resources for recreation and leisure may be a source of conflict;

The same research about siblings of children with disabilities has shown that where there are stresses because of limited financial resources, in a family with a child with a disability, the use of appropriate social supports can buffer some of these negative effects. These supports could include involvement with support groups for children who have a sibling with a disability.

5. Telling friends and teachers can be problematic for siblings;

Suggestions for dealing with the responses of others to having a brother or sister with a disability, is provided in Appendix B: Dealing with Possible Stigma and Embarrassment.

6. Younger siblings may surpass their brother or sister with a disability which may change family dynamics;

At some point the sibling(s) without a disability may surpass the child with a disability, in terms of their physical development. Robert Naseef also notes how;

...the younger "normal" child loses both a role model, and moreover, the attention that she would have naturally gotten as the baby of the family. When parents are sensitive to this they can help their children understand. (p. 186)

⁶ Stoneman, Z., (2005) Siblings of Children with disabilities: Research Themes. Mental Retardation, 42 (2), 339-350.

Resources:

Baker, Bruce, L., & Brightman, Alan J., with Blacher, Jan, B., , Louis J. Heifetz, Louis J., Hinshaw, Stephen, R., & Murphy, Diane, M., (2004) Steps to Independence:

Carers WA

255 Walcott Street
North Perth
WA 6006

Website: <http://www.carerswa.asn.au/>

Phone: (08) 9444 5922 Fax: (08) 9444 8966
24hr Carer Counselling Line: 1800 007 332

Matthews, A., (2001) Being a Happy Teenager, Trinity Beach, Queensland: Seashell Publishers

Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company ISBN: 1-55766-535-4

Powell, T., & Gallagher, P. A., (1993) Brothers and Sisters: A Special Part of Exceptional Families (2nd Ed.) Baltimore: Paul H. Brookes Publishing Company.

Sandler, Adrian, M.D. (2004) Living with Spina Bifida: A Guide for Families and Professionals. (Updated Edition. With a New Preface by the Author.) NC: University of North Carolina Press [ISBN 0-8078-5547-2]

Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook:

Siblings Australia www.siblingsaustralia.org.au

Thompson, Charlotte, (2000) Raising a handicapped child: a helpful guide for parents of the physically disabled [Revised and expanded edition] New York: NY, Oxford University Press ISBN 0-19-513253-x

