

Connecting Siblings

The Siblings Australia Adult Sibling Project – addressing the needs of adult siblings of people living with disability

Background Paper

Many families that include a member living with disability are able to identify many positive outcomes from the experience, for example, closer family relationships, greater compassion and understanding of difference. However, some families struggle, and parents often have concerns about meeting the needs of the child with disability and those of other family members; the lack of integration of the child with disabilities into everyday family life and the wider community; and the effect of the child with disabilities on their siblings now and into the future.

Most people living with disability have brothers and sisters. Understandably, significant resources are spent on addressing the needs of children and adults with disability. However, research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. The special report, *The Wellbeing of Australians: Carer Health and Wellbeing*¹ (largest ever survey into the health and wellbeing of Australian carers) found that the presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibility or not.

It is also recognised that siblings of children with disability often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand the mix of feelings they experience. On the one hand, a child may feel loving and protective toward their brother or sister. At the same time, they may feel resentment, embarrassment, guilt, sorrow and fear. Without the cognitive skills and emotional maturity to understand and deal with those feelings, a child's self esteem can suffer. If children do not access support, anger and guilt can turn inward and lead to shame and a sense of worthlessness² or longer-term physical, emotional and psychological problems.

Why we should support siblings of all ages

Those siblings who have access to support early are less likely to have mental health problems, and more likely to reach their full potential.

¹ *The Wellbeing of Australians: Carer Health and Wellbeing* <http://www.carers-sa.asn.au/healthandwellbeing.html>

² Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), *Burdened Children: Theory, Research and Treatment of Parentification*. Thousand Oaks, California: Sage Publications

Supported siblings are also more likely to contribute to the well being of the person with disabilities. After all, siblings will likely be in the life of the person with disabilities longer than anyone. Why would we not support them? Support is about strengthening relationships across the lifespan. Sibling support enables the whole family to be stronger and more able to support each other.

However, the needs of siblings are still largely overlooked.

Siblings Australia

Siblings Australia is the only organisation in this country that is committed to addressing the unique concerns of brothers and sisters of people with disabilities; including chronic illness, disability and mental health issues.

The focus of Siblings Australia is on strengthening families and it aims to increase the availability of information and support services for siblings of people with disability, through increasing awareness, understanding, skills and capabilities in three ways:

- Direct support to siblings
- Working with parents to enable them to support their children
- Working with service providers to enable them to better support families, in particular, siblings

Siblings Australia has been operating since 1999 and has developed a national and international reputation. Siblings Australia provides workshops, resources (web and print based) and networking opportunities for families and providers across Australia and overseas. The organisation also plays an important role in areas of research and advocacy to inform social policy makers about the needs of siblings.

Siblings Australia and adult siblings

In the past the focus for Siblings Australia has been on prevention; supporting younger siblings and their families. The activities related to adult siblings have been restricted due to a lack of funding, but the organisation has still kept this work on the agenda, including: collection of adult sibling surveys; adult sibling focus sessions; adult sibling panels at conferences, symposiums; internet discussion groups; contact with adult sibling programs in the US, UK, and Italy; adult sibling session at the *Creating Connections* conference in Adelaide 2004; and collection of resources (books, research articles etc) on adult sibling issues. The Director of Siblings Australia has also written a book on sibling issues that has been published in both the UK and US.³

Adult sibling project

In 2008, with the support of the Julia Farr MS McLeod Foundation, Siblings Australia is undertaking a project that will research issues related to adult siblings of people with disabilities. It aims to: explore the needs of siblings; improve awareness of what services are available now; and explore what services and resources are needed for siblings, both for their own benefit and for the benefit of their brother or sister with special needs.

As part of the Julia Farr MS McLeod Foundation funding, Siblings Australia has been able to upgrade the website. This will make it much easier to provide resources to a wide population of siblings,

³ Strohm, K. E., (2002) *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press: Adelaide

parents, providers and researchers. The organisation deals with a high volume of enquiries on sibling issues, both through direct contact by parents and providers with the organisation and through our website (approx. 1000 hits/month).

Adult Sibling Concerns

As mentioned above, young siblings can have a mix of feelings. They might feel love and pride but also resentment, embarrassment, guilt, sorrow and fear.

Many siblings find it very difficult to talk about any of the more difficult feelings. Often they have grown up with no opportunity to express these feelings. They might feel guilty or be given the message that negative feelings are not ok. Over time the issues might become more and more difficult to manage and some siblings move right away from their families. As a result, not only do the siblings miss out on a relationship with their brother or sister but, perhaps more importantly, the brothers and sisters living with disability miss out on a relationship with the sibling. If we give more support to a child sibling it is more likely that the relationship between siblings will be stronger and that the sibling can contribute to the social network of a brother or sister with disability.

What would have helped – reflecting back

Siblings have identified the following as things that would have helped them in their role as a sibling

- Contact with other siblings – to know they were not alone and that others felt the same
- Something to read from a sibling perspective – most books are from the parent perspective
- Parents having greater understanding of children needing to express all feelings
- Support on how to ‘play’ or interact with their brother or sister
- Not so much responsibility/caregiving
- Support to deal with future concerns both for themselves and their brother or sister

Adult sibling needs – the present

It is clear that the needs of siblings can vary enormously, but many siblings need both emotional and practical support.

1. *Emotional support.* Unlike parents, many adult siblings have not had the opportunity to meet with other siblings and share experiences. If there are longer term mental health issues such as depression or anxiety, they need support to work through and understand the legacy and develop strength and self acceptance. Many siblings have taken mainly positive experiences from their childhoods and, certainly, many siblings remain lovingly involved with their brother or sister with disability. However, they can still benefit from greater understanding of the different reactions they have brought from childhood, and the opportunity to share their stories. Even if siblings are happy to be in the lives of their brother or sister they can still struggle with their sibling role and how to incorporate it into other aspects of their lives. Adult siblings from around the world have expressed the same issues, via internet forums and books, and talked about the value of having contact with other siblings. As one Italian brother (31) of a man (33) with Down Syndrome said, “I joined our group (a support group based in Rome) and since then I’ve learnt that the best way to feel better as a sibling is to share one’s experience with people who live the same situation.” Some siblings have sought counselling – for some it has been a very useful exercise. For others it has been frustrating to find the lack of understanding of sibling issues amongst the counselling profession.

2. *Practical support.* Adult siblings might also need practical support in their role as a carer (primary or secondary) for the person with disabilities. Some feel comfortable taking over more responsibility as their parents age. Others are given the responsibility, with little choice, when parents die, often without any resources to cope with the decisions and actions that need to occur. Siblings might need support to deal with a mix of issues including accommodation, financial planning, and medical care for their brother or sister. If siblings are not in daily contact with the family, they may not be aware of their brother or sister's support needs, or understand community services. Of course it is much better if planning for the future can start much earlier, with all members of the family involved in the discussions, but it is a difficult subject and one that many parents and siblings avoid.

Current services

There are very few opportunities for adult siblings to come together and share experiences and support, both for emotional and practical issues. There are many consultations that occur with very little, if any, involvement of siblings in the discussions, even though the lives of siblings are impacted significantly. For example, in regard to the issue of ageing carers, little has been done to engage siblings in these discussions. Little, if anything, has been done to support parents and siblings to come together and plan for the future. This is a very emotional area and families need help to broach these subjects.

Services through Siblings Australia

Sibling to sibling contact- adults

Siblings Australia has provided opportunities for adult siblings to connect in person. However there are some difficulties with this. First, people are busy and finding the time to go out to a venue to meet can be a barrier. Also siblings often want very different things – some need emotional support, others need more practical advice on issues related to their brother or sister with disabilities. Others want to know how to advocate on behalf of a brother or sister, or on behalf of all people with disabilities. One group of siblings has been meeting informally for a couple of years at an Adelaide cafe. Whilst numbers are low the siblings who attend gain enormous benefit from such activities. We have also provided connections via the internet, first an email discussion group and, more recently, a website hosted forum. The initial group went for several years and provided a valuable opportunity for siblings to share experiences and gain strength from each other. In fact, through the strength gained from other siblings, one sibling was able to re-connect with her brother with disability for the first time in many years. Many siblings, both those involved and those more distant from family, described a lifetime of grief, guilt and isolation. For many it was an epiphany to find that other siblings had similar experiences and feelings. As one sibling said, "*Being involved in this internet group has helped me more than I can verbalise.*"

The experience of siblings in similar overseas groups confirms what we have found here in Australia. And the few 'face to face' groups that have been run also confirm these findings, that is, that siblings gain enormous benefit from connecting with other siblings.

Counselling

Siblings Australia has also provided some informal counselling for adult siblings, but this has been very restricted due to funding constraints.

Provider workshops

Siblings Australia has run workshops for providers around Australia to improve awareness of sibling concerns, focussing on childhood but emphasising that these are lifelong concerns. There needs to be further workplace development regarding adult sibling issues.

Parent workshops

Siblings Australia has run workshops on supporting siblings for parents around Australia. Parents are crying out for this type of information. As one mother said, "I have been searching for something like this for over 10 years."

What services are needed?

Some areas of need include (in no particular order)

- Emotional support eg counselling, peer support groups, internet groups
- Practical support eg written and web-based resources, ongoing forums re different issues
- Exploring their own future eg issues around career, finding a partner, having children
- Future planning concerning their brother or sister eg finances, accommodation, guardianship, employment, social connections
- Support of parents and siblings to facilitate future planning together

Connecting Siblings

The Connecting Siblings Project, funded by the Julia Farr MS McLeod Foundation, will explore the needs of adult siblings and develop written and web-based resources. During October/November it will host a number of focus sessions with adult siblings through the metro area of Adelaide and in Murray Bridge. We welcome input from siblings, parents, people living with disability and service providers.

If you would like more information about the project, look at our website:

www.siblingsaustralia.org.au or contact the following project staff:

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