



***Supporting Adult Siblings
of People with Special Needs***

Progress Report

15th April 2008

Project – Connecting Siblings

The Project, Connecting Siblings, aims to strengthen the relationships between people with special needs and their brothers or sisters (siblings). The sibling relationship is the longest of any. It usually lasts long after parents are able to care for a person with disabilities. Siblings can play a key role in the emotional and social health of the person with special needs. However sometimes these relationships can be strained or severed due to childhood difficulties.

This Project, through a process of community consultation, will develop resources and programs that can be used by siblings, families and organisations to better meet the needs of siblings and their brothers and sisters with special needs. The Project will also provide recommendations for the future which will be able to be incorporated, where appropriate, into strategic plans.

Background

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 disabilities.

There are over 200,000 young people under 25 years in Australia with a severe or profound disability or chronic illness. There are many more with mental illness and there are many more who are older. Most of these people will have at least one brother or sister. Understandably, significant resources are spent on addressing the needs of children with a disability or chronic illness. 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 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. Anger and guilt can turn inward and lead to shame and a sense of worthlessness². Research also substantiates that siblings are at risk of developing physical health problems³. These problems are exacerbated by limited access and availability of appropriate services and the practicalities of family life where the needs of a brother or sister take greater priority. Without support, these siblings are at risk of developing longer-term physical, emotional and psychological problems, which can carry over into adulthood.

Whilst many families are able to identify many positive outcomes from the experience, for example, closer family relationships, greater compassion and understanding of difference, many other families struggle, resulting in family breakdown and low family wellbeing. Several studies have shown that parents 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.

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

³ Hogan, D., Park, J., & Goldscheider, F. (2003). Using Survey Data to Study Disability: Results From the National Health Interview Survey on Disability. *Research in Social Science and Disability*, 3, 185-205.

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.

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, 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). This highlights the importance of providing more services and resources to siblings, parents and providers around Australia.

Siblings Australia and adult siblings

In the past the focus for Siblings Australia has been on prevention, supporting young 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 as a priority. Over the last 9 years adult sibling activities have included:

- Collection of adult sibling surveys 1999
- Two adult sibling focus sessions 2002, 2004
- Hosting adult sibling panels at conferences, symposiums
- Internet discussion groups – 2000 until present
- Contact with adult sibling programs in the US, UK, and Italy
- Adult sibling session at the *Creating Connections* conference in Adelaide 2004
- Collection of resources (books, research articles etc) on adult sibling issues

Now that Siblings Australia has funding for a specific adult sibling project it can focus more on this aspect of its work.

1. Evaluation Plan

AIM: To improve connections between adult siblings of people with special needs, and between siblings and their brothers and sisters with special needs.				
OBJECTIVES	STRATEGIES	INDICATORS	OUTCOMES	EVALUATION METHODS
1 To increase awareness of needs of adult siblings	Conduct focus session with stakeholders	Focus session held with 40 attendees	Stakeholders collaborate on future of project	Attendance records Interest re ref group
	Establish a working group of stakeholders – adult siblings, disability orgs, carers groups	4 meetings held over 12 months	Greater collaboration between adult siblings and service providers	Minutes of meetings Attendance records
	Update reference library of articles re adult siblings	Approximately 30 Articles, 10 books on the website	Research on sibling issues available via website	'Hits' on website recording of references
	Conduct needs analysis of sibling adults	Surveys distributed to siblings	Increased understanding of needs of siblings	Records of surveys and follow up results
2 To improve networking opportunities for adult sibling mutual support	Develop support networks for adult sibs (inc meetings, newsletters, internet forums)	4 meetings held in central metro area, 4 regional areas, 50 members SibChat	Siblings feel less isolated Community capacity, services improved.	Record listserv members, follow-up survey of siblings
3 To increase availability of resources and information for siblings	Identify services for adult siblings in South Australia	Directory of sibling services around South Australia produced	Increased awareness of what is available for siblings and gaps	Follow-up survey of siblings
	Develop written resources for hard copy and for website	Draft resources produced	Greater access by sibs to resources and information, sib support, community resources improved	Follow up surveys of sibs and organisations Record 'hits' on website
4 To improve connections between siblings and their bro/sisters with special needs	Explore barriers to sibling connections	Document produced with summary of barriers to sibling connections	Increased understanding of the barriers to sibling connections	Surveys of siblings Document content
	Explore ways in which sibling connections can be improved	Document produced with recommendations for future action	Improved understanding of how connections can be improved	Surveys of siblings

3. Outcomes

OBJECTIVES	STRATEGIES	TIMELINE	UPDATE
1 To increase awareness of needs of adult siblings	<ul style="list-style-type: none"> • Employ project officer • Conduct focus session with stakeholders 	<p><i>End Jan 2008</i></p> <p><i>Beginning May 2008</i></p>	<ul style="list-style-type: none"> • Recruitment of Project Officer – once appointed, the PO took other employment • Employed Tammy Bruecher as part time Project Officer • Preliminary reading and review has been done of local and overseas issues. • Information regarding services and adult siblings needs has been gathered (deleted names) up to and including April 2008 • A distribution list was developed which consisted of approx 40 CEO's and 115 parents, sibs and service providers. • 3 surveys were developed and distributed widely, one each for; parents, service providers and sibling. • Forum flyer and project registration of interest forms were developed and distributed, these were also available on the Siblings Australia website, a mail out was also done • A forum has been booked for the 1st May, service provides, parents, people with disabilities and Sibs have been invited. • Conversing with various service providers, sibs and parents.
	<ul style="list-style-type: none"> • Establish a working group of stakeholders – adult siblings, disability orgs, carers groups 	<p><i>May 2008</i></p>	<ul style="list-style-type: none"> • Forum to be held at DIRC on the 1st May 2008. • Interest is slowly growing; however the majority of returned registrations of interest were from Siblings themselves – none from local providers or people with disabilities.

	<ul style="list-style-type: none"> Greater collaboration between adult siblings and service providers 	<i>June 2008</i>	<ul style="list-style-type: none"> Liaised with Northern Carers network re services currently available, and the establishment of future services for those young siblings entering adulthood, however there is no funding currently available for a future group. Liaised with Sandy Puddy from DIRC Liaised with Autism SA re the establishing of a Sib support group, again no funding is available. Unfortunately we are finding it difficult to collaborate with service providers as they are currently showing little interest in the needs of Adult Siblings
	<ul style="list-style-type: none"> Update reference library of articles re adult siblings 	<i>Aug-Feb 2008</i>	<ul style="list-style-type: none"> Large body of material collected – mainly from overseas, including media articles, journal articles, books etc
	<ul style="list-style-type: none"> Conduct needs analysis of sibling adults 	<i>Jan-May 2008</i>	<ul style="list-style-type: none"> Survey was mailed out and available on the Sibling Australia website Survey information is being correlated. This has established the common needs and key issues amongst Adult Siblings which will be discussed at the forum to establish possible future directions. Increased understanding of the needs and common issues of siblings has been established through the survey results
2 To improve networking opportunities for adult sibling mutual support	<ul style="list-style-type: none"> Develop support networks for adult siblings (including, meetings, internet forums, newsletters) 	<i>June-Aug 2008</i>	

3 To increase the availability of resources and information for siblings	<ul style="list-style-type: none"> Identify services for adult siblings in South Australia 	<i>April-May 2008</i>	<ul style="list-style-type: none"> Established the need for one body to advocate and support the needs of Sibs due to lack of response and collaboration of Service Providers towards the survey, forum and future of Adult Sibs.
	<ul style="list-style-type: none"> Develop written resources for hard copy and for website 	<i>June-Aug 2008</i>	N/A
4 To improve connections between siblings and their brothers and sister with special needs	<ul style="list-style-type: none"> Explore barriers to sibling connections 	<i>Sept-Nov 2008</i>	<ul style="list-style-type: none"> The survey shows the barriers and connections of what has continued to either keep the sibs disconnected or connected into adulthood <ul style="list-style-type: none"> Issues such as having to stay close as they will HAVE to become the future carer. Staying away because the issue is too hard to deal with.
	<ul style="list-style-type: none"> Explore ways in which sibling connections can be improved 	<i>Jul-Sept 2008</i>	<ul style="list-style-type: none"> We have established how sibs currently choose to have contact with their brother or sister with a disability, how often this contact occurs and what activities within the community they prefer to share
	<ul style="list-style-type: none"> Explore existing community connections plans eg Support Circles, PLAN 	<i>Sept-Nov 2008</i>	<ul style="list-style-type: none"> Research/collection of such plans – will come back to this phase later (first phase proving more difficult than envisaged)

Kate Strohm
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