

Background

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. Most of these young 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 special needs 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.

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 special needs; 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 special needs, 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's revamped website is a crucial component of the organisation's strategy.

Siblings Australia has a growing membership (individual and organisational) as well as a networking database with several hundred contacts. 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 both parents and providers around Australia.

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.

2007 Projects

In alignment with the National Action Plan on Mental Health for 2006-2011 and with the support of the Department of Health and Ageing (DOHA), over the past 12 months Siblings Australia has built strong relationships with a number of key mental health, youth and client support organisations. With a strong emphasis on promotion, prevention and early intervention, the organisation has worked to build resilience and coping skills of children, young people and families, and raise community awareness about sibling issues.

The DOHA funded projects have allowed Siblings Australia to:

- Take the first steps to being a national networking point on sibling issues relating to government and organisational policies
- Build a strong relationship with a number of other DOHA funded partners, including Children of Parents with a Mental Illness (COPMI), MindMatters, Kids Matter, KidsHelpline and Beyond Blue
- Contribute, along with COPMI, to an updated version of the Mind Matters resource materials for secondary schools and begin to develop Kids Matter resources for primary schools
- Establish a national reference group for Siblings Australia, comprising siblings, parents and providers
- Reprint the SibworkS Facilitator Manual and Participant Booklets
- Complete a SibworkS program for siblings aged 8-12 years in 2007 in order to develop appropriate measures for evaluation and collect some qualitative data on the program's effectiveness. Results indicated that all siblings enjoyed the group; most parents saw improvements in the siblings' behaviour towards their brother or sister with special needs; and most participants showed improvements in emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour (the Strengths and Difficulties Questionnaire).
- Identify areas in which programs still need to be developed as well as outline research topics that need to be considered
- Conduct a survey of organisations around Australia regarding resource and training needs. This highlighted the need for further resources and networking for workers
- Start to research the best way to present these resources and options for sharing
- In addition to the above survey, another conducted by KidsHelpline of counsellors indicated the value in having a web-based directory of sibling services around Australia for families and providers to access. This finding has been reinforced by families and providers that attend Siblings Australia workshops.
- Explore the support for a conference focussing on sibling support programs. In 2004 SA ran a very successful conference, *Creating Connections*, for families, providers and researchers in Adelaide. The conference attracted 140 attendees, including 10 from overseas. There was tremendous support for the organisation to repeat the conference but, without resources, this was impossible. Surveys and discussions with providers throughout Australia continues to show strong support for a conference to bring together providers who are running or are interested in running sibling programs.

Currently, Siblings Australia is undertaking a project (with funding through the Julia Farr MS McLeod Foundation) that will research issues related to adult siblings and develop resources and services. As part of the funding the organisation was able to upgrade the website. This will make it much easier for Siblings Australia to provide resources to a wide population of siblings, parents, providers and researchers. It will also make it easier to provide mutual links to other relevant organisations such as Life Line, Beyond Blue and Children of a Parent with a Mental Illness (COPMI).

2008 Project Description

Siblings Australia seeks financial assistance to expand the current projects as well as to develop more resources to increase awareness of sibling issues and ways to support its services for siblings of children with special needs, for service providers, parents and siblings. Projects will consist of:

1. Partnerships

This would be done by:

- Expanding and building on the already established relationships with Mind Matters, Kids Matter, Kids Helpline, COPMI, BeyondBlue and other DOHA funded organisations
- Developing further resources and training opportunities through these organisations

Through creating such partnerships both organisations become stronger in their capacity to support their specific target groups.

2. Sibling Leadership Conference 2008

Aim to hold a conference in late 2008 for providers who are running or would like to run sibling programs. We also hope to have a strong research component to the conference. The Director of Siblings Australia has convened a group who have received an 'encouragement grant' through ARACY (the Australian Research Alliance for Children and Youth) for a new collaboration of researchers and providers who are interested in sibling issues. The project will include a forum for researchers and providers to discuss a range of issues related to creating a research agenda and creating some shared outcome measures/evaluation processes for sibling programs. This forum will provide some input into a Siblings Australia conference later in the year.

3. Sibling Support Programs

Access to relevant information and support programs enable siblings to:

- Understand issues pertaining to their sibling's disability or illness
- Understand that they are not alone with their particular concerns and feelings
- Accept that it is normal to experience a full range of possibly contradictory feelings, including love, sadness, guilt, anger and resentment
- Receive support to express and deal with these feelings
- Make a positive adjustment to their family situation

Support for siblings allows them to feel less isolated and helps them build resilience. As a result, they will be more likely to develop to their full potential, and also to contribute to the quality of life of their brother or sister with special needs. Sibling support often enables the whole family to function more positively. We aim to increase the sibling programs we provide but also improve awareness about other available programs around Australia.

a. Directory of Services

Our office receives numerous enquiries about local sibling support programs from both parents and providers from around Australia. Given this fact and the feedback mentioned above, it is clear that there is a strong need for information about local programs to be available.

- Develop and host a directory of services through our website so that parents and providers can access their nearest program

b. SibworkS Quantitative Research

Whilst the SibworkS program run through Siblings Australia in 2007 was very successful, it is crucial that quantitative data be collected in order to determine the reliability and validity for the effectiveness of the program.

- Run more SibworkS programs to comprehensively assess the program

c. Teen Program

Siblings, parents and service providers have identified a lack of support for adolescents aged 13-18 years.

- Expand the current support available to siblings to include support to teens
- Develop some youth participation in these process

d. Sibling Forums

As part of our website redevelopment Siblings Australia has been able to provide forums for siblings and service providers. For many it has been the first time they felt they had a 'voice'. The peer support has been a crucial part of their acknowledging the grief and guilt and moving forward with greater strength. Hosting these forums, especially those for younger siblings, requires significant resources and expertise.

- Maintain and expand forums for siblings to communicate with each other
- Promote these forums to ensure more siblings can have access to this crucial support
- Create a postcard for young siblings that will include information about their internet forums as well as the KHL number (providing we can expand our relationship with KHL)

4. Workforce development

a. Training needs

For some time Siblings Australia has taken the lead in workforce development on sibling issues and support. Since 2002 our Director has presented workshops for providers, from within the disability, health and education sectors, all around Australia (and overseas). We have also provided undergraduate training in the areas of nursing, education, disability studies, and psychology. The goals of such training have been to raise awareness, add to knowledge and skill development in communicating with children and families, and provide opportunities for networking and collaborative practice. Outcomes include a greater capacity for individuals and agencies to support and strengthen families.

Whilst informal evaluation has been extremely positive, there is a need to do some more rigorous evaluation and develop training materials that would be widely accessible at a broader level.

- Investigate what training programs, if any, are being conducted in addition to the Siblings Australia training.
- Explore the appropriate sectors for such training, the needs of each sector and the best ways to implement workforce development in each sector

This training project is one that will require significant resources and we would like to develop this project for 2009.

b. Website resources

In the meantime, the Siblings Australia website will present an ideal opportunity in 2008 to significantly expand our reach to a number of worker populations, in addition to those mentioned above, for example GPs, child welfare and community services.

- Develop resources on our website for both GP's and educators (drafts have been developed).

This latter group fits into the KidsMatter project, with its four components of professional development: (1) positive school community; (2) social and emotional learning for students; (3) parenting education and support; (4) early intervention for students at risk or experiencing mental health problems.

- Develop an education consultation group to explore what schools need regarding information on sibling issues and related to these four areas.
- Include information about our website resources and about our manual for SibworkS in the KM program guide.
- Explore how the SibworkS manual could be adapted for maximum benefit for schools. This updated version could then be included on both our website and in the KM Program guide.
- Via the new website, host a discussion forum for providers, SibServices, which will enable providers to share information and resources regarding sibling programs. It will also have a range of links and lists of relevant resources (books, links, and journal articles).

Future Directions

In addition to the directions outlined above we plan on pursuing the following activities (funded from other sources).

1. Research collaboration

Once some work has been done on developing a research agenda for sibling issues (through the 'new collaboration' exercise above), we hope in future years to be involved in joint applications for research funding for a range of investigations regarding the support of families and, in particular, siblings.

2. Adult Sibling Project

The 12 month adult sibling project mentioned above will lead to a range of services and resources. It will also lead to improved social connections for people with special needs, and more resources for families to explore the future care of the person with special needs. It is hoped to gain more support to expand this project in 2009.

3. Parent resources

In the past Siblings Australia has developed an information brochure for parents (8000 copies have been distributed over the last 5 years) and run workshops for in excess of 2000 parents. There is a need to expand our resources for parents of children with special needs to ensure they can support their whole family, and to develop more extensive training programs for providers to run parent workshops.