

Briefing Paper 2010

Background

There are estimated to be over 300,000 people under the age of 25 years with a severe or profound disability, chronic illness, or mental illness. Understandably, significant resources are spent on addressing the needs of children and adults with disability or chronic illness, both within families and in the community. However, research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. In spite of this, the needs of siblings have been largely overlooked at both policy and service level.

At a broader level, there is much emphasis in our community about the prevention of mental health problems. There is an understanding of the profound effect the early years have on a child's development and their longer term health and wellbeing. There are economic benefits in intervening early and ensuring young people who may be at risk are able to access relevant support services.

The sibling experience

Certainly many siblings of people living with disability are enriched by their experiences. However, many can also face challenges. A recent Australian Institute of Family Studies report found that parents of children with disabilities have higher rates of depression than the general population and siblings also had a significantly increased risk of depression¹. Often these parents do not access services for themselves or their other children as the focus is on the child with special needs. Other studies from overseas have shown that these children have increased rates of physical health problems too². In many cases, these children have to deal with separated parents (it is well accepted that the rate of marriage breakdown is higher in this population), a depressed parent (usually the mother) and also the ongoing demands or difficult behaviour of the child with special needs. They may also face a lifetime of responsibility for a brother or sister.

It is recognised that siblings often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand the mix of feelings they experience. Siblings can experience a range of feelings and reactions to having a brother or sister with disability or chronic illness and these can vary over time. Often there is confusion about those feelings. 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. Such feelings, left unaddressed can lead to lowered self esteem, shame or a sense worthlessness³. 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.

Sibling support

It is important to intervene early and provide support to these children. This needs to include approaches within all the settings in which the child operates, for example, family (immediate and extended), friends, peers, school and community. This support needs to continue over the lifespan, as issues change.

The 'Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009-2014', includes as one of its priorities 'Prevention and Early Intervention'. For a discussion about

¹ Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. *Australian Institute of Family Studies, 2008. Research Report, no. 16*

² 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.

³ 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

mental health promotion for siblings and the need for policy directions, see the following article, published in 2008 in the Australian e-Journal on the Advancement of Mental Health:

<http://pandora.nla.gov.au/pan/107363/20091002-1309/auseinet.com/journal/vol7iss2/strohmeditorial.pdf>

Benefits of sibling support

With support in place, siblings are more likely to develop strength, resilience and tolerance. They are less likely to feel isolated or develop health issues and more likely to contribute to the well-being of their brother or sister with special needs. The whole family is likely to function more positively.

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 range of mixed feelings, including love, sadness, guilt, anger
- receive support to express and deal with these feelings

The Gaps

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings
- There are no policies or strategic national approaches to sibling support
- There is little national funding available for sibling support; if any, it is sporadic and piecemeal
- There is little, if any, collaboration between providers who offer sibling support programs
- There are no standard, co-ordinated policies with regard sibling support programs
- There has been little evaluation done of existing programs; no best practice guidelines

Siblings Australia

Siblings Australia is the only organisation in Australia dedicated to addressing the needs of brothers and sisters of people with special needs [chronic illness, disability and/or mental health issues].

The organisation's Mission is a simple one: *Siblings: Acknowledged, Connected, Resilient.*

Over a period of twelve years Siblings Australia has made huge progress in creating awareness and providing support within the different settings in which a sibling operates, for example, families, schools, community. It has built strong relationships with key mental health, youth and disability agencies. With a strong emphasis on prevention and early intervention, Siblings Australia has worked to build resilience and coping skills of children, young people and families, and raise community awareness about sibling issues.

Research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. The focus is on strengthening families so they are more able to support each other and more able to access support from outside the family. Consequently, the aim is to increase the availability of information and support services for siblings, through increasing awareness, understanding, and skills at three levels:

- direct support to siblings
- enabling parents to support their children
- working with service providers who, in turn, offer support to families (disability, health and education)

Information and support services take the form of written and online materials, workshops, a website and networking opportunities for families and providers. The organisation uses a 'settings' approach to improve the capacity of all areas in which a sibling operates – family, school, community. Workshops have been run for thousands of parents and service providers all around Australia (in both metro and regional areas) and

the Executive Director has been asked to present in Italy, the UK, US and Canada. The workshops, in particular, have served to empower parents in supporting their whole family. Feedback has been overwhelmingly positive. As one parent said recently at the conclusion of a parent workshop, "I have been looking for something like this for over 10 years".

We are in close contact with providers around Australia and similar organisations overseas. The service provider training has included training in the SibworkS model developed by Siblings Australia in 2004. The facilitator manual and participant booklets have been distributed to nearly 200 providers. Training provided by Siblings Australia has included professionals from a number of sectors, including, health, disability, counselling and education.

The organisation also plays an important role in areas of research and advocacy to inform social policy makers about the needs of siblings. The Executive Director's book, *Siblings: Brothers and Sisters of Children with Special Needs*,⁴ generated very powerful responses from around Australia and overseas (It has also been published in the US, the UK, and Korea).

Siblings Australia deals with a high volume of enquiries on sibling issues, both through direct contact by parents and providers with the organisation and through the website. This highlights how the awareness of sibling issues and demand for services and resources is growing by both parents and providers in Australia.

In 2004, and again in 2009, Siblings Australia hosted a national conference on sibling issues, which brought together families, service providers, researchers and policymakers (including several from overseas). At each event delegates reinforced the need for a co-ordinated approach to sibling support measures and called on the Australian government to support such a measure.

Over the last 12 months, with the support of small one-off grants, Siblings Australia has been developing both a booklet and a dvd for parents on sibling issues, carried out an adult sibling project and completed a scoping project of over 100 sibling support programs around Australia. Reports from these projects are available on the website. A directory of sibling support services around Australia was developed on the organisation's website. The Scoping Project highlighted the need to develop a national model of sibling support and to provide greater training and resources to people who are providing sibling support in order to develop best practice and consistency in approaches.

The difficulty for Siblings Australia is developing sustainability as funding has been sporadic and short term. No one government department takes responsibility for this group of vulnerable children and they do not fit into one policy area. They could easily fit into Mental Health, Families and Communities, or Education.

Why Siblings Australia should be valued and supported

- The organisation has twelve years of experience in this area and is in an ideal and unique position to carry this work further – if it is not supported this expertise will be lost
- Siblings Australia has heard from many families and providers who express concern about available services for siblings and the value of Siblings Australia, including through a petition in 2008 when funding was lost http://www.petitiononline.com/mod_perl/signed.cgi?SIBLINGS
- The work we did in 2007 through DOHA funding was not complete – it only just touched the surface
- There is still much more to be done for siblings across the lifespan
- The work that is being done across Australia is unco-ordinated

⁴ Strohm, K.E. (2002). *Siblings: Brothers and Sisters of Children with Special Needs*. Wakefield Press: Adelaide

- Siblings need to have their concerns addressed through national policy and strategic directions, in a similar way to Children of Parents with a Mental Illness (COPMI)
- If just a few cases of depression in siblings can be prevented the costs of intervention will be covered
- Siblings are too important to ignore - support benefits not only families (including the child with special needs) but also governments, the community and tax-payers through longer term savings in social services

The future

If resources were to be made available, directions for the future could include:

- Review of existing policy related to siblings
- Development of a national strengths-based service delivery model
- Increased availability of support services to siblings across the lifespan
- Improved services for families to support siblings
- Evaluation of the SibworkS model of intervention; increased training in the model
- Improved collaboration between providers of sibling programs across Australia
- Improved collaboration between relevant sectors and organisations – eg disability organisations, mental health organisations (Beyond Blue, Headspace, Mind Matters/Kids Matter etc)
- Further development of online services and resources and opportunities for sharing/collaboration
- A national reference group or network to ensure shared goals and practice
- Improved training for workers on sibling support, especially using online training programs
- Improved research directions with collaboration of families, workers and researchers in order to develop appropriate services
- Appropriate evaluation measures developed to ensure best practice sibling support

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