

Submission to Inquiry into Mental Health Services in Australia by Siblings Australia

Concerns of siblings

There are over 200,000 young people under 25 years in Australia with a severe or profound disability or chronic illness (not including mental illness). In the likelihood that there is an average of one sibling per person with disability or disease there is at least a comparable number of siblings in the target group.

Understandably, significant resources are spent on addressing the needs of children with a disability or chronic illness. By the same token, research has now substantiated the fact that siblings of these children may themselves experience significant long-term mental health problems such as, anxiety, depression, low self-esteem and relationship difficulties if their needs are left unaddressed. 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. Research also substantiates that siblings are at risk of developing physical health problems. 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. ^(1, 2)

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 contradictory feelings, including guilt, anger and resentment
- receive support to express and deal with these feelings
- make a positive adjustment to their family situation, which will mean they are more likely to be happier within themselves and more able to contribute to the quality of life of their sibling with a disability.

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 also enables the whole family to function more positively.

National Action Plan on Mental Health 2006-2011

The Mental Action Plan includes five action areas, one of which is Promotion, Prevention and Early Intervention. Within this area there are some specific policy directions that correspond with support for siblings, specifically: building resilience and coping skills of children, young people and families; raising community awareness; improving capacity for early identification and referral to appropriate services. Siblings are relevant to the NAPMH in three main ways.

¹ 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

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.

First, when considering the needs of people with a mental illness it is imperative to consider the needs of siblings, not only in their own right (in order to develop to their full potential) but also in relation to their capacity to support their brother or sister with mental illness. If they are supported, siblings are more likely to contribute to the person with mental illness.

Second, when a child has special needs (disability or chronic illness) the siblings of these children are 'at risk' for developing mental health issues themselves as a result of their experiences. We need to identify and reduce risk factors and identify and increase protective factors in these children. One of the key issues in sibling support is promoting social inclusion.

Third, when a child has special needs the stress involved on families can be quite significant. The parents' relationship can break down and parents can experience depression. Some evidence suggests up to 80-90% of these families experience separation or divorce of parents. Parents don't receive enough support in the early stages of diagnosis to deal with the myriad of feelings they experience. Their needs are often unrecognised and many families feel isolated.

Siblings of these parents need to deal with a mixture of grief and loss issues. These children can then come under the umbrella of 'Children of Parents with a Mental Illness (COPMI). However with the needs of the child with disability or chronic illness taking priority, along with depression of parents, it is likely that the needs of other children will be overlooked.

About Siblings Australia

Siblings Australia is the only organisation in Australia that is dedicated to addressing the unique, life-long and ever-changing concerns of brothers and sisters of people with special needs [chronic illness, disability and/or mental health issues].

Research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. Our focus is on strengthening families. Consequently, we aim to increase the availability of information and support services for siblings of people with special needs, through increasing awareness, understanding, skills and capabilities at two levels:

- direct support to siblings
- working with parents and service providers who, in turn, offer support to siblings

Information and support services take the form of written materials, workshops and websites. Our 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*, (Wakefield Press 2002), provided a 'voice' for siblings and has generated very powerful responses from siblings and parents from around the country – for many it has been the catalyst for a release of hidden feelings. It has also been published in the UK and the US.

The Director is regularly asked to present workshops around the country for both parents and for service providers, in which sibling issues are addressed. Parents, in particular, are crying out for support. The work of Siblings Australia is about strengthening these

families so they are more able to support each other and more able to access support from outside the family.

Siblings Australia also manages several sibling discussion groups: SibChat4Kids; TeenSibChat; Sibchat; and, one for service providers, SibServices. The stories on SibChat [adult siblings] in particular are both powerful and moving as many talk of their recognition that their adult struggles with isolation, pain, self-loathing and the development of eating disorders, depression and, in some cases, self-harm are related to their childhood experiences. These discussion groups hold huge potential for supporting siblings. Unfortunately we have lacked resources to develop them further.

Siblings Australia has produced a manual for people wanting to run sibling support groups for children aged 8-12. The feedback has been extremely positive in terms of outcomes for siblings. We would like to run these groups, along with teen sibling support groups, on a regular basis but lack the resources to do so. We also lack resources to fully evaluate the program.

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, peer groups, community.

We were gratified in early 2007 to receive a one-off twelve month grant through the Children and Youth section of the Mental Health and Suicide Prevention Programs Branch, within DOHA to explore contributing to both the Mind Matters and Kids Matter programs, KidsHelpline and other DOHA funded programs. However it is imperative that the organisation continue to access government and community support to enable its work to continue.

This group of children does not fit easily under an umbrella of support. We have done an enormous amount of lobbying and grant-seeking but this group of children readily 'falls through the cracks' and it is very difficult to get them on the agenda.

Recommendations

This brief submission has tried to highlight the issues for siblings of children with special needs. It is imperative that any promotion, prevention and early intervention plans, both at State and Commonwealth level, consider the needs of these children.

Siblings Australia has developed a national and international reputation for its work on strengthening families. As part of its ongoing work and in talking with thousands of parents and providers around Australia and overseas, Siblings Australia is at the forefront of understanding the issues for families. It is imperative that the organisation is supported in continuing its work.

I urge the Community Affairs Committee to: acknowledge the needs of this group of young people and adults; to ensure this group is on the agenda; and to identify which government department should take ultimate responsibility to ensure their needs are addressed.

Kate Strohm
Director Siblings Australia
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