



Guest Editorial

Too important to ignore: Siblings of children with special needs

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Introduction

Over the last decade there has been an increasing emphasis in Australia on the prevention of mental health problems. It has been accepted that the early years will have a profound effect on a child's longer term health and development and that preventive approaches need to focus on these years. Governments have also started to see the economic benefits of investing in the early years. For example, it has been estimated that the cost of each case of depression is approximately \$10,000 per annum (Sobocki, Jonsson, Angst & Rehnberg, 2006). If we can intervene early and reduce the incidence of such cases, the savings at a population level can be huge.

However, there is still much that could be done in relation to preventive strategies. In fact, there is some concern that the momentum gained in the nineties may have been lost and that the 'pendulum in mental health has swung back to early intervention and treatment' (Parham, 2008) for problems that have already begun to develop. Another concern is that some groups of 'at risk' children are being overlooked at a policy and service level, in spite of much work being done 'on the ground' through the commitment of individuals.

One such group is the brothers and sisters of children with special needs, who can be at risk for developing a number of mental health problems. This editorial explores the mental health issues for this group of children, the risk

and protective factors that influence adjustment, and also the timing of intervention. It then outlines Siblings Australia's approaches to addressing the needs of siblings, and the benefits of this work. The editorial concludes by discussing policy directions and the need for greater recognition of this group of children, both at government and community levels.

Siblings of children with special needs

There are over 200,000 young people under 25 years of age in Australia with a severe or profound disability or chronic illness. It is reasonable to assume that most of those young people have at least one sibling (Australian Bureau of Statistics, 1998).

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* (Cummins, Hughes, Tomy et al., 2007), the largest ever survey into the health and wellbeing of Australian carers, found that more than one third of family carers in Australia are severely depressed and/or stressed. In fact carers have been found to have the lowest collective wellbeing of any group yet identified. The survey also showed 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.

The Australian Institute of Family Studies report, *The Nature and Impact of Caring for Family Members with a Disability in Australia*, also highlights the risk of siblings experiencing depression, especially when a parent has also experienced it (Edwards, Higgins, Gray et al., 2008).

Not all siblings of children with special needs will experience difficulties. Some can be enriched by their experiences and cope well with any concerns that might arise. However, siblings often grow up in a situation of considerable stress; they can experience a range of feelings and reactions to having a brother or sister with a disability or chronic illness; and these reactions 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. 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 worthlessness (Lamorey, 1999). Research also indicates that siblings are at risk of developing physical health problems (Hogan, Park & Goldscheider, 2003). These problems are exacerbated by limited access to 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. Anecdotal evidence suggests that this increases the chance of them turning to risk-taking behaviour, including misuse of drugs and alcohol.

Risk and protective factors

Siblings of children with special needs have a number of risk factors that can reduce their ability to cope with their experiences. For example, they may not understand the special needs of their brother or sister, which can lead to a number of misconceptions. If siblings have difficult experiences they may not feel able to talk to anyone about their concerns. They can feel overlooked within their family, feeling that their needs are on the back burner, but they might also want to 'make things right' and not

burden parents with extra stresses. They might feel guilty about complaining, or feel that others don't understand:

I felt completely isolated. I thought I couldn't share any of that part of my life with my friends. They didn't understand and I felt alienated from them. Other kids never had the same responsibility (Strohm, 2002, p.19).

They also can experience 'disability by association' (Burke, 2004), as indicated by the story from a child who found that other children wouldn't play with her as she had 'disability germs'. As a result, they can develop a sense of isolation or a lack of connectedness to family and friends. Such experiences, along with a mix of feelings that they can't express, can lead to anxiety or depression – a known risk factor for longer term mental health problems.

On the other hand, protective factors seem to be open communication within their family, strong connections with family and friends and with outside sources of support - for example, sibling support programs and school programs. Many adult siblings say they wish they had been able to connect with other siblings when growing up, as this would have helped them enormously to cope with the situations they faced.

The trajectory of isolation

In 2005, the ABC Four Corners program looked at the role of several carers in its documentary *The Hidden Army* (ABC TV, 2005). One family's experience, especially the sibling outcomes, highlighted the importance of early intervention and shows very clearly the trajectory that can unfold when that intervention does not occur. A transcript extract from that program, shown in Box 1, has the journalist, Quentin McDermott, exploring the impact of having two children with special needs, both on mother, Felicity, and her other child.

So when could we have intervened with this family? Could the teenage boy have had contact with a school counsellor, or other therapist, who understood the issues for siblings and had some resources to provide support? Could he have attended a peer support group, such as *SibworkS* (Nesa & Strohm, 2005), as a younger child to learn that he was not alone and to find ways of coping with the lack of parent attention and the

Box 1. Transcript from *The Hidden Army* (ABC TV, 2005)

QUENTIN McDERMOTT: When she was younger, Felicity embarked on a successful career as a nurse. Then, after her children's disabilities were diagnosed, she and her husband split up, a common occurrence in families caring for disabled kids.

FELICITY: My full-time career came to a grinding halt after the end of my marriage, and the support needs of the children sort of meant that I needed to be at home, and so I had to quit work.

QUENTIN: The emotional stress of caring for her two disabled children was compounded by the devastating effect on her third and eldest child.

FELICITY: He was teased unmercifully at school because both his brother and sister had a disability. Also, his feeling of being neglected, and I had, you know, a young man of 11 crying to me one day, saying, 'If I had a disability, would you love me, too?' And, I mean, that just rips your heart out. For him, his inability to cope, or his self-esteem within a family dynamic, has resulted in drug and alcohol abuse, addiction, um, with criminal activity, and, um, he now has an acquired mental illness.

teasing from students? Could the mother have attended a parent workshop such as those run by Siblings Australia, and become empowered to provide support to her able-bodied child, alongside the children with special needs? Could intervention have occurred even earlier, when the new mother and father were grappling with their own reactions to having one, and then another, child with special needs?

Men and women react quite differently when a child is born with, or later acquires, special needs. There might be a mix of feelings, including shock, despair, fear, grief and self-doubt. Melbourne psychologist, Liz Bruce, likens the experience of such parents to that of Post Traumatic Stress Disorder (Bruce, n.d.). Certainly, through running workshops for thousands of parents around Australia and overseas, I have learnt that the feelings and how they are expressed can be quite different for the father and mother. And yet, how many of these parents have access to immediate counselling to help them sort through their own feelings of loss, shock and/or anger, and learn how to support each other? What often happens is that the relationship becomes quite fragile. If we had supported the parents in the above scenario it is likely both parents would have been more able to support the son.

If the relationship does break down, siblings of a child with special needs can grow up in a single parent household, feeling the loss of the child playmate they thought they were going to have

and also the loss of a parent (usually the father). In addition, there are likely to be financial issues as the family income can be adversely affected due to added costs, reduced income and greater carer demands on one or both parent(s).

The frustrating aspect of the story on Four Corners is that it could have been so different. Even if intervention had not been able to save the marriage, there are a whole range of programs that could have supported the mother and the sibling in order to strengthen each individual and their family relationships. In the end, the costs (economic, health and social) were enormous, not only for the family but for the community in general.

Siblings Australia

Siblings Australia (www.siblingsaustralia.org.au/) is the only organisation in Australia that is dedicated to addressing the needs of brothers and sisters of people with special needs (chronic illness, disability and/or mental health issues). It has developed a national and international reputation for its work with families and professionals. Workshops for parents and providers have been presented not only in Australia but also in Italy, the United Kingdom, the United States and Canada. In 2004, Siblings Australia staged an international conference focused on sibling issues and support. It was attended by 140 professionals and families from around Australia and overseas.

The focus of Siblings Australia is on strengthening families, hence the aim is to increase the availability of information and support services for siblings of people with special needs, through increasing awareness, understanding, skills and capabilities at three levels:

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

Information and support services take the form of written materials, workshops and a newly upgraded website. The organisation also plays an important role in areas of research and advocacy to inform social policy makers about the needs of siblings.

The Australian Institute of Family Studies (2004, pp. 30-31) reported that:

Siblings Australia clearly taps into a need in our community. It has developed a comprehensive approach to early intervention and support that acknowledges the need to intervene at the individual, family and community level and to do so with services, information, education, resources and policy change.

The organisation's Mission is 'Siblings: Acknowledged, Connected, Resilient.' Siblings of children with special needs are often *overlooked* within their family and by government and community services. They can become *isolated*; which in turn makes them *vulnerable* to a range of emotional and mental health problems. The work of Siblings Australia aims to raise awareness of the issues for siblings, so that they and others *acknowledge* the challenges, give them opportunities to *connect* with others and also learn the skills to deal with their experiences so that they can become more *resilient*.

Interventions with siblings

The following is a list of possible interventions with siblings; it is not comprehensive, but it details some of the approaches taken by Siblings Australia. A 'settings approach' has been used, in that the focus is on supporting siblings within their families, with peers, at school and in the community. Although the resources to formally evaluate all the programs has been lacking,

feedback from families and providers has been extremely positive and affirms that this work contributes to strengthening families and improving the capacity of the organisations that support them.

1. Direct intervention with siblings

Siblings Australia has developed a 6-week (two hours per week) peer support program, *SibworkS*, for children aged 8-12 years and also has produced a manual for people wanting to run these groups. Some quantitative evaluation, though limited, has been carried out. The feedback has been extremely positive in terms of outcomes for siblings, both from families and providers. The *SibworkS* program ensures the involvement of parents through face-to-face discussions and regular updates on what subjects are covered in the program.

Siblings need greater access to such groups. Children gain enormous strength from sharing experiences, from learning new ways to cope with difficult situations, and learning that they are not alone. A participant in a *SibworkS* peer support group commented: '*At least I have somewhere I can talk where no-one laughs.*'

However, face-to-face groups are not the best intervention for all young siblings. Some are much better suited to individual or family approaches, for example, counselling or family therapy. Some can gain much through being in contact with other siblings via the internet. Siblings Australia manages several internet forums for siblings: *SibChat4Kids*; *TeenSibChat*; and *SibChat* (for adult siblings). The internet forums allow siblings to connect with each other and share experiences and strategies for coping.

Adult siblings talk about similar feelings of relief through connecting with others who can share the grief, guilt and isolation. Some siblings have reported that the peer support has enabled their relationship with their brother or sister to become stronger. The stories on *SibChat* in particular are both powerful and moving as many talk not only about their love and caring for a brother or sister, but also the recognition that their adult struggles with isolation, low self-esteem, depression, and anxiety, are related to their childhood experiences. These forums hold huge potential both for identifying needs and for peer support.

2. *Parent workshops/education*

Siblings Australia has presented workshops for parents around Australia and overseas, in which sibling issues are addressed. Parents are crying out for such support, and they leave these workshops feeling empowered to more ably support all their children. One parent said they had been 'looking for something like this for 10 years'. Parents are also looking for sibling support programs for their children. Siblings Australia has attempted to develop a national directory of services around Australia for both parents and providers, to be accessible through the website, but funding issues have stalled this work.

3. *Workforce development*

Siblings Australia has presented extensive training for service providers and undergraduate students from a variety of sectors including disability, health, education and community services. Service providers gain enormous insight into the needs of families and go away with clearer directions for family support. We also provide training in the *SibworkS* model of sibling support. There has been a huge increase in awareness of sibling issues and needs through these workshops and, in some cases, local networks of providers have been established as a result. There is huge potential to provide training, including e-learning options, to a range of sectors.

During 2007, we contributed to the *MindMatters* and *KidsMatter* resources (national mental health initiatives for secondary and primary schools respectively) in order to improve awareness and inclusion of sibling issues and started to develop curriculum materials on sibling issues. School support for siblings has always been a focus for the organisation and this work consolidated many of our approaches. Further work is needed however to develop resources and training for this sector.

4. *Research*

At the moment there are many programs for siblings being run around Australia, but there is no quality control over the programs, nor are consistent outcome measures used to evaluate them. We need better research to assess the benefits of different approaches. In 2007, Siblings Australia took a lead role in developing

a collaboration of researchers, providers and families from around Australia to set an agenda for sibling research when a child has special needs. The group was successful in gaining an encouragement grant through the Australian Research Alliance for Children and Youth (ARACY) New Collaboration Grants, and it is hoped that further progress can be made via more extensive research grants.

The need for policy directions

The difficulty for Siblings Australia is that the demand for services has far outstripped the capacity and resources to provide them. The support from government and philanthropic bodies is usually only short term, which makes it extremely difficult to plan for the future and develop the capacity of the organisation. This group of children does not fit easily under an umbrella of support. There has been an enormous amount of lobbying and grant-seeking but this group readily 'falls through the cracks' and it is very difficult to get them on the agenda. Without a policy framework it is very difficult to have a mandate for action.

Siblings Australia has attempted to develop services at a grassroots level and this has had major outcomes in terms of awareness and the number of sibling support programs now in place. But, in order to really make progress and develop best practice approaches, there needs to be a broader scale strategic action plan, supported at government level with policy.

In the United Kingdom, the *Children Act 1989* is the framework for the support offered to children 'in need', including those with disabilities. It emphasises that the child is part of their family. The guidance under the *Children Act* states that 'the needs of brothers and sisters should not be overlooked, and they should be provided for as part of a package of services for the child with a disability' (Great Britain Department of Health, 1991). Siblings are provided for at the policy level which means that there is an expectation that they will be considered by agencies. In addition, the report, *Aiming High for Disabled Children: Better Support for Families*, often refers to the needs of siblings and stresses the importance of 'focused, effective support early in life and at key transition points, with early support for disabled children and their families,

which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all' (HM Treasury and the Department for Education and Skills, 2007).

Clearly, a policy framework is needed here in Australia for this group of at risk children. With the ground work that has been done, there is the potential to develop a comprehensive intervention strategy with relative ease, and in keeping with good mental health promotion practice. If we can better support siblings and, in the process, reduce the incidence of mental health problems, the benefits for siblings, for families, for the community and for governments would be enormous. These children are too important to ignore.

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