



families
australia

***Towards improved
recognition and support for
siblings of those with a
chronic condition***

A report on consultations

FAMILIES AUSTRALIA

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About Families Australia

Established in 2001, Families Australia is a not-for-profit, national peak organisation which seeks to inform and influence national public policies in favour of greater family wellbeing.

Families Australia defines a 'family' broadly as taking many forms, all of which deserve respect and support.

Families Australia's work is based on the concept that family wellbeing is multi-dimensional and includes factors such as mental and physical wellbeing, safety and connectedness to community, as well as economic considerations.

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Executive summary

Families Australia has collaborated with Siblings Australia to explore ways to better identify and provide support to infants, children and young people whose wellbeing may be compromised or at risk as a result of growing up with a brother or sister who has a disability or chronic illness.

This brief paper has been informed in part by a Royal Australian & New Zealand College of Psychiatry (RANZCP) scoping study which identified support needs for siblings of children with a disability or chronic condition. The RANZCP Position Statement recommended increased support for this cohort in order to enhance their physical and mental health and wellbeing.

In preparing this paper Families Australia participated in the RANZCP expert reference group, held discussions with Siblings Australia and conducted focus group discussions with adult siblings. In the latter process, participants were asked to reflect on key emotional themes from their childhood and to suggest ideas for policy and practice that could benefit the wellbeing of today's sibling cohort.

Discussions with adult siblings revealed a number of common experiences during childhood, including: significant levels of anxiety, loneliness, grief and low self-esteem; perceived lack of normality in relation to family and social opportunities; and a strong sense of responsibility for family members.

While there are limits to the conclusions which can be drawn from this study because of the small numbers involved, Families Australia makes recommendations for policy and practice which affirm and build on the RANZCP report.

Aims

This brief paper has been prepared by Families Australia in order to:

- (i) investigate further the key issues for siblings and the effects of growing up with a brother or sister with a disability or chronic health condition including mental illness; and
- (ii) identify and suggest areas for further policy development

Context

The origin of Families Australia interest in this issue began in 2009 with attendance at the Creating Connections Conference, a national conference hosted by Siblings Australia. The conference culminated in a Conference Resolution, which was sent to the Commonwealth Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon. Jenny Macklin MP (Attachment A)¹. Subsequently, Families Australia collaborated with Siblings Australia in developing a National Action Plan for Siblings (2010) (Attachment B)² and later participated in RANZCP expert reference group for a scoping study into the needs and gaps in support for siblings of a brother or sister with a chronic condition. In addition, Families Australia's work over the past two years on families affected by mental illness has contributed to a greater awareness of the value of investing in children and young people's early nurturing in order to help them overcome situations where early experiences of adversity may have long lasting consequences.

Methodology and data collection

This study focuses on the needs and interests of children and young people who grow up with a brother or sister who has a chronic illness or disability. 'Siblings', as a short-hand term, will be the term used throughout this paper to denote this group.

Face-to-face consultation with individuals or small groups is one of the ways which Families Australia gathers information about family-related issues; according to Calderon, Baker, and Wolf (2000), this method is well suited to conducting research among minority and vulnerable populations. Previous research into family-friendly methodologies undertaken by Families Australia identified focus groups as the best way to stimulate discussion among participants, and may be particularly helpful when

¹ <http://www.siblingsaustralia.org.au/assets/submissions/conf-resolution.pdf>

² <http://www.familiesaustralia.org.au/publications/pubs/siblingsselection2010.pdf>

discussion delve into sensitive or complex issues (Litoselli, 2003) and where participant attitudes and opinions can be utilised to promote learning (Morgan, 1997).

Two focus groups were co-facilitated by Families Australia and Siblings Australia, each consisting of six participants ranging in age from 20 to 69. All participants except one were over 40 years of age and four were male. Invitations were distributed through a range of community sector and government agencies providing family services and support across Adelaide. There were two sibling status exceptions who registered: a parent with two children one of whom has disability and a grandparent who regularly cares for grandchildren in support of his daughter who has a child with a developmental delay.

Families Australia had hoped to recruit greater numbers to the focus groups; tellingly, however, there are no existing directories or support groups to facilitate access to this cohort. We appreciate the assistance provided by the Julia Farr Centre, Uniting Communities SA and South Australian local office staff in the Department of Families, Housing, Community Services and Indigenous Affairs in promoting the siblings focus group invitation through their networks.

The rationale for this investigation with adult siblings was to understand in greater depth the effects for those who had grown up with a brother or sister with a disability or other chronic condition, and to investigate the extent to which these experiences were consistent with the recommendations of the Royal Australian & New Zealand College of Psychiatry (RANZCP) (2011) report (Attachment C). Group discussions focused on four main questions:

1. What have been early life experiences as a sibling of a child with a chronic condition?
2. How and in what way were expectations different for the sibling in comparison with other children and families?
3. What could have helped or made a difference? What did the sibling wish for?
4. What helping strategies and practices could assist young siblings of a child with a disability or chronic condition?

The focus groups were conducted in Adelaide outside of working hours to allow for people with work, parenting or study commitments to attend. Adelaide is the headquarters of Siblings Australia, from where that organisation has developed a national and international network of siblings, families, academics and service providers who are interested in issues impacting on siblings. The focus groups were conducted using a standard set of questions with participants working in groups of two and reporting back to the whole group, except for the first activity, which was conducted with the whole group.

The questions were exploratory in nature, to encourage reflective responses and open dialogue and leading to the fourth activity which aimed to focus the discussion on analysis and interpretation of the personal histories that had been elicited. The facilitators recorded participant responses to the brainstorm and group feedback, which have been collated and synthesised for this report.

Consultation responses

The sibling experience

Both groups of adult siblings were asked to describe the effect on their lives as siblings. This line of questioning arises from the suggestion in the RANZCP report that chronic illness or disability affects the lives of all members of the family and that the majority of resource allocation is directed towards the person with the chronic condition (RANZCP, 2011, p. 6). The focus group responses indicate that sibling childhoods were often overlaid with significant levels of confusion, grief and stigma which, in turn, had adverse impacts on education, health, wellbeing and life choices as young adults. Some of the responses included:

'I wanted to walk away...'

'There was a lot of family secrecy, due to the stigma. We didn't openly discuss what was happening for me at school.'

'Somehow I felt as if I was to blame.'

'I felt isolated from my parents and worried about what would happen if anything happened to them.'

'I felt completely alone with no-one to turn to about my ongoing anxiety. I felt like I was a really bad person because I often wished I did not have to deal with the ongoing issues related to my sister.'

Both groups of participants identified similar emotional impacts during their childhoods which they generally had difficulty discussing with their parents. Some stated that they received messages from parents or others that they should not complain. They also had difficulty talking about their issues to other people who they felt did not understand. A common theme in the focus groups and in other research with adult siblings (Siblings Australia, 2010) has been the fear that talking about difficulties was a betrayal of their family. Also, many siblings state that negativity about their brother or sister with disability has led to extreme guilt.

Emotional issues described by siblings included feelings of isolation and loneliness, grief, guilt about their own abilities, frustration and anger. For some siblings, these responses have led to the development of a range of mental health and wellness issues, including low self-esteem, low self-confidence, depression and high anxiety.

'I struggled all through high school and young adult life with anxiety, sleep problems, and low self-esteem. It impacted my education, career and relationships.'

Some appeared to use avoidance strategies, including alcohol or drugs. Despite these intense emotions, participants talked about being exceptionally well behaved as children so as to not add further burden to their parents. They reported having a strong sense of responsibility towards their parents and their brother or sister with the chronic condition, as well as feelings of resentment and embarrassment concomitant with grief and loss. This juggling of reactions and responses was reported as leading to varying degrees of confusion and secrecy as they felt constrained about expressing their needs during childhood and adolescent years.

Family life

In preparing for this aspect of the focus group discussion, Families Australia notes that various reports infer that sibling relationships are likely to be the most enduring over a lifetime and hold potential for significant impact on wellbeing (Heller, T. & Kaiser, A. 2008; Noller, Blakeley-Smith & Conway, 2007; Siblings Australia, 2010; RANZCP, 2011.) Difficulties in sibling relationships may be heightened when children experience comparison or competition with their siblings (Dew, Llewellyn, & Balandin, 2007; Giallo & Gavidia-Payne, 2008 and 2006; Siblings Australia, 2009.)

In light of the potential impacts for wellbeing and life choices we asked participants to explain how growing up with a brother or sister with a chronic condition affected them. Participants suggested that their lives were impacted in ways that their peers could not understand, and which teachers and other family members did not understand or acknowledge. Some of the terms used by participants to describe their childhood experiences were not dissimilar to other child cohorts who experience adverse childhoods, such as secrecy, unable to hold personal boundaries, hyper-vigilance and anxiety. Yet, this group remains generally unacknowledged and unsupported. This lack of acknowledgement was generally thought to arise from being seen as 'able' and resilient. Siblings talked about growing up with the knowledge that others' needs were more important than theirs and they often learned to suppress their own needs, even when this had detrimental effects on their health and wellbeing.

'In the past there was no thought for the other children in the family.'

'Teachers often misunderstood [my] inattention and tiredness and made adverse comments. I felt tired, poor sleep, anxiety, depression, sometimes panic, and worry for my parents.'

'I seemed to have less choice and opportunity than the others at school who did not have a brother or sister like mine.'

'The experience has influenced choices for later life including education work and intimate relationships, for example as I got older...if I thought my date would be embarrassed or just wouldn't accept my sister, it just didn't happen.'

What would have made a difference?

Asking participants to reflect on and analyse their experience to identify practical strategies for the contemporary world of siblings prompted a wide range of responses. Participants were able to draw on their experiences across the lifespan to identify various structural and systems supports that could have made a difference and which are not universally available for children and young people in this cohort.

'At no stage did any of the professionals that worked with my brother ask me how I was and if I needed any support. And the counsellors I went to did not understand.'

'I just wish my parents had been given help to support me as they were so stretched themselves. I wish I could have talked to someone who understood, and who could help me manage the range of stresses.'

A chart has been developed to synthesise the key themes and proposed strategies suggested by focus group participants. The key themes relate to intervening early with a prevention focus; strengthening family awareness and functioning; maximising education and care systems appropriate for each child; developing workforce competency to address family needs holistically; developing data and evaluation; and building accountability into program/service responses for families impacted by children and young people with a chronic illness or disability.

The table below maps the key themes, issues and practical supports for siblings and their families.

	Within family	Early child development and education	Medical and allied health	Community support and welfare
Workforce development	Broaden family support focus beyond parent and child with disability or another chronic condition to ALL family members.	Support access to early education and care programs; develop alert system of potential additional needs of siblings; strengthen awareness of siblings needing support to achieve developmental milestones for wellbeing and social adjustment; clarify the role and responses of education sector.	Create awareness of siblings in a whole family focus in primary health sector e.g. GPs, and allied health. Develop referrals for Family Mental Health Support Services and other Targeted Community (Mental Health) Care; ensure access to emotional wellbeing assessment and supports.	Create awareness of sibling issues; identify a range of family and child wellbeing supports; identify suitable pathways to community support for sibling support that enhance social, emotional and physical development and security of identity for siblings.

Data & Information collection	Include all family members at diagnosis.	Record sibling status at enrolment to improve teacher awareness and school based supports.	Collect data/info on siblings in case notes etc.	Assist inclusion of siblings and child with chronic condition in community activities.
Assessment of needs	Assess whole family when diagnosis made; link families with family support services appropriate for each member of the family.	Alongside IEP or equivalent also assess siblings' need for support. Could be part of 3 year old wellbeing assessment.	Assess whole family when diagnosis made and ongoing interaction with services.	Include the degree of community inclusion in assessment of needs.
Action Plans	Support all family members at diagnosis; offer information & access to a menu of services; focus on strengths, social support and communication; provide access to couple counselling to prevent family breakdown; grief and loss education; help parents develop skills in parenting children with different abilities; help in understanding issues for siblings and how to respond & support.	Acknowledge sibling and provide practical help to cope with their circumstances; identify suitable supports and provide access; help develop sibling relationships; help for play across different abilities; provide early childhood specialists and programs for siblings; utilise curriculum to teach about diversity and prejudice including sibling perspectives; offer specialised counselling for teen siblings to help them with future directions and interests.	Understand that siblings often have their own particular health needs or fears and need appropriate medical advice and counselling; identify strategies for integration and cross-referral between adult and youth services.	Identify ways to support siblings to take part in community activities e.g. recreation, specialist school holiday programs; assist inclusion of all children; plan for transport options. Ensure respite options are flexible to allow siblings to spend with parents alone OR help to do community activities WITH child with disability or chronic illness
Peer support	From diagnosis, link parents and siblings to peer and professional support.	Peer support for siblings in various education settings.	Build awareness of peer support for siblings and appropriate referrals.	Build awareness of peer support for siblings and appropriate referrals.
Research & evaluation		Research behavioural indicators of stress in siblings that impact on educational achievement; evaluate assessment methods and responses for early detection and prevention.	Research and development of strategies for children experiencing stress and trauma arising from behavioural issues.	Broaden current family support concepts for inclusiveness of all members beyond the parent/s and the child/ren with special needs.
Performance measurement	Link improved awareness and strategy implementation to performance appraisal and review systems in family support programs	Link improved awareness and strategy implementation to performance appraisal and review systems in ECE, PS and secondary teacher professional standards	Link improved awareness and strategy implementation to performance appraisal and review systems in medical and allied health professional standards	Link improved awareness and practice implementation to performance appraisal; review systems in community services to enhance awareness of gaps in services for siblings.

What is new or different for 21st century siblings?

The RANZCP report suggested that while some services now exist for young siblings, there are still generally scarce supports for siblings. Also, there is little known about the efficacy of the programs that do exist, as evaluations are rare (RANZCP, 2011, p. 8).

A number of reports confirm the experiences of the group, principally that siblings and families of children with disability or chronic illness experience isolation, lack of awareness of community resources and may be at higher risk for developing behavioural problems and mental illness ((AICAFMHA, 2011; Lobato, D. J. & Kao, B. T. 2002; RANZCP, 2011).

More troubling still are the early findings of a small scale survey, conducted by Siblings Australia, of siblings, parents and service providers about the sensitive issue of siblings being physically hurt by a brother or sister with disability. A final report is not yet available, yet early indications suggest that some children and young people experience persistent aggressive and threatening behaviours, supports are extremely limited and that seeking help is rare by parents due to fears of child abuse notifications to government authorities. The Siblings Australia website has a preliminary report on this survey which concludes that some parents and service providers are aware of behavioural issues impacting on other children in the family. Some service providers have suggested strategies to address the issues although with a caveat, that within current systems, responses are limited (Siblings Australia Blog, 2012).

In terms of strategic directions, several focus group participants identified overly-bureaucratic language and identification of siblings as carers as potential stumbling blocks to gaining access to support. Focus group members suggested that most young siblings would not identify with the term 'carer' (a term which is generally used for access to government support programs) and that they and their parents would probably not want siblings to be identified in this way.

At the conclusion of the focus group discussion, topics that had arisen as a result of the life course discussion and which were not appropriate for children and young people were transferred to another table, below. Many of the older-age group reported that they have taken over primary care of both ageing parents and brothers or sisters with a

chronic condition, usually at great personal cost to their wellbeing and with limited or no support in these roles. The table identifies longer-term issues for siblings across the life course.

Emotional support	Roles/ acknowledgement	Legal issues/finance planning/medical	Welfare, community and supported housing	Other
Access to help with counselling and other issues arising from past and current emotional issues.	Recognition of roles in transition from elderly caring parent to sibling as appropriate; recognition by agencies of valuable family knowledge.	Advice and help to address guardianship, finance and administrator; create awareness in guardianship and legal services about lifelong planning needs for family advocates and guardians	Information about housing options; include siblings in discussions particularly where they will assume caring and family advocacy roles.	Dealing with both ageing parents and person with disability or chronic illness.
Identify suitable supports to help siblings and ageing parents discuss future planning.	Help with choices about roles which change over time; with choice relating to capacity to intervene and support other family members. Increase understanding that sibling roles may not include direct caring but they may contribute in many other important ways e.g. adding to social and emotional wellbeing of person with a chronic condition	Investigate advocacy services for family members to assist with access to services; issues for siblings in later middle age.	Broaden focus of support beyond parents; recognise that siblings carry a caring load but may not be recognised as primary carer;	Ensure supports are family focussed rather than carer specific as most members of the family carry some of the burden of care

While this study has been small in scale, the lived experience of the participants has helped to amplify issues raised in the RANZCP (2011) report. The experiences of these adult siblings helps provide a better understanding of the impacts of growing up with a brother or sister with a disability or chronic health condition and that there are significant lifelong impacts and consequences for siblings. The study also strongly suggests the need for greater attention by governments and NGO service organisations to the needs of this group.

Recommendations

This brief study has highlighted the needs of siblings and suggests that further examination be undertaken of ways to understand and support them. Families Australia's principal recommendations are that:

- Further comprehensive research is undertaken to understanding the breadth of needs for siblings.
- Subject to a needs examination, professionals working holistically with families are supported to take into account the needs of siblings, including in service assessment stages.
- Opportunities are provided to assist older siblings with complex caring responsibilities to be able to advocate the full extent of their needs to governments and service providers.

In light of this study, Families Australia also recommends the governments carefully consider the RANZCP recommendations with particular attention to: the identification of an Australian Government agency which would take a lead role and responsibility for siblings; development of effective data collection on siblings and their needs; development of suitable assessment processes for sibling needs from early childhood and into early adulthood; improve workforce awareness of the needs of siblings and appropriate interventions and supports; undertake evaluation to identify promising practices, and consideration for a national non-government resource centre which would act as a clearing house for information and coordination of support approaches which focus on the needs of siblings, linking sibling issues with community, welfare and health supports.

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Attachment A: Creating Connections Conference, Siblings Australia, Conference Resolution (2009)

In November 2009, Siblings Australia held a national conference, which included family members, service providers, researchers and policy makers. At the conclusion of the conference the delegates endorsed the following resolution.

We, the delegates at the Siblings Australia 'Creating Connections' conference held in Adelaide 19-20 November 2009, affirm that siblings of people with a disability or serious physical or mental illness:

- have the longest relationship with, and often play a vital role in the support of, their brothers and sisters who live with a disability, but can face serious challenges in fulfilling this support role across their lives,
- face risks in relation to their long-term emotional, mental and physical well-being, irrespective of their caring role,
- have difficulty, both individually and collectively, in speaking out about their own needs; and
- currently have inadequate recognition or support within government programs related to health, families and disability.

We therefore call on the Australian Government to acknowledge the important needs and contribution of siblings of people with a disability or serious physical or mental illness by:

- recognising that support for siblings is a good investment and reflecting this in relevant policy,
- nominating a single Australian government department to take lead responsibility to encourage a whole of government approach for child and adult siblings,
- ensuring fair access to funding for quality services for siblings across their life span, and
- providing secure resources for a national sibling's body with responsibility for advocacy, advising government, disseminating information and facilitating collaboration, training, research and evaluation practices.

Attachment B: Families Australia-Siblings Australia, National Action Plan for Siblings (2010)



National Action Plan for Siblings of a child with a disability, chronic ill health or mental illness – 2010

There are hundreds of thousands of people in Australia living with severe or profound disability, chronic illness or mental illness. Disability or illness affects the whole family, including siblings. Sibling relationships are likely to be the longest of any. Across the life span, siblings often play a vital role in the support of their brothers and sisters living with disability. Siblings may also face risk in relation to their own long-term emotional, mental and physical well-being, which can result in significant costs to governments and the community.

Some siblings are certainly enriched by their experiences. However, children with a disability or illness need a lot of time and attention and it is easy for siblings to be overlooked both within the family and by the community. Growing up, siblings may experience a range of stresses within the family and also through other peoples' reactions. Without the cognitive skills and emotional maturity to understand and deal with those feelings, a child's self-esteem can suffer. They can feel quite isolated, become vulnerable to neglect, and longer term mental health problems may follow. For example a recent report³ found that siblings (as well as parents of a child living with disability) had a significantly increased risk of depression.

It is important to intervene early and provide support for siblings. This needs to include strategies within all the settings in which the child operates, for example, family (immediate and extended), friends, peers, school and community. Support for siblings can overcome feelings of isolation and help build resilience. As a result, not only will siblings be more likely to develop to their full potential, but also more likely to contribute to the quality of life of their brother or sister with special needs.

Empirical and anecdotal evidence confirms the national effort to support siblings is uncoordinated, under-funded, fragmented and sometimes duplicated. We know that siblings and their families will benefit from coordinated and holistic individual and social support.

Siblings Australia and Families Australia call for urgent joint effort by Federal and State/Territory Governments to ensure that the concerns and needs of siblings are given attention.

First, establish a national NGO coordination service.

Provide a co-ordinated voice for raising awareness of the particular roles and needs of siblings.

Develop data collection about siblings in conjunction with relevant organisations to estimate the numbers and needs of this cohort.

- Develop a national strengths-based service delivery model.
- Link families and siblings to early intervention and support services.
- Maintain a national overview of sibling support initiatives in order to address gaps and reduce the risk of duplication.
- Facilitate effective collaboration between organisations, to achieve flexible sibling supports.
- Initiate and manage the research required to underpin effective sibling programs.
- Develop and implement quality assurance systems that ensure consistent delivery, evaluation and reporting of sibling support programs.

³ 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*

**Attachment C: Royal Australian & New Zealand College of Psychiatry Report:
Addressing the needs of siblings of children with a disability or chronic illness
(2011)**

There are two parts to the RANZCP; a [Position Paper](#) and a longer [Issues Paper](#)