

I am following up from the roundtable that was held in Adelaide November 21st and would like to raise some thoughts/issues for the Council to consider. As the Director of Siblings Australia, my focus is on family support, in particular, siblings. First, I will respond to some of the discussion topics from the roundtable, and then explore the experiences of siblings, why they are overlooked, and why support is so important for them and for the person with disability. I will then follow with some recommendations for action. An Appendix will provide information on the work of Siblings Australia.

Throughout this piece, I will sometimes use the acronyms PWD (person/people with disability) and CWD (child/ren with disability).

Roundtable discussion

It was encouraging to hear from members of the Council that family support will be an important component of the NDIS approach. Certainly the local SA office has been very supportive in my attempts to include sibling/family support in individual plans, but there are some bigger picture issues that must be addressed if siblings are to be an integral part of family support approaches.

Topics from the discussion:

1. The *Shut Out: the Experience of People with Disabilities and their Families* report. Whilst this is a good summary of the disability sector, in spite of a lengthy submission by Siblings Australia, it had nothing meaningful to say about the experiences and needs of siblings. It was NOT a true reflection of 'family' experiences. This document is a prime example of the rhetoric around family support; in reality, family support is focussed on parents. Family support was also raised by a member of the roundtable but it was not able to be pursued further. Siblings Australia comes from the premise that disability affects the WHOLE family and siblings have the longest relationship of anyone with the person with disability. There is a wide range of policies/programs for the child with disability and their parents, but there are no specific policies/programs of support for siblings of children with disability, who are at risk themselves for a range of mental health issues. The aim should be to strengthen family relationships over a lifetime. Whilst the NDIS aims to provide more practical support to people with disability and therefore reduce the day to day responsibility of families, there is also a need to support the family emotionally as well and nurture/strengthen the relationships within it. And that needs to have a preventative focus.
2. Maurice Corcoran raised the issue of older people with intellectual disability being alone. If we supported siblings from a young age it might be that more would be involved in the life of their brother or sister over a lifetime.
3. There was a discussion about 'reasonable and necessary supports' for the person with disability and that PWD need to be able to live an 'ordinary life'. We also need to ensure that siblings can live an 'ordinary life'. We need to try to reduce the stress for siblings on a daily basis but also in terms of lifelong concerns. One parent at a workshop I ran said that he has two little girls and a boy with autism. He regularly tells them that they will have to look after their brother in the future as 'no-one else will'.

As a signatory to the UN Convention on the Rights of People with Disability, we must consider the needs of PWD but we cannot do that to the exclusion of the needs of their

families. Australia is also a signatory to the United Nations Convention on the Rights of the Child which is built on four fundamental principles relating to: non-discrimination; the best interests of the child; survival, development and protection; and children's participation and voice in decisions that affect their lives. That must include CWD AND their siblings. In continuing to overlook siblings, the government is overlooking its obligations as a signatory to both Conventions. Siblings, like other children, have a right to a childhood free from stress and emotional/physical harm. If we are to keep children with disability with their families, as we should, then we need to assist the other vulnerable children in the family to manage the stresses involved.

4. The issue of CALD communities being overlooked was raised and Rhonda responded by saying that this community needed to become stronger and ensure their voice is heard. This raises the issue of how any community ensures their voice is heard. It is particularly difficult to ensure siblings have a voice; partly because we (Siblings Australia) lack resources but also, siblings resist speaking out for a number of reasons. In addition, other people tend to look right through them, ignoring their needs, resulting in this group of children being referred to as 'glass children' – see 'Why siblings are overlooked' below. Over the years we have tried to engage with adult siblings (Adult Sibling Project, which researched the experience of adult siblings, both at the time and looking back on their childhood, as well as through our conferences, local gatherings and online). We have a closed Facebook group for adult siblings and several of those are keen to do more in getting siblings together. But again numbers are small and it is difficult to mobilise a bigger group, especially when there are no databases to which we can turn. We need resources to engage with more adult siblings. At a broader level we have an Australian Sibling Advocacy Network but this also needs to be developed further.
5. The National Disability Strategy. Again, in spite of submissions by Siblings Australia, there is cursory mention of siblings. It does state that The National Disability Strategy (NDS) highlights the importance of family in the life of a person with disability (PWD). The NDS was one of the key recommendations of the 2007 Senate Inquiry into the Commonwealth, State and Territory Disability Agreement (CSTDA), which highlighted the need for a co-ordinated, high level, strategic policy to address the complex needs of people with disability, their families and carers in all aspects of their lives. Again, the support available is really for the PWD and their parents (usually the mother). The NDS states that "multiple disadvantage can be experienced by people with disability". In fact the whole family can experience disadvantage and siblings are often dealing with this at a young age, when their emotional and social maturity has not fully developed.
Following the National Disability Strategy there was the COAG agreement between States and the federal government. One of the outcomes included 'families and carers supported'. At the time, I approached the State government to offer my contribution to ensure that outcome and was told that I needed to realise that such an outcome was 'purely aspirational'. I have met this type of response repeatedly over the years.

The sibling experience

In Australia, there are estimated to be more than 200,000 young people under the age of 25 years with a severe or profound disability. Of course, there are many more above this age range. We can assume a similar number of siblings. Certainly, some siblings are enriched by their experiences of growing up with a brother or sister with disability and can enjoy a lifelong reciprocal relationship;

others face significant challenges but they may not have the cognitive and emotional maturity to cope with those challenges. Research both here and overseas shows that, without support, they can be at risk for a range of mental and emotional health issues, at huge cost to themselves, their family and the community. For example, the 2008 AIFS report¹ showed that siblings had higher rates of depression, regardless of any caring role they may or may not play. There is some evidence that their physical health can also be affected².

Siblings Australia has had contact with many families and providers – through workshops, phone and email. The stories from both families and providers, and the countless requests for information about services, reinforce the above research about the need for sibling support.

Such stories outline a range of stresses due to the disability of a brother or sister, family experiences and also societal attitudes. Siblings may feel overlooked and isolated within their family as parents focus on the child with disability. Such perceived neglect can have greater impact on a young child's self worth and sense of identity when another child in the family is, in their view, very 'un-neglected'. And growing up with a child with disability can result in them subjugating their own needs, which can have impacts on other relationships into adulthood.

There may be ongoing stress due to the demands or difficult behaviour of the child with disability. There is emerging evidence that some experience direct physical harm from their brother or sister with disability, but this is often not reported as parents are fearful of what might ensue. Siblings Australia has developed a [draft report](#) on a small survey it conducted re this issue.

There might be other trauma related to witnessing the impacts of the disability on their brother or sister, e.g. seizures, hospital visits, 'meltdowns'.

There may be added stress if the parents' relationship breaks down (a more likely occurrence in families with disability), and the single parent, usually the mother, is also likely to have depression. These children may miss out on a childhood as the responsibilities can seem so great, and a pattern of worry can result.

At a community level, these children may miss out on recreational opportunities due to the demands on parents, their educational experience may be affected, and they may experience discrimination and stigma.

Finally siblings might experience confusion about their mixed feelings - on the one hand, love and protection towards their brother or sister, but at the same time, they may feel resentment, embarrassment, guilt, sorrow and fear. Such feelings can lead to low self esteem, shame or a sense of worthlessness³

All of 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

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

support, these siblings are at risk of developing longer-term physical, emotional and psychological problems.

And it is not just Siblings Australia that is highlighting the needs of siblings. For example, the RANZCP has released a Position Statement and Issues paper, *Addressing the needs of siblings of children with disability or chronic illness*, which was endorsed by over 70 major organisations around Australia.

'There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health problems, at considerable cost to them, governments, and the community.' RANZCP Position Statement. See 'Advocacy' in Appendix 1.

Families Australia developed a paper in response to the RANZCP papers, *Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations*. See 'Advocacy' in Appendix 1.

In addition, AICAFMHA's Position paper, *Improving the mental health of infants, children, and adolescents in Australia*, and the *Report of the Inquiry into the Mental Health and Wellbeing of Children and Young People in Western Australia*, by the Commissioner for Children and Young People, both refer to the risks for and needs of siblings.

A recent article in the journal, *Pediatrics* (2013; 132: e476–e483Pa), reported significant impact on siblings and concluded that *'Health care professionals need to consider a family-based health care approach for families raising children with disability.'*

Jenny Macklin, at the Communities in Control conference June 2008 highlighted the needs of siblings of children with disabilities. Referring to the Australian institute for Family Studies report (Edwards et al, 2008), she said the following:

The research tells us; 1) That carers worry about the impact on other family members, particularly the brothers and sisters of a child with a disability; and 2) That apart from carers themselves having significantly higher rates of mental health problems, their partners and children also experience high levels of depression.

Benefits of sibling support

With support in place, siblings are more likely to develop strength, resilience and tolerance, and less likely to feel isolated or develop ongoing health issues. They are more likely to understand issues pertaining to their brother or sister's disability or illness; understand that they are not alone with their particular concerns and feelings; understand and express a range of mixed feelings, including love, sadness, guilt, anger; and learn skills to manage the challenges.

In addition, if siblings are supported they are more likely to remain involved and contribute to the social and emotional wellbeing of their brother or sister with disability over a lifetime. Siblings will likely be in the life of someone with disability longer than anyone. In addition, they can also contribute to the understanding of professionals who work with the person with disability. And over time, they can be a crucial player in 'succession planning' with respect to the support of a person with disability, as parents become less able to provide that support.

We regularly see the effects of sibling support. Parents report that attendance at a *Sibworks* peer support program for primary school aged siblings results in the sibling showing more patience and understanding of the CWD. Siblings from such groups report greater understanding of disability in general. Unfortunately the number of groups run is very limited. Also, we see powerful examples of the benefit of peer support for adult siblings; one member of our SibChat forum had not had contact with her brother with disability for many years – in fact, she had panic attacks when in the same room, as he had been very aggressive toward her as a child. With the support of other siblings, along with the agency that supported him, she was very gradually able to renew her relationship and now they are an important part of each others' lives. Other members of SibChat have found emotional support for the challenges they face, but many also find an avenue for discussing the roles they may or may not play and find out about services and supports for their brother or sister with disability.

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
- Current mental health programs/policies for young people do NOT meet the needs of siblings
- There is no national funding available for sibling support; local programs are 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
- Any services that do exist are uncoordinated and lacking in evaluation. This is a serious gap in not only the disability sector but also across Health, Community Services and Education.

Why siblings are overlooked

1. Siblings are not good self advocates

It can be difficult for siblings to ask for help when they see a brother or sister struggling, and they may grow up feeling that their needs are less important. Often they are given – and believe – messages that they should feel lucky. They don't want to add to the considerable burden parents may face so in many cases, as we have seen, they try to be the 'good' child. Even into adulthood, many siblings have difficulty expressing their own needs. Some talk of feeling some disloyalty if they open up about their experiences.

2. Families stretched

Some parents are mindful of the impacts on siblings. Others, when under stress, may be too focused on the child with additional needs to recognise the challenges for siblings. In some cases, parents are struggling with their own stress, grief and acceptance and their emotional resources are stretched to the absolute limit.

3. Issues not recognised by service providers

Health professionals, teachers and other providers often lack understanding of the issues for siblings. This can hinder their ability to respond to a sibling in a supportive way. It is relatively easy for professionals to understand the effects on a child whose family experiences a range of other challenges but, in relation to siblings, the issues can be complex and less clear. And some of the

material on sibling support available through bigger and so called 'reputable' organisations is considerably less than 'best practice'.

4. Lack of resources

Due to limited funding, professionals who do understand sibling issues are often restricted in what they can do. The funding can come from philanthropic bodies or government, but might be time-limited or sporadic. A program initiated may not be funded to continue.

5. Lack of government policy

In spite of intense lobbying by Siblings Australia and government rhetoric about supporting whole families, the reality in Australia is very different. Whilst there is much evidence to indicate that siblings need support and that many parents are very keen to access support for their 'other' children, siblings are nowhere to be found in government policy. There is still no co-ordinated approach to sibling support.

One disturbing trend in terms of policy is that siblings are starting to be included under the 'young carer' policy umbrella, and so some people think that sibling support is covered by 'young carer' policies. However, this is not the case and nor should it be. The issues for young people caring for parents (the original 'young carer') and those for siblings can have some overlap but also have some major differences.

Whilst some siblings do provide some caring roles for a brother or sister, it can be detrimental if they are referred to as 'young carers'. Many siblings already have a heightened sense of responsibility and this term can add to their anxiety about the role they might be expected to play, even from a young age. It can also add to the difficulty in developing an identity that is not totally focussed on being a 'helper' and putting the needs of others first. Using the term 'carer' for siblings can frighten some of them away from an active involvement in their family as they can be afraid that the 'carer' role and all it encompasses may pass to them.

Second, the majority of siblings do not provide care, as the parent carer is present, and so we would miss many siblings if we went down that policy path. Many siblings, rightly so, are not eligible for carer programs. They need policies that focus on their particular needs across a lifetime.

And finally, the term 'carer' in this context does not add to the dignity of a young person with disability. What 15 year old boy with disability would want his younger sister to be known as his carer? If we are interested in young people with disability, we need to nurture the relationship between siblings, in order to benefit both.

By contrast, in the UK, the *Children Act* provides a more comprehensive 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 issued under the *Children Act* (Great Britain Department of Health, 1991) 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'. Siblings are provided for at the policy level, meaning there is an expectation they will be considered by agencies.

Questions for consideration

- What data is available regarding siblings of PWD? How many are there? What roles do they play? Are they happy with the roles they play? What support would they like?
- As they get older, do they talk to parents and the PWD about the future? Are there plans in place for the future of the PWD? Are they comfortable with those plans? Are they comfortable with the roles they will play in that future? What knowledge do they have of

the services available for the PWD – accommodation, medical, employment, recreation?
What knowledge do they have about such processes as Guardianship and Advocacy?

- As adults, what roles do they play in supporting parents and/or the PWD? How many are not involved with their brother or sister with disability? Why are these siblings not involved? Do they wish it was different?
- What support do siblings need as children and then as adults? Do they feel comfortable asking for help?
- Who should take responsibility for sibling support?
- What should the role of Siblings Australia be? If it has a role, how should it be resourced? Through the NDIS? Social Services? Health? Education?
- What sibling related services can be included in a participant's plan? Currently, Siblings Australia is providing limited parent training on supporting siblings, but what about parent workshops, sibling workshops, adult sibling information sessions?
- Who should carry out this work? How can we ensure it is best practice?
- How do we develop capacity in this area?

What needs to happen

The following are important to ensure siblings are supported and families can become stronger:

- Siblings are recognised as important family members who will likely be in the life of the PWD longer than anyone
- Relevant data is collected about siblings and their needs
- Siblings have their own concerns addressed through national policy and strategic directions, in a similar way to other vulnerable groups
- There is a national initiative that co-ordinates the relevant research, guides policy and develops 'best-practice' approaches to sibling support across the lifespan
- Intervention takes a preventative focus, both with individual siblings but also in developing stronger families
- There is significant workforce development to ensure all sectors have the necessary skills and training to support siblings
- There are clear guidelines developed on what can and cannot be included under 'family support' in a participant's plan, and also who can deliver these services
- The NDIA advocates for the importance of siblings at the federal government level to ensure that work already done in this space is not lost

Concluding thoughts

Siblings Australia believes that a cross-portfolio approach is required to truly address the needs of siblings. Family, school and wider community services comprise the settings within which sibling support approaches should operate and hence the Education, Disability (Social Services), and Health portfolios could all play a role in supporting siblings. Better integrated approaches are recognised both nationally and internationally as the optimal way of meeting the needs of children and families. Until now, in spite of much effort, Siblings Australia has found this approach to be very difficult to secure as it has found resistance to communication across sectors.

However, the NDIS presents a very real opportunity to highlight the needs of siblings and to facilitate their support.

It is acknowledged that sibling support is currently able to be included in NDIS plans through the area of 'family support', but this does need further refinement and clarity to ensure effective uptake and delivery of the services that can be made available. However, the NDIS also has the opportunity to highlight the gaps that exist in the national policy context concerning siblings and to engage with the other relevant sectors, as above, to ensure a cross sectoral national strategy to grow capacity in this area. Just as the NDIA would advocate for more speech pathologists if it found that there were not enough qualified speech pathologists available to meet the needs of families, so too it needs to highlight the gap in relation to sibling support in the national policy arena and ensure that they are recognised and supported. I would welcome the opportunity to work with the NDIA to further this process.

Appendix 1

Siblings Australia

Siblings Australia is the only organisation in Australia dedicated to addressing the needs of brothers and sisters of people with a chronic condition [disability, chronic illness and/or mental health issues]. The organisation's Mission is a simple one: *Siblings: Acknowledged, Connected, Resilient*.

Over a period of nearly 16 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 relationships with family, mental health, youth, education 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. The organisation has developed a national and international reputation for this work.

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.

For a discussion about this work and, in particular, mental health promotion for siblings and the need for policy directions see the [guest editorial](#), published in 2008 in the Australian e-Journal on the Advancement of Mental Health.

Workshops

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 (3 times), 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”.

Siblings Australia is in close contact with providers around Australia and similar agencies overseas. The service provider training has included professionals from a number of sectors, including, health, disability, counselling and education, and where appropriate has included training in the *Sibworks* model developed by Siblings Australia in 2004.

Resources

The organisation has developed a range of resources both in hard copy and online, including:

- *Sibworks* peer support program for siblings aged 8-12 years
- *Stronger Siblings* DVD for parents
- *Siblings and Mental Health factsheet* for siblings of young people with mental health issues

These resources can be purchased or downloaded for free via the [website](#), which also includes a range of information and networking opportunities, including a directory of sibling support services. In addition, the Executive Director’s book, [Siblings: Brothers and Sisters of Children with Disability](#),⁴ generated very powerful responses from around Australia and overseas. (It has also been published in the US, the UK, and Korea and a revised edition was released early in 2014.)

Research

The organisation has played an important role in areas of research to inform social policy makers about the needs of siblings, including: [Phone-in re sibling support](#) (2013), [Sibs and physical harm](#) (2012), [Scoping Project](#) (2009), [Adult Sibling Project](#) which also produced some resources, available [here](#) (2009), [ARACY Collaboration Report](#) (2008).

Advocacy

Siblings Australia has provided a number of [submissions](#) to government and other inquiries. Other bodies have also highlighted the needs of siblings, either as a focus or as part of an overall interest in child wellbeing. These can be found [here](#). Of particular note are the [Position Statement](#) by the RANZCP and the follow up [paper](#) by Families Australia that highlighted concrete directions for the future.

Also, Families Australia and Siblings Australia together developed a [National Action Plan](#) (along with a [briefing paper](#)) leading up to the 2010 election and this was presented to the Minister for FAHCSIA. 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. However, support for this could not be found.

⁴ Strohm, K.E. (2014). *Siblings: Brothers and Sisters of Children with Disability*. Wakefield Press: Adelaide

Siblings Australia deals with a high volume of enquiries on sibling issues, both through direct contact (phone, email) by parents and providers, 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. However, no one government department takes responsibility for this group of vulnerable children/adults and they do not fit into one policy area. The organisation has been functioning for the last 7 years through the voluntary efforts of its people but this cannot continue indefinitely.

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