

## Introduction

Siblings Australia welcomes the opportunity to contribute to the *Early Intervention Best Practice discussion paper*. The organisation has a particular interest in the health and wellbeing of siblings of children and young people with a chronic condition (disability, chronic illness, mental illness). We also recognise that siblings will likely be in the life of the child with disability longer than anyone. It is hard to understand why they are not a priority when addressing the needs of children with disability.

There is a lot of rhetoric within national strategies, policy and programs about the need to support families (alongside the child with disability), but in reality the focus is on parents. This is highlighted by the fact that many millions of dollars are spent on parent support through a number of national programs. There are no resources provided for a co-ordinated national approach for sibling support.

Siblings Australia does not have the resources to give more detailed feedback on the content of the discussion paper but will raise some broad concerns about the issue of 'family support', and ideas for what needs to be done, both at a wider level but also by the ECI sector.

This submission will then follow up with some background to support these recommendations and will provide information about Siblings Australia. The author can be contacted for further discussion.

## Early Intervention Discussion Paper- What needs to happen

At the outset, Siblings Australia would like to emphasise the cross-portfolio approach needed 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 can 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.

The ECI Discussion Paper outlines the *Early Intervention Seven Key Principles* and these include several which reflect the importance of family in the development of children but also the importance of supporting the whole family. But what does this mean, specifically, in relation to siblings?

The key elements of best practice in ECI also include reference to 'family-centred' and 'family-focussed' services. But how does this look, specifically, in relation to siblings?

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 child/adult longer than anyone
- Siblings need to be recognised as being 'at risk'. They can be particularly vulnerable within the family as they are dealing with the stresses as children. Their rights and needs should be considered alongside other family members.
- Siblings need to be recognised as playing an important role in the social and emotional wellbeing of young people with disability, not only as children but also over a lifetime. If we support siblings we are supporting the child with disability.
- The discussion paper should stress the importance of siblings having their concerns addressed through national policy and strategic directions, as with other vulnerable groups
- Relevant data is collected about siblings and their needs
- 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 role Early Intervention services can and should play in addressing the needs of siblings
- The ECIA advocates for the importance of siblings at the federal government level to ensure that work already done in this space is not lost

I stated earlier that 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. The NDIS may enable more of this cross sector collaboration.

It is understood that the Early Intervention sector may not be able to support siblings effectively but the sector should be highlighting the gap in national policy/programs for siblings in the same way this would happen if, say, there were not adequate or qualified allied health services. The ECI Discussion Paper presents a very real opportunity for the ECI sector to highlight the importance of siblings and to facilitate their support. I would welcome the opportunity to work with the ECIA or other relevant agencies to further this process.

## Background

Understandably, significant resources are spent on addressing the needs of children and young people with disability or chronic illness, both within families and in the community. However, research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members. In spite of this, the needs of siblings have been largely overlooked at both policy and service level.

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

## Why siblings are vulnerable

Certainly many siblings of people living with disability are enriched by their experiences. However, many can face significant challenges. A 2008 Australian Institute of Family Studies report found that parents of children with disabilities have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role<sup>1</sup>. Often these parents do not access services for themselves or their other children as the focus is on the child with disability. Other studies from overseas have shown that these children have increased rates of physical health problems too<sup>2</sup>.

The following is a list of reasons why siblings may be vulnerable to a range of mental and physical health problems, in no particular order:

- Parent relationship may break down (it is well accepted that the rate of marriage breakdown is higher in this population)
- Having a depressed parent (usually the mother)
- Ongoing stress due to the demands or difficult behaviour of the child with disability. Some siblings are both physically and emotionally harmed by a brother or sister with disability

<sup>1</sup> 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*

<sup>2</sup> Hogan, D., Park, J., & GoldschElder, 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.

- Physical harm to a sibling is often not reported by parents as they are fearful of what social services might do
- Possible trauma from seeing the impacts of the disability on their brother or sister eg seizures, 'meltdowns' etc.
- Teasing or bullying from peers; feeling the stigma
- Growing up with the needs of someone else always taking priority; they learn to put their own needs second which can also have implications for relationships over the lifespan.
- Can feel some neglect, and a child experiencing neglect can be impacted much more in terms of identity and self esteem when another child in the family is very 'un-neglected'
- Education outcomes may be affected by anxiety, tiredness, depression, social stigma and worry for parents
- Confusion about their 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 worthlessness<sup>3</sup>
- Worry about their brother or sister and a lifetime of responsibility for them

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

*'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 under [Advocacy](#) below.

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.'*

As well as siblings being vulnerable, recent policy directions can exacerbate/confuse the situation. For example, 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.

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 from a young age and across their lifetime. And finally, over the long term, such terminology does not add to the dignity of children and young people with disability.

## 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.

Access to relevant information and support programs enable siblings to:

- understand issues pertaining to their sibling's disability

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<sup>3</sup> 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

- understand that they are not alone with their particular concerns and feelings
- accept that it is normal to experience a range of mixed feelings, including love, sadness, guilt, anger
- receive support to express and deal with these feelings
- learn skills to manage the challenges
- develop a stronger relationship with their brother or sister with disability

As mentioned, siblings will likely be in the life of the child with disability longer than anyone. They have much to contribute to the social and emotional wellbeing of the person with disability over a lifetime. 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. But family relationships are built during childhood.

Sadly, many siblings move away from their families. If intervention occurred earlier and the sibling relationship nurtured, outcomes might be very different, both in childhood and beyond.

## 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/disability 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

## Why siblings are overlooked

There are a number of reasons why siblings are overlooked when it comes to considering families.

### 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.

### 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

Professionals may 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.

### 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.

Many government inquiries have explored the needs of families affected by disability and Siblings Australia has provided submissions. In spite of this, inquiries make little, if any, reference to the impact on siblings. This is alarming, as siblings will have the longest family relationship with the person living with disability and, potentially, will have a major influence on their lifelong wellbeing. Such reports influence government policy and at this point it is clear that governments in Australia have other priorities and these children continue to fall through the cracks.

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.

## 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](#),<sup>4</sup> generated very powerful responses from around Australia and overseas. (It has also been published in the US, the UK, and Korea and the second 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](#) and Issues Paper from the RANZCP and the follow up [paper](#) by Families Australia that highlighted concrete directions for the future.

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.

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/young people 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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<sup>4</sup> Strohm, K.E. (2014). *Siblings: Brothers and Sisters of Children with Disability*. Wakefield Press: Adelaide