

## Proposal to the NDIA

Submitted January 2016

### Introduction

This document outlines how Siblings Australia might contribute to the work of the NDIA through the NDIS. In summary, Siblings Australia can offer:

- direct services to families via a Participant's Plan
- expertise, having a national and international reputation as a voice for siblings and provider of services over 17 years
- research into the roles and needs of siblings
- workforce development, or sector capacity

This paper includes some background on the issues, a more detailed proposal, and an exploration of both the issues for siblings and the work of Siblings Australia via two appendices.

### The issue and opportunities for the NDIA

There are estimated to be 200,000 people under the age of 25 years with a severe or profound disability. (Australian Institute of Health and Welfare (Australian Bureau of Statistics, 2009 *Survey of Disability, Ageing and Carers*). There are many more who have a chronic illness or mental illness and who are older than 25 years. Many, if not most, of these people will have one or more siblings who will grow up alongside them. Understandably, significant resources are spent on addressing the needs of children and adults with disability, and in providing support to their parents. However, currently, there is no recognition in government policy or programs of the particular needs of siblings of people with disability, nor are there appropriate resources dedicated specifically to their support.

Research and anecdotal evidence supports the view that illness and disability affects the lives of *all* family members and that siblings of people with disability or chronic illness may experience particular stresses which make them vulnerable from an early age to a range of mental health difficulties, including anxiety and depression.

The Australian Institute for Family Studies report from 2008, [\*The nature and impact of caring for family members with a disability in Australia\*](#), showed that the presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have carer responsibility or not. The report highlighted the risk of siblings experiencing depression, especially when a parent has also experienced it.

[The Royal Australian and New Zealand College of Psychiatrists](#) noted in 2011:

*"Siblings of children with disability or chronic illness 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. In spite of considerable lobbying over a number of years, there remains a lack of coordinated activities and national action to support this group of at risk children."*

Unfortunately, in Australia at this time, unlike the case with parents (eg MyTime, carer services etc), there are no national policies or support programs for siblings. The government has continued to

overlook this important vulnerable group who have the potential of contributing much to the social and emotional wellbeing of people with disability.

There have been some attempts to include siblings under the 'young carer' or 'carer' umbrella but this is not appropriate for a number of reasons. The development of the NDIS affords an opportunity to utilise the knowledge and experience of Siblings Australia to establish more effective measures nationally for the support of siblings of people with disability, in order to meet this unfortunate gap.

Whilst the NDIS focuses on the participant and their needs, the NDIA has also recognised the importance of 'informal supports'. A large component of this 'informal support' originates in the family. Family functioning plays a huge role in determining how a child and then adult with disability fares in both the family and the community and, therefore, it is imperative to strengthen the family unit from its early stages. Parents of children with disability are often both emotionally and practically stretched, and may experience poor mental health. One of the key issues for them is how to balance the needs of all family members. Sibling support is a crucial part of assisting parents, who often say that the sibling becomes more of a worry than the child with disability. Siblings Australia has much experience in working with parents.

Sibling support is also crucial in maximising 'informal supports' for a person with disability over a lifetime. People with disability are at risk of becoming isolated. And yet so little is known about the roles and needs of their siblings, who potentially have the longest relationship of any; why some siblings remain involved and some move away from the family; what the barriers and enhancers to involvement might be? The NDIA has the opportunity to tap into the experience and expertise of Siblings Australia to ensure greater understanding of sibling roles and needs.

For a more detailed discussion on the issues related to sibling support please see Appendix 1 and for more information about Siblings Australia please see Appendix 2.

## Proposal

With adequate resources, Siblings Australia could provide the following:

1. Direct services to parents and siblings via NDIS Participant Plans, in order to address an unmet need
  - a. Deliver parent information sessions, parent workshops and the sibling peer support program, Sibworks.
  - b. Deliver peer support and information to adult siblings who are becoming more involved in supporting their adult brother or sister with disability.

Siblings Australia is registered in South Australia to deliver these services but there needs to be greater exploration of the training and resource development needed to expand these services, for which there is a high need, both in SA and other States.

2. An experienced and expert voice to assist in guiding policy and practice approaches to sibling support nationally
  - a. Provide a co-ordinated voice for raising awareness of the particular roles and needs of siblings across their lifespan
  - b. Collect data about siblings in conjunction with relevant organisations to estimate the numbers and needs of this cohort

3. Research into the roles and needs of siblings. Siblings Australia has already conducted considerable research in these areas, either solely or working with other organisations – see <http://siblingsaustralia.org.au/research-sibsaus.php>

In addition there have been two journal articles on the evaluation of the Sibworks peer support program carried out by the University of Adelaide Psychology department. See Appendix 2 for details.

4. A clearinghouse for information related to sibling needs, local, national and online sibling support services, completed research into sibling issues and needs, and various policy directions related to sibling and whole family support:
  - a. Further develop the organisation's website to provide information and resources as well as opportunities for sharing/collaboration for families and providers, including schools, pre-schools, disability and health organisations
  - b. Maintain a national overview of sibling support initiatives in order to address gaps and reduce the risk of duplication
  - c. Link families and siblings to prevention, early intervention and support services across the lifespan
5. The development of 'best practice guidelines' and an accreditation process for sibling services around Australia
  - a. Initiate and manage the research required to underpin effective sibling programs
  - b. Carry out a scoping project (building on the 2009 Scoping Project) of all services that might be available for siblings (within disability, health, education and community agencies) to highlight both good practice and also the gaps
6. Development of a national service delivery model, including how this fits into Participant Plans
  - a. Establish a national reference group and relevant consultation groups to ensure shared goals and practice
  - b. Explore the workforce development needs of different sectors, including families and communities, disability, mental health and education, including the use of online training programs
  - c. Facilitate effective collaboration between sectors and organisations, for flexible sibling supports
  - d. Explore or expand partnerships with relevant government programs to value add to what is happening already – e.g., *National Framework for Protecting Australia's Children, Family Support Program, Communities for Children, Children and Family Roundtable, Mental Health programs, Autism and Early Intervention, the new National Carer Gateway, Supporting Children with Autism.*
  - e. Develop and implement quality assurance systems that ensure consistent delivery, evaluation and reporting of sibling support programs – this could include a certification process for services
7. Development of specific support for adult siblings, which again could be provided through Participant Plans
  - a. Carry out research into the needs of adult siblings (building on the 2009 Adult Sibling Project) but focussing on the different roles they play, and the barriers/enhancers to their involvement in the life of their brother or sister with disability over a lifetime. (See further discussion re adult siblings in Appendix 1)
  - b. Develop a particular model for the support of adult siblings, both in terms of their own needs but also to assist them in their support role of a brother or sister with disability.

For a more detailed look at particular strategies regarding families, school, and community, please refer to the table included in the Families Australia paper [Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations](#) (a follow up to the RANZCP advocacy work mentioned below in Appendix 2). This paper explores some of the activities which fit under a range of sectors including disability, health and education.

If the NDIA agrees that sibling support can be included in a participant's plan, there needs to be greater clarity around what can be included. Also, there are likely to be a range of agencies providing sibling support programs. This means that the NDIA will need to have some means of assessing the

legitimacy of these programs. At the moment there is no accreditation process or even 'best practice guidelines' in place. The sector is un-coordinated and lacking in skills and resources, which is why we are suggesting that Siblings Australia could help the NDIA through providing some form of accreditation for sibling support programs. The other issue is cost-effectiveness – there needs to be some planning for how to deliver support in the most economically viable way eg individual vs group approaches and timing of intervention ie at diagnosis or later.

At the moment, Siblings Australia is registered to provide its services in SA. This includes or could include in the future, sessions with parents on how to support siblings, young sibling workshops and adult sibling information sessions/peer support. These can also be done via phone/skype/webinars so they could easily be transferred to families in other States.

Siblings Australia understands that development of the sibling support sector does not rest solely with the NDIA. However, it urges the NDIA to recognise the importance of siblings in the life of a person with disability and to facilitate the provision of support for siblings as part of its operations. Siblings Australia would be happy to explore with the NDIA how this might happen, including through Participant Plans but also through consideration of how the Sector Development Fund (SDF) and the Information, Linkages and Capacity Building framework (ILC) might recognise siblings.

For those aspects of sibling support that are not able to be made a part of the NDIS, it is imperative that the NDIA highlight to government the gaps in sibling support via both disability and mainstream services. At the moment, in spite of government claims, siblings are not able to access appropriate support via mainstream services. Again, Siblings Australia would be happy to further explore this with the NDIA.

## Appendix 1

### The sibling experience

Certainly many siblings of people living with disability are enriched by their experiences. However, many face significant challenges. As mentioned earlier, the 2008 Australian Institute of Family Studies report found that parents of children with disability have the lowest wellbeing of any group and higher rates of depression than the general population. It also found that siblings had a significantly increased risk of depression, regardless of any caring role<sup>1</sup>. Often 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>. In many cases, these children have to deal with separated parents (it is well accepted that the risk of marriage breakdown is higher in this population), a depressed parent (usually the mother) and also the ongoing demands or difficult behaviour of the child with disability.

It is recognised that siblings often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand the mix of feelings they experience. Siblings can experience a range of feelings and reactions to having a brother or sister with disability or chronic illness and these 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. Such feelings, left unaddressed can lead to lowered self-esteem, shame or a sense of worthlessness<sup>3</sup>. Their education outcomes may be affected by anxiety, tiredness, depression, social stigma and worry for parents. These problems are exacerbated by limited access and availability of appropriate services and the practicalities of family

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<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., & 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.

<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

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.

Siblings can also feel a lifetime sense of responsibility and as they become older another set of concerns can arise. They may struggle with what might happen to their brother or sister if parents cannot provide care for some reason. Will they find a partner to share the responsibility? Should they have children of their own and what if they have a disability? Adult siblings have been referred to as the ‘club sandwich’ generation if they have responsibility for ageing parents, a brother or sister with disability, and their own children. Adult siblings have much to contribute but they should be given support to manage their own needs and those of their brother or sister. More work needs to be done to facilitate effective communication within families so as to ensure a good life for all members.

## Sibling support

It is important to intervene early and provide particular support to siblings as children. This needs to include approaches within all the settings in which the child operates, for example, family (immediate and extended), friends, peers, school and community. And this support needs to continue over the lifespan, as issues change.

## Benefits of sibling support

With support in place, siblings are more likely to develop strength, resilience and tolerance. They are less likely to feel isolated or develop health issues and more likely to contribute to the well-being of their brother or sister with disability. The whole family is likely to function more positively.

Access to relevant information and support programs enable siblings to:

- understand issues pertaining to their sibling’s disability or illness
- understand that they are not alone with their particular concerns and feelings
- accept that it is normal to experience a 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

## The Gaps

Currently, there are significant resources provided to support services for other family members but not for siblings.

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings (parents regularly identify siblings as one of their major concerns)
- 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
- Current family/carer programs/policies 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 (how do we know that they are not doing harm?)

There have been some attempts to include siblings under the ‘carer’ umbrella but this is regrettable for a number of reasons, not least of which that the needs of siblings go way beyond any caring role they

may or may not play. Some siblings provide no direct care to a brother or sister but contribute much in other ways. And even if not playing a caring role, they can still face significant challenges. It is important to support siblings in whatever role they choose to play in the lives of their brother or sister over a lifetime, and siblings have said they would rather this support came from specific sibling services. They are likely to have the longest relationship of any with the person with disability and whether they play any 'hands on' caring role or not they may still play an important role in the social and emotional wellbeing of a person with disability. At the moment, regrettably, siblings do not have a voice.

## Appendix 2

### Siblings Australia

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

Over a period of 17 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.

As mentioned, 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 (both children and adults)
- 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.

#### Workshops

Workshops have been run for thousands of siblings, parents and service providers all around Australia (in both metro and regional areas) and the Executive Director has been asked to present in the UK, US, Canada and several times in Italy. The workshops, in particular, have served to empower parents in supporting their whole family. Feedback has been overwhelmingly positive.

We are in close contact with providers around Australia and similar organisations 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](#)

These resources can be purchased or downloaded via the [website](#), which also includes a range of information and networking opportunities, including a directory of sibling support services. The organisation has a strong social media presence and facilitates closed Facebook groups for siblings, one in conjunction with the US Sibling Support Project. There is potential to greatly improve the quality and reach of these. In addition, the Executive Director's book, *Siblings: Brothers and Sisters of Children with Disability* (first published in 2002 and revised in 2014)<sup>4</sup> generated very powerful responses from around Australia and overseas. It has also been published in the US, the UK, and Korea.

## Research

The organisation has played an important role in areas of research to inform social policy makers about the needs of siblings, including (from newest to oldest):

- [An evaluation of the Sibworks program](#) 2015  
A controlled trial of the SibworkS group program for siblings of children with special needs, published in *Research in Developmental Disabilities*  
A second one has also been published  
Rachel M. Roberts, Anastasia Ejova, Rebecca Giallo, Kate Strohm & Meredith E. Lillie (2016): Support group programme for siblings of children with special needs: predictors of improved emotional and behavioural functioning, *Disability and Rehabilitation*, DOI: 10.3109/09638288.2015.1116621
- [Phone-in re sibling support](#) 2013  
Siblings Australia conducted a phone-in on January 12<sup>th</sup> 2013 to gauge families' thoughts on the availability of sibling support and what would help.
- [Sibs and physical harm](#) 2012  
For some time Siblings Australia has been concerned about the issue of siblings being physically hurt by a brother or sister with disability. We developed surveys for parents, siblings and service providers and whilst we understand this is a sensitive topic, we also believe that it is an issue worthy of consideration. We hope that this small research project will lead to more extensive research through which we can gain more insight into the support needs of families.
- [Scoping Project](#) 2009  
This research investigated what sibling programs were operating around Australia, what models were used and what workforce development was needed. Over 100 providers of sibling programs responded and reinforced the idea that there needed to be more collaboration, more resources and skill development as well as more funding for these programs.
- [Adult Sibling Project](#) 2009  
This research explored the concerns and needs of adult siblings of people with disability. It also produced some resources for adult siblings, available [here](#).
- [ARACY Collaboration Report](#) 2008  
Siblings Australia had long been concerned about the lack of collaboration and co-ordination around research into sibling issues and models of support. After contacting researchers around the country we established a group of researchers and together we were successful in gaining a small encouragement grant to facilitate some collaboration between researchers and service providers. Unfortunately with limited resources and other factors, this work could not be continued.

## 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 (this was endorsed by many organisations and provided to government) and the follow up [paper](#) by Families Australia that highlighted concrete directions for the future.

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

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. There is a need for another such gathering to share and learn from each other.

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.

The difficulty for Siblings Australia is developing sustainability as funding has been sporadic and short term. No one government department takes responsibility for this group of vulnerable children/adults and they do not fit into one policy area. They could easily fit into Mental Health, Families and Communities, or Education. Ideally they should be considered by all of these portfolio areas.

For a discussion about mental health promotion, in particular, 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.

### *Funding History*

Siblings Australia was first established in 1999 and since that time has developed a national and international reputation for its work with families and professionals. In the early years the organisation received funding from a variety of government and community sources, but with project based funding being so limited, it struggled to develop sustainability. Over a few years prior to 2007 the organisation received funding through the FAHCSIA run Stronger Families and Communities for Children initiatives via the federal government and in 2007 received funding through DOHA, via the Mental Health, Early Intervention and Prevention area. We began to develop relationships with a number of DOHA funded programs, including Beyond Blue, Mind Matters, Kids Matter, KidsHelpline, but more work was needed.

Toward the end of that year we were invited by two government officers to submit a proposal for the following year's funding. Before we were able to complete that task a federal election was called and so no new contracts could be considered. When the new government came into office the organisation was told that it could not access funding. Since then it has been continuing to operate as best as it can, largely through the voluntary efforts of its people.

### **Why Siblings Australia should be valued and supported**

- The organisation has over 17 years of experience in this area and is in an ideal and unique position to carry this work further – if it is not supported this expertise will be lost
- Siblings Australia continues to hear from many families and providers who express concern about available services for siblings and the value of Siblings Australia, including through a petition in 2008, forwarded to government when funding was lost, and another in 2015. The comments from some of the signatories for the first petition can be viewed [here](#) and the second [here](#)
- The work that is being done across Australia is unco-ordinated – Siblings Australia with its extensive networks and experience has the capacity to ensure greater consistency in approach

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