

Siblings Australia welcomes the opportunity to provide a submission to the *General issues around the implementation and performance of the NDIS* inquiry. The organisation has also provided a submission to the *Provision of services under the NDIS Early Childhood Early Intervention Approach* Inquiry by this same committee.

This submission will explore the following:

- 1) The NDIS and families
- 2) The NDIS and parent caregivers
- 3) Why siblings should be considered
- 4) The NDIS and siblings
- 5) Recommendations
- 6) Appendix 1 The sibling experience
- 7) Appendix 2 Siblings Australia – its history and work

The NDIS and families

The National Disability Insurance Scheme (NDIS) is the ‘new way of providing support for Australians with disability, their families and carers’. The NDIS helps people with disability to, amongst other things, ‘maintain informal support arrangements - the help people get from their family and friends. It is support people don’t pay for and is generally part of most people’s lives’.

This new approach to funding for people with disability puts them at the centre, providing them with choice and control of what supports they need. This is how it should be. However, there has been scant attention given to the importance of a ‘whole family’ approach in support of people with disability. Of course, if people with disability are able to access better supports, there will be flow on benefits for families and carers. However, not all challenges/stresses for families will be erased with these better service systems.

Family relationships are crucial for people with disability, not only those which involve caregiving. The family is the first social and emotional ‘network’ and this might continue to be the case over the lifetime of a person with disability. 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. However, there are ongoing stresses for the whole family, which can impact family functioning and which go beyond whatever services might be accessed. Some families cope well with these stresses but others struggle. It depends on a range of factors including the strength of the parental partnership, number of children, type of disability, the strength of social support networks, previous experience of disability by parents, religious beliefs and many more.

Whilst this is recognised through the statement that the aim of the NDIS is to ‘help people with disability to maintain informal support arrangements’, the NDIS does not give enough attention to HOW those informal support arrangements might be nurtured over time and how whole families might be supported. It can be complex, and the issue cannot be understood unless there is more serious exploration of the dynamics within a family which includes a member with disability.

The NDIS and parent caregivers

There has, and continues to be, considerable awareness of the impacts on parent carers of people with disability. People can understand to some extent the stresses on parents, e.g., the grief and possible guilt, stress on partner relationships, loss of income and social connections. The Australian Institute for Family Studies (AIFS) found in their 2008 study on the wellbeing of parents of children with disability, [*The nature and impact of caring for family members with a disability in Australia*](#), that parent carers had higher rates of depression than the wider population (and showed the same for the other children (siblings) in the family). Other international studies have confirmed the impact on the longer term mental health of parents.

Whilst the NDIS doesn't directly provide parent support (there is indirect support via the programs/services for the person with disability and some direct parent training available), the NDIA, and the disability sector in general, recognises the needs of parents and is aware of other policies and programs that support them. Many millions of dollars of federal government funding are put into parent carer information, support and advocacy through a variety of programs such as Carers Australia, Carer Support and Respite centres, the new Carer Gateway, and MyTime. And these continue with strength as the NDIS rolls out.

However, 'this new way of providing support for Australians with disability, their families and carers' continues to not give adequate attention to the 'whole family' and, in particular, continues to overlook siblings of people with disability. This is common to all sectors that support people with disability – in most cases the term 'family' is used when what is really meant is 'parents', and most usually mothers. There is no need to ask the question 'why consider parents?' However, before consideration is given to the NDIS and siblings, it is important to think about why siblings also are important.

Why consider siblings?

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 physical 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.

See Appendix 1 for a broader look at the experience of siblings, but what follows is a discussion on the importance of considering siblings when thinking about people with disability and their families. Siblings are important for three main reasons.

First, as mentioned above, siblings have been found to have higher rates of mental and physical health problems. If there is a genuine intention to support people with disability and their FAMILIES, the outcomes for siblings also need to be considered and addressed. This situation has implications in terms of preventative mental health approaches. If a known group of Australians are at risk, there should be some targeted approaches to their support. Of course, this should not be the responsibility of just the NDIS, but if the intention of the scheme is to support families, then the NDIS should be considering the needs of siblings and where/how they could be supported.

Second, sibling support is a crucial part of assisting parent carers, who often say that the sibling becomes more of a worry than the child with disability. Many parents recognise the impact on siblings and see the signs of distress in their children, but have limited time and emotional energy to address it. This only adds to the guilt, sadness and general distress of many parents. Parents of children with disability are often both emotionally and practically stretched and need assistance to balance the needs of all family members, if they are to feel competent and supported.

A particularly difficult area for parents to manage is the aggression directed towards siblings by some children with disability. In fact, in more serious instances, where a sibling needs medical attention, many do not share the information about how a sibling might have been harmed for fear of the consequences for the family if that information is divulged.

Third, siblings are important because they usually have the longest relationship of any with the person with disability. We know that people with disability are at risk of becoming isolated as they age. And yet so little is known about the roles and needs of siblings. Some siblings will have a very close relationship, and contribute a huge amount to the wellbeing of a brother or sister with disability over a lifetime. Research both here and abroad has shown the considerable contributions of siblings. Some become strong advocates or provide direct support. Some take on full time care, in some cases, at the expense of their own life goals. Some move right away and lose contact – which is a tragedy for all. Surprisingly, there is little attention given by the disability sector to these crucial relationships. Why do some siblings remain involved and others move away from the family? What are the enablers of siblings having a strong relationship? What are the barriers? How can we best support siblings throughout their lives? How can we support families through the different stages of transitioning family caregiving roles, allowing siblings to make choices? How can we ensure siblings are able to create a ‘good life’ for their brother or sister with disability and themselves?

It is interesting to note some reasons why siblings are so overlooked. They are not good self-advocates, having grown up with the message that the needs of others are more important. They are often told how ‘lucky’ they are to not have a disability and, on some occasions when they have dared to raise their own challenges, they are met with derogatory comments using such words as ‘selfish’ and ‘pity party’. Parents are often too stretched to advocate on their behalf, there is little understanding in the wider community of their needs and, with no relevant policy, there is little imperative to consider siblings. Unlike in Britain, where the Children Act specifically mentions that both children AND their brothers and sisters need to be supported, here there is no such guidance.

The NDIS and siblings

Unlike the situation with parents as discussed above, there is no recognition in broader government policy or programs of the particular contributions and needs of siblings of people with disability, nor are there appropriate resources dedicated specifically to their support. Very few siblings access support. In spite of assurances in the early stages of the NDIS that whole families would be supported, and that no-one would be worse off, there is no provision for sibling support within the current NDIS. In fact, the few services available for siblings through disability agencies appears to have dropped even further since the introduction of the NDIS (see Appendix 2).

There have been some attempts to include siblings under the ‘young carer’ or ‘carer’ umbrella but this is not always appropriate for a number of reasons, not least of which is that the needs of siblings go way beyond any caring role they may or may not play. Even if not playing any caring role, they can still face significant challenges. And even without a ‘hands on’ caring role, they might contribute much in other ways to the social and emotional wellbeing of the person with disability. The notion of ‘young carers’ also needs to be considered in the context of Children’s Rights and the dignity of people with disability. See [here](#) for further discussion on these issues.

Of course, some siblings who take on significant caregiving may be able to access support through carer focused agencies but, again, these are only relevant and appropriate for a small percentage of siblings. 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, run by peers who fully understand their experiences.

So where and how should siblings access support? Siblings Australia understands that development of the sibling support sector does not rest solely with the NDIA. However, the NDIS website states that it will ‘fund supports that family members need as a result of a family member’s disability, as

well as supports that enable sustained caring by family members'. See <https://www.ndis.gov.au/families-carers/family-supports>.

If there is funding for such support the two choices would be either via Participant Plans or through the Information, Linkages and Capacity Building framework (ILC).

Currently, funding for family support is not reflected in the NDIS Price Guide to be used in reference to Participant Plans. The only thing that refers to family support is the support item 'Training for carers/parents' with the Support Item reference number of 15_038_0117_1_3, with the description 'Training for carers in matters related to caring for a person with disability'. Again this has moved away from 'family' to 'carer'. There is nothing in this item list that refers to siblings.

If sibling support were able to be included in a Participant Plan, there would need to be greater clarity around what could be included and what assessment tools would be utilised to ensure legitimacy of available services. At the moment there is no accreditation process or even 'best practice guidelines' in place within the small group of providers of 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 e.g. individual vs group approaches and timing of intervention i.e. at diagnosis or later. At the very least, these discussions should be happening now to ensure siblings are recognised appropriately.

If the NDIS is not able to support siblings through its Participant Plans, it should identify where this might be possible elsewhere within the NDIS (e.g. ILC) or remove the above statement about family supports from both its online and written materials.

Of course, siblings SHOULD be an important part of the focus for a range of sectors – disability, health, families, education, community services. The NDIS website states, 'the community services system continues to have responsibility for broad population wide programs and services including family support, counselling, parenting skills, and aspects of the child protection system'. Certainly such services provide a lot of support to other groups of vulnerable children but siblings are not provided for in a meaningful way. Given this, the NDIA should be doing more to ensure siblings are catered for through these wider systems.

Recommendations

These recommendations explore a number of options for sibling support, directly through NDIS, indirectly through ensuring support for Siblings Australia and, finally, through strong advocacy re siblings to wider sectors and to government. If the NDIS recognises the importance of siblings for people with disability, it needs to advocate for a stronger sibling support sector.

Direct action NDIS

1. Clarify what the NDIS will fund in terms of family support
2. Clarify which direct services to parents and siblings, both children and adults (e.g. parent information sessions or workshops on sibling support, peer support for siblings) might be possible via NDIS Participant Plans
3. Support the development of a national service delivery model for both children and adult siblings, including how this fits into NDIS Participant Plans or ILC approaches or other sectors. This might include workforce development across different sectors, collaboration between sectors and organisations, for flexible sibling supports, and 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, Mental Health programs, Autism and Early Intervention, the new National Carer Gateway, Supporting Children with Autism*.

Support Siblings Australia

4. Support Siblings Australia in its role as an experienced and expert voice to assist in guiding policy and practice approaches to sibling support nationally

5. Support research into the numbers, 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 further details.
6. Support the development of ‘best practice guidelines’ and an accreditation process for sibling services around Australia
7. Support 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:

Advocacy

8. The NDIA needs to highlight to government the gaps in sibling support and advocate that one department takes responsibility for addressing those gaps. This could be preceded by a Joint Standing Committee Inquiry into the roles/needs of siblings of people with disability

Appendix 1

The sibling experience

Many siblings of people living with disability share a mutually loving and close relationship with their brother/sister with disability. For others, that is not possible in spite of trying. Even with a close relationship, siblings may experience particular stresses, especially given the fact they are children when first experiencing such stresses, which make them vulnerable from an early age to a range of longer term mental (including anxiety and depression) and physical health difficulties¹. [The Royal Australian and New Zealand College of Psychiatrists](#) Position Paper and Issues Paper, 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.”*

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 caregiving responsibility or not. The report highlighted the risk of siblings experiencing depression, especially when a parent has also experienced it and regardless of any caring role².

The challenges for siblings will vary from family to family, depending again on a range of factors, including their age, whether they are younger or older than the child with disability, how many other kids in the family, the type of disability, parent attitudes, social support etc. As mentioned, these challenges usually begin when siblings are quite young. They are unlikely to have the maturity to cope – unlike parents, they are babies, toddlers, children or young adolescents. 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.

Siblings might be very confused by what is happening around them and by their own 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

¹ 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.

² 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*

can lead to lowered self-esteem, shame or a sense of worthlessness³. There might be regular anxiety due to health crises for their brother or sister or, if the disability includes difficult or aggressive behaviours, there may be anxiety about the safety of parents and themselves. Some deal with intense bullying because of their brother or sister. We all wish this didn't happen but it does and sibs need support. They might experience grief – for the struggles of their brother/sister, for their parents who are giving so much, but also for themselves not being able to have the relationship they see other brothers and sisters having together. They might have feelings of guilt about doing things their brother or sister can't. They might miss out on time with parents and have their needs put on the 'back burner'. Growing up feeling less important can have a huge impact on longer term self-worth. 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 life where the needs of a brother or sister take greater priority, to the point where parents might not access services for themselves or their other children.

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
- understand and accept 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/carers programs/policies do NOT meet the needs of siblings

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

- There is no national funding available for sibling support or advocacy; 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?)

Appendix 2

Siblings Australia

Siblings Australia is the ONLY organisation in Australia dedicated to addressing the needs of brothers and sisters of people with disability. The organisation's Mission is a simple one: *Siblings: Acknowledged, Connected, Resilient*.

Over a period of 18+ 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 both a national and international reputation for its work.

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. 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.

However, with no imperative for agencies to include siblings, and given the constraints in funding for most agencies, the uptake of such activities has gradually reduced. In fact, since the introduction of the NDIS, requests for the above workshops have almost stopped completely. See NDIS below.

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)⁴ 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*
- [Phone-in re sibling support](#) 2013
Siblings Australia conducted a phone-in on January 12th 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.
- [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
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 collaboration between researchers and service providers.

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

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.

Advocacy

Siblings Australia has provided a number of [submissions](#) to government and other inquiries. There have been regular meetings with government Ministers and department representatives. 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, again, 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](#) (*Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations*) by Families Australia that highlighted concrete directions for the future through a range of sectors.

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. People continue to 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. Comments from some of the signatories for the first petition can be viewed [here](#) and the second [here](#).

NDIS

At the moment, Siblings Australia is registered to provide its services in several States. This includes or could include in the future, one-on-one sessions or workshops 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. Currently just a few one-on-one parent information sessions have been completed, feedback has been very positive, but the awareness of such services is low and, with scant resources, the organisation cannot do more to promote this. In addition, the focus within the NDIS is very much on the person with disability and, therefore, many planners, LACs etc. are not pursuing this service.

As mentioned above, interest in siblings by agencies has reduced considerably. Previously, with block funding arrangements, agencies had the capacity to use some of their funds to provide sibling support programs. The NDIS, with its direct funding to participants, has resulted in less flexibility for agencies to provide these services. And with no other imperative, e.g. policy or guidelines re sibling support, agencies have other priorities.

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 a contract could be signed a federal election was called and so no new contracts could be considered. A new government was elected and the organisation was told that it could not access funding. Since then it has been continuing to operate as best as it can, with no funding, in a largely voluntary capacity. In addition to its one staff member/volunteer there is a Board of management that includes a number of experienced professionals, e.g. a child psychiatrist, retired school counsellor, retired law professor. It includes 3 adult siblings.

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 only one policy area.

Current work

This year Siblings Australia has received two grants – one through the Sector Development Fund to explore the needs of adult siblings and to develop a range of online and face to face support options. That work is almost completed, but there is no further support available to continue it. The other grant, through the Information, Linkages and Capacity Building program, is to map current sibling services around Australia, develop a picture of the needs of siblings and the gaps in their support. We are developing surveys for providers, parents and siblings. So far, the provider surveys show very few direct services for siblings and, those that do exist do not follow 'best practice' approaches. The sector is still unco-ordinated. These findings look very similar to those in 2009. At that time, there was no response when those findings were given, along with recommendations, to the government.

The future

The future of Siblings Australia is very insecure. If core funding cannot be found for the organisation by early next year it will need to close. It will be regrettable that governments over several years have ignored what we and very reputable bodies have said about the need for more sibling support. And the expertise and experience of an agency that should have been valued and supported will be lost.

Kate Strohm, Director, Siblings Australia

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