Mapping Project
Support for Siblings of Children and Adults with Disability

Final Report

Project Duration
Jan 2017-Dec 2017

Funded by
National Disability Insurance Scheme (NDIS)

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Executive summary

Over the period January 2017-December 2017, Siblings Australia was supported by the National Disability Insurance Scheme (Information Linkages and Capacity Building; ILC) to carry out a mapping project of sibling support in Australia.

A note on language and format: Although ‘sibling’ is a generic term, in this report the term will be used only to refer to the child/adult without disability. Also, specific quotes from parents, providers and siblings are highlighted in italics.

Project aims

The aims of this project were to:

a. Understand the current situation for support for siblings of people with disability (PWD), including mapping of current supports, needs and gaps. The mapping was to be:
   o Underpinned by a definition of what constitutes ‘support’ for siblings of PWD; and need to then make sure this definition is stated explicitly in the report.
   o Differentiated according to the supports that are available to, and/or needs and gaps for, siblings of PWD by age cohort, kind/type of support available and function.

b. Outline how such initiatives may contribute to the achievement of the ILC outcomes.

c. Update the current online directory of supports/services.

d. Support a national consultation group to provide input and share information.

e. Draw on complementary projects being conducted by Siblings Australia to inform findings.

f. Produce a final report for the NDIA capturing the information from items a. to d. and evaluation of the project.

Method

Three separate surveys were developed by the project team and circulated through email lists and social media to (1) organisations from a range of sectors, (2) parents / carers of children and adults with disability and (3) adult siblings of PWD.

The survey was interested in the following types of sibling support:

1. Direct support that specifically targets and involves siblings (e.g. sibling-specific counselling or peer support programs)

2. Indirect support that addresses sibling issues, but does not directly involve siblings (e.g. advice/resources for parents on support of siblings)

3. Other broader supports that are not specifically for siblings but may still benefit them (e.g. school based resilience programs).

In response, completed surveys were received from 48 service providers\(^1\), 198 parents and 106 adult siblings.

\(^1\) A further 27 responses were received that did not answer beyond the first 2-3 questions, meaning that they did not provide enough information to be included in the sample.
**Key findings**
The overall finding of the project is that there is an extensive need for sibling support services in Australia, but very few exist.

Further, the project highlights a number of other recurring themes (listed in brief in Table 1 below and discussed further in Section 4 of the full report):

<table>
<thead>
<tr>
<th>Table 1. Themes</th>
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| **Needs (sibling concerns)** | - Parents, providers and siblings all confirm that siblings of children and adults with disability can be very vulnerable.  
- Many siblings have experienced health or mental health problems that they say are a result of the stresses involved in their family situation.  
- Sibling needs change over a lifetime - they need support to manage their own challenges, but as they become older they also need support to assist in their brother or sister having a ‘good life’. |
| **Parent concerns** | - Watching the impact on siblings and being unable to find specific support for them adds to stress and frustration for parents. |
| **Sibling support services** | - There are a handful of sibling specific services around Australia  
- Most sibling specific services are subject to eligibility criteria, e.g., that the siblings who take part come from families already receiving services from the provider.  
- Sibling programs can be difficult to define; sibling support is often included with other family activities or services for children with disability, rather than provided as sibling specific support.  
- Some carer services include siblings; however, the role of sibling and carer should not always be conflated and carer services are not always relevant or appropriate for siblings. |
| **Gaps** | - There is little recognition of the contribution and needs of siblings across the lifespan by professionals in the disability, health and education sectors and by policymakers.  
- There is a significant gap in support services for siblings; even more so in rural areas.  
- With the introduction of the NDIS, sibling support services have reduced significantly.  
- Few siblings accessed specific support in childhood or adulthood and only a small number of those believed that the support they did access had fully met their needs.  
- The sibling support sector is un-coordinated and lacking in ‘best practice’ approaches.  
- There is limited evaluation of the few existing sibling support programs. |
There is little or no collaboration between sibling support services, or referrals between such services.

There is no policy framework for sibling support and without it there is little imperative for agencies to provide such support.

There are many barriers to agencies providing sibling support services, including lack of policy that directly relates to siblings, lack of funding specific to siblings, and a lack of understanding/skills by professionals regarding sibling needs and models of support.

RECOMMENDATIONS IN BRIEF

Based on the information collected in the project, recommendations have been developed. Below is a brief summary; Section 6 of the full report contains a more detailed list.

1. Policy
   Siblings should be recognised in policy to ensure that there is greater imperative for sibling support service provision.

2. Support for siblings
   Support for siblings should be provided across the lifespan in order for them to reach their own potential and contribute to the wellbeing of their brother or sister with disability.

3. Sector development
   Significant workforce development is required in relation to improving the understanding of the contributions and needs of siblings; development of knowledge and skills to address these needs, through best practice approaches; and, a collaboration framework across and within sectors.

4. Research and education
   Further research is required to determine the factors that influence the strength of the sibling relationship, what best practice approaches are most effective and efficient for the support of siblings, followed by an awareness/education campaign across the disability, health and education sectors.
1. **Introduction**

Over the period January 2017-December 2017, Siblings Australia\(^2\) was supported by the National Disability Insurance Scheme (Information Linkages and Capacity Building; ILC) to carry out a mapping project of sibling support in Australia. The purpose of the project was to map sibling support options in Australia, that is, to understand what sibling support is currently being provided in Australia and what the gaps and barriers are to the provision of further support.

**Note re language and format.** Although ‘sibling’ is a generic term, in this report the term will be used only to refer to the child/adult without disability. Also, specific quotes from parents, providers and siblings are highlighted in italics.

The specific aims of this project were to:

- a. Understand the current situation for support for siblings of PWD, including mapping of current supports, needs and gaps. The mapping was to be:
  - o Underpinned by a definition of what constitutes ‘support’ for siblings of PWD; and need to then make sure this definition is stated explicitly in the report
  - o Differentiated according to the supports that are available to, and/or needs and gaps for, siblings of PWD by age cohort, kind/type of support available and function.

- b. Outline how such initiatives may contribute to the achievement of the ILC outcomes
- c. Update the current online directory of supports/services
- d. Support a national consultation group to provide input and share information
- e. Draw on complementary projects being conducted by Siblings Australia to inform findings
- f. Produce a final report for the NDIA capturing the information from items a. to d. and evaluation of the project.

2. **Methodology**

As the purpose of the project was to map sibling support options in Australia, the project required a methodology that could contact as many relevant organisations as possible which might be involved in providing sibling support, either currently or in the past, as well as ask adult siblings and parents about their sibling support needs. It was decided that the fastest and most effective way to reach all relevant parties was through an online survey and follow up communication via phone or email.

Three surveys were developed by the project team, with reference to previous work by Siblings Australia, and hosted online via Survey Monkey. The surveys were for (1) organisations who provide sibling support, (2) parents / carers of children and adults with disability and (3) adult siblings of PWD.

The survey was interested in the following types of sibling support:

1. Direct support that specifically targets and involves siblings (e.g. sibling-specific counselling or peer support programs)
2. Indirect support that addresses sibling issues, but does not directly involve siblings (e.g. advice/resources for parents on support of siblings)

\(^2\) For more information about Siblings Australia, see Appendix 4.
3. Other broader supports that are not specifically for siblings but may still benefit them (e.g. school based resilience programs).

Survey questions asked a range of questions about the needs of siblings, the types and availability of support services for child and adult siblings, and evaluation processes applied to existing sibling support options.

The invitations to participate in the online surveys were disseminated widely through email lists, social media, websites and personal contacts. While this method may not have reached all relevant service providers and families, Siblings Australia’s networks are broad and allowed many relevant parties to be contacted. The survey remained open for approximately one month, and reminders were sent prior to closing to facilitate additional responses.

3. Key survey findings

Completed survey responses were received from 48 service providers\(^3\), 198 parents and 106 adult siblings. The key findings from each survey are included in Table 2 below, followed by more specific quantitative statistics. The table shows that there were some consistent messages between each of the survey types, while each group also provided some of their own key insights. The full reports from each survey are included in Appendices 1, 2 and 3.

<table>
<thead>
<tr>
<th>Table 2. Key findings</th>
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<tbody>
<tr>
<td><strong>Providers</strong></td>
</tr>
<tr>
<td>Siblings are very vulnerable but their needs are often not a priority.</td>
</tr>
<tr>
<td>There are few specific sibling support services.</td>
</tr>
<tr>
<td>Some carer services include siblings but these are not always relevant or appropriate for siblings.</td>
</tr>
<tr>
<td>The sibling support sector is un-coordinated and lacking in ‘best practice approaches’.</td>
</tr>
<tr>
<td>There is little or no collaboration between sibling support services.</td>
</tr>
<tr>
<td>The barriers to agencies providing sibling support</td>
</tr>
</tbody>
</table>

\(^3\) A further 27 responses were received that did not answer beyond the first 2-3 questions, meaning that they did not provide enough information to be included in the sample.
include lack of funding, the current disability services model (NDIS), which allows for less flexibility with funding, lack of understanding by professionals regarding siblings’ contributions and needs, and lack of policy directly applying to siblings.

- Without a policy framework, there is little imperative for agencies to provide sibling services.

- There is a lack of understanding by professionals in the disability, health and education sectors of the needs of siblings across the lifespan.

### 3.1 Respondent demographics

**a) Adult sibling respondents**

Of the 106 respondents, 9.3% were male, 88.7% were female and 1.2% identified as other. The majority (80.2%) had 1 brother or sister with disability; 14.1% had 2 brothers/sisters; 1.9% had 3 brothers/sisters and 3.8% had 4 or more brothers/sisters with disability. The gender distribution of brothers/sisters was 63.2% male, 35.8% female, and 1% other.

The majority had brothers/sisters with intellectual/cognitive/developmental disability (80.2%), followed by physical (41.5%), autism spectrum (38.7%), psychological/mental health (22.6%), complex communication (21.7%) and sensory disability (21.7%).

**b) Parent respondents**

Of the 198 respondents, 91% were mothers, with a small percentage of each of fathers, grandparents, foster parents completing the survey. The majority (81%) had 1 child with a disability in the family, 14% had 2 children, and less than 5% had 3 or more children with disability.

Autism spectrum was the most frequent disability type (25.8%), closely followed by intellectual/cognitive/developmental disability (24.2%). There was a relatively even spread between sensory (14.9%), physical (10.4%), complex communication (9.4%) and psychological/mental health (9%) disabilities.

**c) Service provider respondents**

A total of 75 responses were received. However, 27 of these only completed the first 2-3 answers and so cannot be included in the overall findings. Providers of disability services were the largest group (30% of respondents) with people working in other sectors (health services, mental health services, education, community services, family support, carer support) each representing less than 10% of respondents.
3.2 Challenges of being a sibling

Adult siblings and parents were asked about the challenges of being a young sibling from their perspective. The survey focused on challenges because the project aim was to map unmet needs, but the literature also shows that there can be positives that come from these sibling experiences. Respondents could select as many responses as applied to them. The top five responses from each are in Table 3; their responses indicate congruence between the two groups of respondents.

Table 3. Challenges of being a sibling

<table>
<thead>
<tr>
<th>Adult sibling respondents</th>
<th>Parent respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family stress – 83.8%</td>
<td>Missing out on time or attention due to time required to care for child with disability – 80.1%</td>
</tr>
<tr>
<td>Missing out on time or attention due to time required to care for sibling – 70.5%</td>
<td>Family stress – 72.9%</td>
</tr>
<tr>
<td>Feeling isolated and that others don’t understand – 68.6%</td>
<td>Feelings like anger, sadness, envy, resentment, guilt – 59.2%</td>
</tr>
<tr>
<td>Embarrassment about behaviour of their brother or sister with disability – 67.6%</td>
<td>Embarrassment about behaviour of their brother or sister with disability – 52.5%</td>
</tr>
<tr>
<td>Feelings like anger, sadness, envy, resentment, guilt – 66.7%</td>
<td>Not being able to take part in community activities – 41.3%</td>
</tr>
</tbody>
</table>

3.3 Impact of being a sibling

Adult siblings and parents were asked about the impact of the challenges above from their perspective. Respondents could select as many responses as applied to them. The top five responses from each are in Table 4. Anxiety was the highest response in both groups; with many adult respondents experiencing some form of health or mental health problems. Only 16.7% felt they had not experienced any health or mental health problems.

Table 4. Impact of being a sibling

<table>
<thead>
<tr>
<th>Adult sibling respondents</th>
<th>Parent respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety - 65.7%</td>
<td>Anxiety - 58.9%</td>
</tr>
<tr>
<td>Depression - 53.7%</td>
<td>Acting up - 58.9%</td>
</tr>
<tr>
<td>Low self-esteem - 53.7%</td>
<td>Acting as ‘parent’ to a brother or sister with disability - 57.4%</td>
</tr>
<tr>
<td>Lack of confidence - 46.1%</td>
<td>Trying to be the ‘good’ child - 46.3%</td>
</tr>
<tr>
<td>Sleeping problems - 35.3%</td>
<td>Withdrawal - 36.3%</td>
</tr>
</tbody>
</table>
3.4 Needs of siblings
A more general question was asked of all three respondents groups, about the types of support needed to effectively support siblings across the lifespan. Parents and adult siblings were provided with a selection of responses; service providers gave open-ended responses. Again, the responses shown in Table 5 were very congruent.

Table 5. Needs of siblings

<table>
<thead>
<tr>
<th>Adult sibling respondents</th>
<th>Parent respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resources/ training for service providers – 77.7%</td>
<td>Resources / training for parents on how to support siblings - 64.5%</td>
</tr>
<tr>
<td>Resources/ training for parents – 74.5%</td>
<td>Counselling opportunities for siblings - 60.7%</td>
</tr>
<tr>
<td>Advocacy for siblings – 67%</td>
<td>Recreational activities for siblings - 60%</td>
</tr>
<tr>
<td>Counselling support – 61.7%</td>
<td>Peer support for young siblings - 58.7%</td>
</tr>
<tr>
<td>Peer support for young siblings – 61.7%</td>
<td>Advocacy for siblings - 56.7%</td>
</tr>
</tbody>
</table>

Service providers focussed on issues such as support to manage mixed and difficult feelings; assistance in asking for help; information to help them better understand what is happening in their family; time with parents and help to develop their own identity and to feel valued.

3.5 Support accessed
Adult siblings and parents were asked about the types of support which they had accessed, and whether the support met their needs. Respondents could select as many responses as applied to them. The top five responses from each are in Table 6.

Table 6. Support accessed and needs met

<table>
<thead>
<tr>
<th>Adult sibling respondents (support accessed as children)</th>
<th>Adult sibling respondents (support accessed as adults)</th>
<th>Parent respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal support from family/friends - 26.7%</td>
<td>Individual counselling - 43%</td>
<td>Recreational activities - 52%</td>
</tr>
<tr>
<td>Individual counselling - 21.8%</td>
<td>Online peer support - 33.7%</td>
<td>Face to face peer support - 49%</td>
</tr>
<tr>
<td>Information about their brother’s/sister’s disability - 19.8%</td>
<td>Information about brother’s/sister’s disability - 32.5%</td>
<td>Individual counselling - 34%</td>
</tr>
<tr>
<td>Recreational activities - 18.8%</td>
<td>Informal friendships with other siblings - 24.4%</td>
<td>Information about their brother’s or sister’s disability - 32%</td>
</tr>
<tr>
<td>Friendship with other siblings - 15.8%</td>
<td>Face to face peer support - 20.9%</td>
<td>Support from extended family or friends - 31%</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>---------------------------------</td>
<td>-----------------------------------------</td>
</tr>
<tr>
<td><strong>Did support meet needs?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 42% no support available to them;</td>
<td>• 26.5% of adult sibling</td>
<td>• 30.4% of the parent respondents felt that the support they received fully met their family's needs;</td>
</tr>
<tr>
<td>• 13.5% felt these supports had met their needs as children;</td>
<td>• respondents felt that support had met their needs as adults;</td>
<td>• 62.7% felt that the support partially met their family's needs;</td>
</tr>
<tr>
<td>• 47.2% that support had only partially met their needs;</td>
<td>• 53% felt that support had only partially met their needs;</td>
<td>• 6.9% felt support had not met their needs at all.</td>
</tr>
<tr>
<td>• 9.3% felt support had not met their needs at all.</td>
<td>• 20.5% felt support had not met their needs at all.</td>
<td></td>
</tr>
</tbody>
</table>

One of the factors influencing satisfaction with support services was the understanding by professionals with whom they had contact. Adult sibling respondents felt that understanding of sibling issues could be improved across the board in schools (89.9% felt it could be improved), disability services (83.1% felt it could be improved) and by GPs (88.6% felt it could be improved).

Parent respondents felt that understanding of the issues experienced by siblings could be improved across the board in schools (79.4% could be improved), disability services (58.9% could be improved) and by GPs (79.8% could be improved).
4. Discussion

This discussion starts with some context for sibling support, then looks further at current services, and the gaps in sibling support revealed by the surveys, and follows with implications of this work for the disability sector.

4.1 The context for sibling support

To fully understand the sibling experience and the roles that siblings play in the life of the PWD, it is important to take a lifetime view. Family is a key connection for most people across their lifetime. It is one of the main influences on a child’s skill and confidence development and their connection to community. Siblings in particular can play a crucial part in each other’s emotional development, allowing for companionship, learning of social skills and influence on identity development. The relationships that all siblings share can be one of the longest of any, complex and ever-changing, and can literally last a lifetime. Siblings, uniquely, can be there for the ‘whole journey’.

When one sibling has a disability, these relationships can be even more complex, but still of utmost importance for both the person with and without disability. Each sibling experience is unique and affected by a range of variable factors. The following section will look at childhood experiences and the impacts on parents, some of the factors that influence the nature of the sibling relationship, adult sibling experiences, sibling needs and the benefits of sibling support.

4.1.1 Childhood experiences

Through this project, parents, providers and adult siblings gave us a strong message about the impact on siblings. The majority (over 80%) of parents and siblings mentioned ongoing family stress. See Results section above and Appendices for further details and statistics. It is well known that early stress can have a longer-term impact on a child’s development (National Scientific Council on the Developing Child 2005/2014). Siblings are experiencing these issues at a time when it is likely they lack the understanding and emotional maturity to cope.

Growing up in a family with a child with disability can be unpredictable, especially if the child with disability has difficult or aggressive behaviour, and or sleep problems. Siblings and parents talked about siblings missing out on time or attention, difficult feelings like isolation, anger, sadness, guilt and embarrassment, the reactions of others, excessive responsibility and worry about the future.

Over half the adult sibling respondents (52.4%) talked of taking on extra responsibility, which if kept in balance can be a positive, but for many the responsibility adds more and more anxiety. The responsibility can be not only to their brother or sister with disability but also for their parents, who they see as being stressed. Siblings can be more and more worried as they try, with limited success, to ‘make things right’. Some respondents talked about siblings being prepared from a young age to take over the role of carer for their brother or sister, and cautioned against this. All three surveys highlighted the risk of longer term health impacts. See Results section above for further details and statistics.

These findings are backed up by international research and anecdotal evidence supports the view that illness and disability affect the lives of all family members. Research substantiates the fact that
siblings of these children may themselves experience significant long-term physical (Hogan, Park and Goldscheider 2003) and mental health issues, including anxiety, depression and low self-esteem (Lamorey 1999). It has also been suggested that these issues become more difficult as the individual with disability becomes older (Cuskelly 1999). A 2008 Australian Institute for Family Studies report highlighted that not only parent carers of children with disability have higher rates of depression, but so do the other children in the family (siblings), regardless of any carer role they may or may not play (Edwards, Higgins, Gray et al. 2008).

There can also be challenges from outside the family – the responses of others to the child with disability, or to the sibling, including being bullied or ostracised. As they move into teen years, siblings can face further challenges, as being connected to peers becomes even more important. In addition, they start to wonder how to balance their own needs with those of their family? What life choices should they make? Is it ok to move away? Will they find a partner to share the responsibility? Should they have children?

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.

**4.1.2 Parent stress**

Parents reported that they carry huge concerns about the siblings in their family and need help to strengthen sibling relationships when one has disability. Parents talked of feelings of guilt, sadness and worry over the impact on siblings. They saw siblings facing significant challenges in childhood, with 72.9% mentioning a stressful family environment. Others highlighted social isolation, extensive responsibility and, in some cases, difficult behaviours by the child with disability, including sometimes violence/aggression, which added to the stress. They believe that siblings need help to interact positively with, or to manage any difficult behaviour of, their brother or sister.

These findings reinforce what parents consistently tell Siblings Australia, through phone/email, workshops and surveys. Many contact Siblings Australia seeking support for their children, many have searched but without success. Parents can find it enormously difficult to juggle the needs of their whole family and this can add another layer to the stress they experience. (Edwards et al., 2008).

**4.1.3 Factors affecting the sibling relationship**

All of the above experiences will contribute to the quality of the sibling relationship. Importantly, there is no one sibling experience just as there is no one experience of disability. Various factors will influence the relationship, including: the type of disability, respective ages and birth order, gender of both the sibling and the child/adult with disability, family and friends’ attitudes, social networks, socio-economic status, cultural factors and the type and level of support accessed.

Some family members indicated that there may be particular sub-groups of siblings that are more vulnerable and this aspect could benefit from further research. For example, children who grow up as the only sibling, that is they are the only non-disabled child in the family, might face particular stresses not only in childhood but also into adulthood, especially if social networks are not strong.
Also, children who grow up in sole parent families, or with a child with disability who has particularly difficult behaviours, including aggression, might also be more vulnerable. It also seems that different cultures, socio-economic status might make it easier or more difficult for siblings.

It is the childhood experiences that set the scene for the nature of the sibling relationship in adulthood. It is clear that stressful childhood experiences can have lifelong impacts on both the sibling and their relationship with a brother or sister with disability. However, there is little knowledge about what the barriers and enhancers to developing a stronger relationship between siblings in this situation might be.

4.1.4 Adult sibling experiences

Sibling relationships can be ever-changing as both siblings become older. This project found that siblings can carry a lot of the impact of childhood stresses into adulthood, with more than half experiencing longer term anxiety, depression and low self-esteem, and many more experiencing a range of other difficulties. Many also showed a strong commitment to their brother or sister with disability, but they also reported having real concerns about how they might provide support now and into the future, with 66.7% citing worry about the future as an issue. There can be tension between this commitment and their own needs.

Other work by Siblings Australia confirms this. For example, the Siblings Australia Adult Sibling Project, conducted in early 2017, with support from the Sector Development Fund, showed that adult siblings provide extensive support for their brothers and sisters (see Figure 1. below for the types of support provided), but sometimes still grapple with left over feelings from childhood, and trying to balance the needs of their original family (parents and person with disability) alongside their own families, now potentially including a partner and children, as well as with work commitments. Don Meyer from the Sibling Support Project in the United States has often referred to these siblings as the ‘club sandwich generation’, given their possible responsibility for three different generations.

**Figure 1. Types of support provided**

4 The larger the word, the more it was mentioned in survey responses
The roles that siblings take on are varied. Some reported that they feel they have limited choices. Some take on the primary carer role at the expense of their own needs, others provide a more limited hands-on caring role, but might step in to support parents or give them a break. Some take on a more ‘sibling’ role, offering emotional support alongside helping out with transport, facilitating connection to family and the community etc. Others move right away from the family, to remove themselves from stress or any expectations.

Formal planning for the future and the open discussion of expectations on siblings is rare. These can be difficult discussions to have and many families just cannot take those steps to explore the future needs of a person with disability. Sometimes the expectations of siblings (both their own contributions and the goals for the person with disability) can be quite different from parents. It can be particularly fraught when the person with disability has limited capacity to contribute to these discussions.

Currently there is little recognition of the roles or needs of siblings and there is no imperative for agencies to address those needs or support the sibling relationship. Adult siblings report to Siblings Australia that the system does not often recognise their role or their unique knowledge and understanding about their brother/sister with disability.

The other issue to consider is that it is extremely difficult to contact adult siblings – there are no databases. Certainly some, who are connected to the disability system or who take part in social media, were reached via this survey, but there are many more who are not connected and there will be a wide diversity of experiences - some may have moved away from their family; some will have no time to be involved; others might be quite happy with their family relationships and not seek support. It is important that these siblings be reached in order to get a full picture of the enhancers and barriers to these relationships.

4.1.5 Support for siblings

This project and previous research by Siblings Australia confirms the following themes:

- Support needs to start in early childhood and continue throughout their lives. In the beginning support needs to:
  - Assist siblings to understand the disability and its impacts, and the different feelings they might experience about what is happening in their family.
  - Give children the tools to manage the stresses and to connect them to sources of support, both within their family/friends circle but also with other siblings and within the community.
  - Different types of support might be needed for different siblings, e.g., groups may not suit all siblings, some siblings will have particular stresses which need particular interventions.

- Adult siblings said that in childhood they needed:
  - Sibling specific resources and information about the disability at age-appropriate levels.
  - Support to manage the stresses
• connection with other siblings who experience similar issues
• Help to manage other people’s reactions.

• And as they became older, they needed:
  • support to develop their own independence whilst still ‘looking out’ for their brother or sister with disability
  • information/understanding about disability and other services to help them develop a ‘good life’ for their brother/ sister with disability and themselves
  • support, especially from peers, to process their experiences and feel more able to support a brother/ sister with disability.
  • help to navigate difficult family discussions, especially if they hold more open views about goals/independence for their brother/ sister with disability.

Some siblings talked about the fact they only received attention when there was a crisis, for example, self-harm attempts. Siblings stressed the importance of adults recognising the needs of siblings and providing support. As one sibling said,

*I saw the school counsellor often ‘just to chat’ and cry I suppose.*

Siblings also want greater recognition of their contributions and needs – not as young carers/carers but as brothers and sisters, as support provided in that context. The needs of siblings can be quite different to those of ‘carers’. It can be complex, but it is not in the best interests of PWD (dignity) or siblings (identity) that siblings are referred to as ‘carers’. Both PWD and siblings express their preference for not using this term in relation to their relationship. This is discussed further under ‘policy issues’.

### 4.1.6 Benefits of support

Most parent respondents could not find support for their children who are siblings, but the few who did access support reported that siblings, after such programs, often interact more positively with the child with disability, feel more understood, less alone and have more understanding of the impacts of the disability. Siblings themselves who accessed support as children reported that it helped them feel less alone and helped them feel more confident. Some siblings recognised that they projected an image of being strong and so people did not see them as needing support when in fact they did. One sibling who did receive support said it ‘really shaped me as a well-rounded, confident individual’.

There have been several studies into the effect that sibling support programs, especially for children, have on siblings and their relationships. Many of these studies have focused on support group programs, and identified many positive outcomes through mostly qualitative evaluation. Key findings are that through sibling support programs siblings feel less isolated, they gain a better understanding of the needs of their brother or sister and improve their relationship and involvement within the family (Evans, Jones and Mansell 2001, Naylor and Prescott 2004, Conway and Meyer 2008). Their anxiety levels have been seen to decrease (Houtzager, Grootenhuis and Last 2001) and they improve the way that they feel about themselves (Evans, Jones and Mansell 2001, Naylor and Prescott 2004, Smith and Perry 2004). As a result, they may be more likely to develop to their full
potential and also to contribute to the quality of life of their brother or sister with disability. Sibling support can also enable the whole family to function more positively (Naylor and Prescott 2004).

A Randomised Controlled Trial (RCT) of the Siblings Australia Sibworks program (Roberts et al., 2015) showed that children in the intervention group had improved emotional and behavioural functioning with a medium to large effect post intervention and at the 3-month follow-up.

While the effects of other types of support programs have been less documented for siblings, one study identified that similar effects were attained through sibling camps (Sahler and Carpenter 1989). Additionally, Naylor and Prescott (2004) noted the benefits that siblings appeared to derive through individual adult attention.

Some sibling responders to this current survey talked of eventually accessing support in adulthood. Whilst this misses the opportunity for early intervention and preventative support, it can still have positive outcomes for both the sibling and other family members. As one said,

*I am in a much better place and my brother benefits from instead of having a sister with high anxiety who avoided contact (which just compounded my guilt) to having a sister who is involved in his life.*

Another sibling said that,

Learning more about my brother’s disability means I can advocate better.

Other work by Siblings Australia confirms the benefits of support from other adult siblings via a variety of peer opportunities. For example, one described the support she received from other siblings as a ‘lifesaver’. Another sibling reconnected with her brother with severe disability (he had been very aggressive in childhood causing her to feel great anxiety around him) after gaining support from other siblings and the agency that supported her brother.

### 4.2 Current services

There are few services for siblings of PWD. For families looking for support, it is a ‘hit and miss’ scenario, with access depending on whether someone lives near and is eligible for one of the few services that operate. Only four agencies in Australia offer an open support service. A few other agencies, usually agencies that support children with disability, provide support just for families of their clients. A handful provide one-off events, camps, or support is available through some young carer programs. The support might be via peer support, counselling, and recreational activities.

All surveys highlighted a lack of skills/knowledge in the workforce. In addition, there is very little evaluation of the few approaches being used, and limited funding for agencies to provide support. The sibling support sector is unco-ordinated, with little if any collaboration.

Many providers and parents talked of programs stopping or preparing to stop due to the introduction of the NDIS, as agencies have even less flexibility with funding. Siblings Australia has heard several anecdotes confirming this. In the past agencies were block funded; it meant if they
were able to make savings in certain areas they were able to spend money on other services such as sib or family support, capital works, etc. With a focus on the PWD through Participant Plans, there is less flexibility.

Also, previously, Siblings Australia was regularly asked to provide workshops for parents/professionals, through individual agencies. That work too has virtually ceased since the NDIS, again due to less flexibility with funding.

As mentioned, siblings can be included under the ‘young carer’ and ‘carer’ umbrella of services but this is not always relevant or appropriate. There can certainly be some overlap, especially as siblings age but, as mentioned under ‘policy issues’ below, it is not always in the best interests of siblings or PWD for this to occur.

4.3 Gaps and challenges

This project found several key gaps and challenges with respect to sibling support available in Australia. These are discussed below, first, gaps in the delivery of services to meet the needs of siblings and, second, challenges which organisations face in providing support for siblings (funding, organisational priorities, and expertise).

The first major gap relates to the lack of attention given to siblings within the disability sector, in spite of the long-lasting nature and importance of this relationship. Parents and siblings regularly commented on what a nice change it was that siblings were a focus for this survey.

Respondents highlighted the gaps in sibling support and stressed that siblings needed more opportunities to mix with peers in social and educational groups. Additionally, noted was the importance of this support being consistent, both in approach and provision (not so dependent on irregular funding). Most families could not access support and most agencies did not have services to which they could refer. There was virtually no support available for pre-schoolers, nor teens or adults, with the few services available mainly targeting primary school aged children.

There is no consistent identification of siblings, no assessment to determine particular needs, little flexibility in programs to address particular needs and virtually no referral pathways.

From an organisational perspective, the project findings show that many service providers recognise the value of and need for sibling support, however they are constrained by the current circumstances of their organisations in providing it. Therefore, to enable providers to better and/or further offer sibling support, work is needed to ensure siblings are within the scope of needs that service provider organisations have a remit to address, that staff are trained and briefed in siblings’ needs and best practice, and that dedicated funding is set aside to ensure that sibling support can have a defined place within organisational priorities. In order for this to occur, there is a need for policy and decision makers to be aware of the impacts on and needs of siblings, make provision for them in policy, and to recognise the benefits of enabling service provider organisations to dedicate specific time and funding to this group.

The project also noted that respondents indicated they felt awareness of sibling issues is low more broadly across community, families and government.
Part of the challenge in providing workforce development is the lack of consistent, best practice approaches. However, a collaborative approach with a consistent base practice model would make additional training across multiple organisations more economical and effective.

Finally, some respondents also noted the importance of addressing the challenge for rural sibling support. Whilst only a couple of people commented on this gap, the project also noted that there were very few regional based programs. Opportunities such as teleconferencing, internet forums and social networking could assist in addressing this challenge.

5. Implications for the disability sector

So why are siblings important in the context of disability? The findings of the project highlight several implications for the broader disability sector. These findings are contextualised by siblings usually having the longest relationship of any with the person with disability.

First, the survey confirmed that disability impacts not only the person with disability but the whole family. Siblings can face additional challenges and often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand and cope with those stresses and the mix of feelings they experience. Several disability related national documents emphasise the importance of family and the need to address the complex needs of all family members (see ‘policy issues’ below).

Second, the family is the first support network for PWD. If a child and then adult with disability is to reach their potential and connect into the community; strengthening that whole family should be a crucial part of any approach to inclusion. Parents identified through the survey that concern about their children who are siblings is a significant issue for them. Part of strengthening the family involves identifying and trying to address stresses on parents, including about their ‘other’ children.

Third, the surveys showed that there is scant attention given to siblings and the sibling relationship within the disability sector. This is in spite of the potential of this relationship, if supported, to guard against social isolation of PWD. There is evidence that many PWD, especially those with intellectual disability, become isolated and more vulnerable to neglect and abuse. Siblings are an integral part of the PWD’s informal social network and likely to have the longest relationship with the PWD. If the relationship becomes strong, siblings can help to connect their brother/sister with disability, especially those with intellectual disability, to family/friends, services, and the community, thereby reducing isolation and risks to safety over a lifetime. There is no attention given to what might be barriers to the relationship and what might enhance it. Some siblings move away from the family and the person with disability as they are not able to cope with a mix of stresses. More support options from childhood might prevent that happening.

Further to the sibling relationship itself, there is still very little known about the roles that siblings play, their challenges and their needs, and what barriers/enhancers influence the relationship between siblings and the roles played. This and other projects by Siblings Australia highlight the amount that siblings are contributing to the life of the person with disability, parents and the wider community. And the emotions around that can be complex. As one sibling said,
The whole NDIS thing has been really stressful and has brought up a lot of grief and anxiety for me about the welfare of my sister and parents.

As minimal data is collected about siblings’ roles and their support of their brother or sister, the dollar value of the contributions that siblings make to their family is unknown; it is likely to reflect considerable financial savings to the Government which would otherwise need to be provided via NDIS funding. It is interesting too that as this project attempted to engage with disability/parent groups, there was some resistance to the idea that siblings might need support. There is general acceptance and understanding of the need for parent support but there was a definite lack of understanding about the impacts on siblings from some areas of the disability and broader community.

On the other hand, there is a sense from some quarters, and confirmed by these surveys, that siblings will simply ‘take over’ once parents are no longer able to continue caring. This expectation raises two issues for the disability sector. First, if the sector does have an expectation that siblings will move into this role, then it is imperative that more resources are provided into supporting that transition. Second, if siblings are not expected to take over these roles, then the disability sector needs to be planning now for when ageing parents are no longer able to provide care.

Some siblings have reported (both through this survey and other consultations by Siblings Australia) taking over the parent/primary carer role at the expense of their own life goals. Further consideration should be given to whether this is the best approach for either the sibling or the person with disability. Does it really promote choice and control? It is a situation that can contribute to resentment within families, can disrupt siblings enjoying a special relationship as siblings (not as carer and cared-for) and may influence the breakdown of sibling and other family relationships.

Policy makers and government would do well to consider the role of supporting siblings of PWD. It is clear from these findings sibling support is important – and policy makers could explore the specific ways siblings could be recognised in the context of NDIS and identify responsibilities between other service systems such as the disability sector, health and education. Policy consideration could also be given to NDIS sibling support in participant plans and/or ILC.

5.1 Policy issues

In Australia, much of the policy and service provision related to PWD is focused on the PWD and their ‘carers’, usually parents. Parent and other carers have some voice/support via major funded advocacy/support organisations outside of the disability sector (NDIS). This is not so with siblings.

Sibling support programs have been run for many years overseas particularly in the US and UK. In the UK, these children are recognised through legislation. The Children Act 1989, which provides a framework to provide support to children “in need” including those with disabilities, specifically states that the needs of brothers and sisters of children with disability should not be overlooked. In Australia, such provision is not included in legislation.
In Australia, whilst much of the policy and service provision suggest a family approach, the reality often means a focus on PWD and parents. This is in spite of the international research showing that disability impacts the whole family, regardless of whether they play a ‘carer’ role or not (Edwards et al., 2008).

The National Disability Strategy (NDS) highlights the importance of family in the life of PWD, and calls for a co-ordinated, high level, strategic policy to address the complex needs of PWD, their families (emphasis added) and carers in all aspects of their lives. However, several years after the NDS was released in early 2011, there is still very little attention given to whole families and, in particular, siblings. Siblings continue to be largely disconnected from both policy and services.

There has been some attempt to include siblings under ‘carer’ and ‘young carer’ policy but this is not always relevant or appropriate for siblings, and means that many siblings are missing out. Many young carer programs will accommodate siblings in their programs and there can be benefit for siblings through attending these groups. However, provision of carer programs should not exclude equal provision of specific sibling policy/programs. The challenges and needs of siblings can be quite different to those who care for parents or spouses with disability. Within families, many siblings will take on caring responsibilities for a brother or sister with disability. However, they are rarely identified as carers as in most cases the parent is identified as the primary carer; and nor should they be; they are children first. If they do provide care to a brother or sister with disability, and this is kept in balance, it can be very rewarding and add to self-worth.

However, for some children, being identified as a ‘carer’ from a young age can complicate their identity development and reinforce the message that others’ needs usually come first (Burke 2004, Strohm 2014). Anecdotal reports suggest this can lead to problems in adult relationships. Even if siblings are providing no care, they can still experience significant challenges; the caring role they might play can be the least problematic part of their experience. If ‘young carer’ programs are used with siblings, this may miss many siblings who need support. Even if siblings do not provide any ‘hands on’ caring, there can still be considerable challenges and support is still very important. The Australian Institute for Family Studies (Edwards, 2008) report on parent carer wellbeing, found that siblings were at higher risk of depression, regardless of any caring role they may or may not play. This current project, and previous projects by Siblings Australia confirm this.

Many parents, siblings and PWD have said in workshops and Siblings Australia consultations they prefer siblings NOT to be called ‘young carers’; that they are siblings first. This finding is also supported by Australian research (Meltzer, 2017). For dignity reasons for PWD it is not appropriate for siblings to be called ‘carers’ – a 12-year-old boy with disability is unlikely to prefer his younger sister be called his ‘young carer’, while calling her his sister would be appropriate. Of course, many adult siblings do take on more of a ‘carer’ role, but the term still implies and inequality in the relationship. Siblings will play a mix of roles with their brother or sister with disability across their lifetime and they need support whatever those roles might be.

5.2 How sibling initiatives might contribute to ILC outcomes

The National Disability Insurance Scheme (NDIS), is designed to ‘support a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers’. The Information, Linkages and Capacity (ILC) part of the NDIS has as part of its mission ‘personal
capacity building’ which is ‘about making sure PWD and their families have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people’.

As such, a main part of this aim of the ILC is to ensure PWD are connected. One way of ensuring PWD, especially those with intellectual disability, are connected and have information they need to enable social and community participation is to strengthen sibling relationships and ensure siblings have the commitment, knowledge and skills to support their brother/sister with disability. Further, when siblings are supported themselves, they may be in a better position to contribute to good outcomes for their brothers and sisters.

A strong sibling support sector, with a national agency that provided co-ordination, training, advocacy and research, could ensure the following outcomes:

1. Siblings are recognised as an important part of the lifelong social support system for PWD regardless of whether they are playing a direct caring role or not.
2. Siblings are included in meaningful ways within NDIS documents, such as the ILC framework.
3. Young siblings access support to manage the challenges they face and to strengthen the relationship with their brother or sister with disability.
4. Parents feel more competent in parenting all of their children to ensure family relationships can be as strong as possible, including as parents age and become less able to provide support to the PWD.
5. Young PWD enjoy strong family relationships which encourage and assist their connection to family/friends, services and the community.
6. Adult siblings have improved capacity to ensure a ‘good life’ for their brother or sister with disability and themselves (including information, linkages and referrals).
7. Agencies have greater capacity to engage with siblings and ensure they have the information, linkages and referrals to support their brother or sister with disability.

These changes would contribute to ILC outcomes through the following areas:

a) Strengthening of ‘informal supports’.
b) Information, linkages and referrals.
c) Counselling and peer support for families, including siblings.
d) Improved capacity within parents to support their whole family.
e) Improved capacity of siblings to be a lifelong supporter of the PWD.
f) Increased access by adult siblings to high quality, accessible, relevant and easy to understand information to enable them to plan a ‘good life’ together with their brother or sister with disability.
g) Improved connection for siblings and PWD with disability and mainstream/community services.
h) Improved individual capacity of PWD.
i) Improved capacity of the disability and other sectors to support the whole family using ‘best practice’ guidelines.
6. **Recommendations**

To ensure siblings are recognised and supported, Siblings Australia makes the following recommendations:

**Recommendation 1: Policy**

**1.1 Policy**
Siblings of children and adults with disability are recognised within government policy as an ‘at risk’ group and their needs are acknowledged accordingly. They are also acknowledged for the contributions they make to the lifetime wellbeing of a brother or sister with disability.

**1.2 National advocacy, information, research and training agency established.**
This agency would assist with co-ordination and collaboration and provide direction to sibling support in Australia.

**Recommendation 2: Support for Siblings**

**2.1 Funding**
Appropriate resources are allocated to the support of siblings of children and adults with disability.

**2.2 Parent resources and training**
Parents are provided with resources and training to assist them in supporting their whole family, and strengthening those relationships, from the time or birth or diagnosis of a child with disability.

**2.3 Adult siblings**
Adult siblings are connected to information, linkages and referrals to ensure they understand what services are available to them and their brother or sister with disability, both now and into the future.

**2.4 Peer support opportunities for siblings are further developed.**
Young and adult siblings are provided with a range of different peer support options – face to face and online.

**2.5 Rural Support**
The particular needs of siblings living in rural or remote areas of Australia are explored further and a rural support program is developed.

**Recommendation 3: Sector Development**

**3.1 Workforce development**
A workforce development program is put in place to raise awareness and skills in relation to the needs of siblings across a range of sectors, e.g. disability, health and education.
3.2 Best practice
A ‘best practice’ framework for sibling support is developed, including an agency recognition system to show the extent to which they are aware of and catering to sibling issues.

3.3 Collaborative Framework
A collaborative framework for organisations supporting siblings is developed.

3.4 National Consultation Group
A National Consultation Group for Sibling Support made up of service providers who have (or potentially could have) an interest in sibling support within Australia is established.

**Recommendation 4: Research and education**

4.1 Additional Research
More research is carried out to determine the numbers of siblings, their different roles and the barriers to engagement, resulting in greater understanding of the factors that support a sibling to remain involved in the life of the PWD, and the barriers to engagement.

4.2 Evaluation
Appropriate evaluation measures are developed to ensure best practice sibling support.

4.3 Support Strategies
Research is done to explore the most effective strategies to support siblings across the lifespan, including policies and principles to ensure programs meet best practice.

4.4 Identifying Needs
Research explores the best ways to identify siblings, assess their individual needs and refer to appropriate supports.

4.5 Guidelines
Promotion and dissemination of general practice guidelines for all sectors and specific standards of practice for sibling support programs should be carried out.
7. References/further reading


Appendix 1  Parent survey report

The parent survey was one of a series of three surveys; as part of a broader project intended to help understand more about where and how siblings are being supported; where the gaps are and what people believe should be happening in the area of sibling support. This survey was directed towards parents to better understand what supports are available and in which areas further support is still required.

The survey was developed by the project team, and circulated widely through email listings, Facebook, Siblings Australia website and personal contacts. The survey remained open for approximately one month, and reminders were sent prior to closing.

Note re language and format. Although ‘sibling’ is a generic term, in this report the term will be used only to refer to the child without disability. Also, specific quotes from parents, providers and siblings are highlighted in italics.

Key Findings

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<th>Survey findings</th>
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<tr>
<td>• Siblings of children with disability are very vulnerable</td>
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<td>• There is a big gap in support services for siblings</td>
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<td>• Watching the impact on siblings and being unable to find support for them adds to the stress on parents</td>
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<td>• There is a lack of understanding by professionals in the disability, health and education sectors of the needs of siblings</td>
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<th>Implications/why findings matter</th>
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<tr>
<td>• The family is the first support network for people with disability</td>
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<td>• Siblings will likely have the longest relationship of any with the child/adult with disability</td>
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<td>• Siblings can contribute much to the lifetime wellbeing of the PWD</td>
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<td>• Siblings have their own needs, which should be addressed if they are going to be able to reach their own potential but also contribute to a ‘good life’ for the person with disability</td>
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<td>• Many PWD become isolated – strengthening sibling relationships should be a crucial part of any strategy to improve wellbeing for PWD</td>
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<tr>
<td>• Support for siblings is likely to have benefits for siblings, parents and the child/adult with disability</td>
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<th>How issues could be addressed</th>
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<td>• Recognition of the needs and contributions of siblings</td>
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<td>• A true ‘family focus’ when considering the impacts of disability</td>
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<td>• More research into ‘best practice’ models of lifetime support for siblings</td>
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<td>• More workforce development across relevant sectors</td>
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<td>• Policy development to ensure there is some imperative to consider siblings</td>
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Respondents
There were 198 respondents, with 94% of people who started the survey completing all questions. The survey was predominantly completed by mothers (91%), with a small percentage of each of fathers, grandparents, foster parents completing the survey. Further details of respondents are included in Attachment 1.

Challenges for siblings
Respondents were asked to select from a range of feelings and situations in relation to their children growing up with a brother or sister with disability. As the survey was focused on the availability of support for siblings, information was sought about the challenges experienced by siblings. Respondents were able to select all that applied. The top 12 responses were:

1. Missing out on time or attention due to time required to care for sibling – 80.1%
2. Family stress – 72.9%
3. Feelings like anger, sadness, envy, resentment, guilt – 59.2%
4. Embarrassment about behaviour of their brother or sister with disability – 52.5%
5. Not being able to take part in community activities – 41.3%
6. Feeling isolated and that others don’t understand – 37.2%
7. Worry about the future – 37.2%
8. Difficulty with other people’s reactions to their brother or sister with disability – 36.7%
9. Too much responsibility - 35.2%
10. Confusion about brother’s / sister’s disability – 33.1%
11. Physical harm from brother/sister with disability – 32.1%
12. Seeing brother/sister being teased – 25%

Figure 1. Challenges for siblings
Only 6% of respondents indicated that their children who were siblings had no concerns and coped well.

Respondents added more detail in comments and also outlined many other challenges their sibling children faced. Whilst a few parents reported no concerns about their children who are siblings, the vast majority had concerns about their children. Some highlighted the anxiety they see in siblings:

- *Both of my children have extreme anxiety disorders. My 16-year-old son does not want to have children for fear of having to raise a child like his sister.*

- *Sibling was the victim of his brother’s violence. It was hell on earth and has caused trauma for the whole family, especially the sibling.*

- *Teasing and bullying at school, which was not addressed has resulted in my son having anxiety and behavioural issues requiring ongoing counselling.*

Other anxieties were mentioned in the comments around seeing the child with disability in pain or suffering; worry about abuse of brother or sister by agencies; the responsibility of being a sibling and future care; a lack of privacy and respect for belongings; atypical behaviours including meltdowns by the child with disability; guilt about a brother or sister’s disability leading to sibling developing low self-esteem.

Several comments reflected a lack of understanding of the disability by the sibling, leading to confusion and worry. One child would not touch anything that belonged to the child with disability and screams if she touches anything of his.

Also, some parents see their children becoming isolated, along with the whole family, due to limited social circles or not being able to do things that other families do.

One parent mentioned that the sibling felt upset not being able to do the activities a brother or sister might e.g. yoga, art therapy (funded but no funding for activities for sibling). Some families just couldn’t afford such extras:

- *They need social opportunity we just can’t afford. If I could just get tutoring for my son and singing lessons to grow his social confidence.*

It was also mentioned that siblings would like more support to participate in activities with their brother or sister, and that some are upset by the barriers they see that exist in terms of their brother or sister accessing the community.

**Signs of stress**

Respondents were asked to indicate the signs that show that their children who are siblings faced challenges. Respondents were able to select all that applied. More than half the respondents felt their children showed signs of anxiety (58.9%); acting up (58.9%); and acting as ‘parent’ to a brother or sister with disability (57.4%). Other key signs included trying to be the ‘good’ child (46.32%),
withdrawal (36.32%), physical complaints (e.g. headaches, stomach-aches) (32.1%) and depression (25.26%). Other issues included difficulty making friends (14.2%) and struggling with school work (22.6%).

Figure 2. Signs of stress

Some parents reported that the sibling voices their concerns but most show signs of stress in their behaviour. For example, some siblings withdraw, retreating to their bedroom when home and don’t want other children coming to their home due to the behaviour of the child with disability. Others don’t want to be home and stay away as much as possible. As they become older, some move right away from family. One parent fully supported a sibling’s attempts to move to another country.

On the other hand, some children are very clingy to parents, needing comfort and attention, in some cases, refusing to go to school. One parent described her child as:

... attention craving, wanting to be with parents through the night for comfort, not being able to speak to parents because they are ‘always busy’, getting yelled at for minor behaviour issues due to family stress etc.

Some children seek attention through acting up; some might respond with aggression if the child with disability is aggressive. Some siblings complain about unfairness; that the sibling gets special treatment or doesn’t have to do things they do.

Sometimes siblings will get into the habit of always ‘giving in’ or putting their own needs last to avoid difficult behaviours in the child with disability e.g. meltdowns. One parent said that this was
then flowing onto other areas of the sibling’s life; the sibling was giving into others and putting their own needs last.

Some parents reported troubling signs of stress, such as anorexic behaviour or self-harm. Parents believed that a contributing factor to these could be the sibling feeling powerless in their situation.

**Impact on parents**

Some parents said they feel guilty about the impact on siblings. They see them struggling and fear that perhaps they as parents are responsible. They worry and feel guilty about siblings missing out on their attention due to the demands of the child with disability, and about the stress that siblings experience.

Parents talked about the stress of watching the impact on siblings:

> I’m watching my two girls struggle to retain friendships and have a carefree childhood and some sort of normal life. Support for them outside the family is crucial on so many levels not only for them to feel like they fit in. The gap for them is huge and I am watching it widen due to the restrictions we have as a family because of our other daughter’s disability. It’s heartbreaking.

> I have watched with great sorrow as my children have struggled with their sister’s disabilities – my eldest with anger and shame and my youngest with distress to see her sister so upset at times.

**Support for siblings**

Respondents indicated the top 10 major needs of their children who are siblings included:

1. Strategies for stress - 65.5%
2. Contact with other siblings of children with disability - 63.5%
3. Managing feelings - 63.5%
4. A counsellor to talk with about concerns - 51.3%
5. Learning ways to interact positively/have fun with their brother/sister with disability - 50.8%
6. Having increased knowledge about their brother’s/sister’s disability - 43.9%
7. Having help in accessing community activities - 43.9%
8. Learning self-protection - 31.7%
9. Strategies for coping with teasing - 24.8%
10. Information about future care of their brother or sister with disability - 32.2%

Parents talked about the need of siblings to learn healthy ways to deal with their emotions and time away from the stresses of family life and the need to do fun things both with their family and outside the family. Some siblings need help in making friendships and parents recognised the particular importance of having contact with other kids who ‘get it’. More awareness by schools of the needs of siblings is important as is help with schoolwork. One parent said that the sibling needed help to ‘be heard’ by teachers.
Support with schoolwork is something which is desperately needed. I wish there was a service to offer this. Our child with disability won’t let us have that one on one interaction with our other children.

Some parents talked about the sibling need to be protected from harm and learning to protect themselves.

Protection from harm is the biggest need for my younger children. They cannot be around their much older brother without constant close supervision. It is exhausting trying to keep a 6 and nearly 2-year-old away from a very mobile and hyperactive 11-year-old.

Another parent talked about the sibling needing help to manage the left-over trauma from past years of physical abuse.

Other comments included:

At the moment needs are strategic methods of dealing with teasing, managing interactions with child with disability and being an active member of the community.

Understanding how their brother’s condition affects them, how this is not necessarily their fault or unusual, and how to talk about, inform others about how this affects them, and learn helpful ways of dealing with this in the family, with their brother, at school and with their friends.

Access to support

Approximately half the respondents (48.7%) had used some sort of support for their children who are siblings. This support came from the following avenues:

1. Disability specific organisations – 38.7%
2. Carer organisations – 20.8%
3. Sibling specific organisations – 18.9%
4. Informally from family or friends – 17.9%
5. Community organisations – 17%
6. School – 16%
7. Health providers – 13.2%
8. Online – 7.5%

Types of support

Note that the following percentages only relate to those respondents who indicated they had accessed some support or their children (approximately 100 respondents).

The most commonly utilised types were: recreational activities (52%), face to face peer support (49%), individual counselling (34%), information about their brother’s or sister’s disability (32%), support from extended family or friends (31%) and friendship with other siblings (30%). Resources directed at parents were only accessed in a small number of instances (17%).

Those parents who had accessed support for siblings had done so through the few agencies identified in the provider survey conducted earlier and repeatedly talked about the benefits
(discussed below). Others had accessed one off or once a year activity like camps or day social events.

Some parents talked of the support they give within their family, including extended family. Whilst not direct sibling support as such, some parents saw the importance of ensuring that siblings attend extracurricular activities.

We have started to see a psychologist and made sure that our 6-year-old is getting opportunities for extracurricular activities like martial arts.

Extracurricular activities can add to a sibling’s social network. In some cases, such as with martial arts, it can also help them with self-protection issues. In the above instance, it is not clear what the main intention was.

One interesting finding was the difference in supports for siblings of children with disability and siblings of cancer.

One of my children (who is a sibling) is now receiving treatment for cancer and all of the sibling support services we have accessed relate to siblings of children with cancer, not disability.

Did support meet their family’s needs?

Only 30.4% of the 100 respondents felt that the support they received fully met their family’s needs, while 62.7% felt that the support partially met their family’s needs. 6.9% felt it didn’t meet their needs at all. A few respondents outlined why their needs were not being fully met.

I wish there were more of these types of things [support services] on a more regular basis

Lack of continuity and availability of a friendly ear when needed rather than at a scheduled and place. We lack extended family support and haven’t found any suitable replacement.

Some parents talked of accessing support but that it had been discontinued, usually due to a lack of funding.

It met our needs until it stopped.

Gaps in support

Many parents commented on the lack of support services for siblings, and the fact that those few that might be available are hard to find and often come at high cost.

I asked everywhere and got nothing

Very little professional help. No Dr has ever offered us or our family any help other than medical and saying how difficult it must be.

I have found it very hard to source any information or avenues about how to support siblings. It’s often not as easy to find as is sadly the last on a list for emotion and time poor parents.
Schools in general should be more aware too of the extra support needed for siblings, not just the parent having to be an advocate for the sibling as well.

My son misses out on many opportunities that are available to other children who don’t have a brother or sister with disability. It would be nice to be in a society that understands or at least acknowledges this and gives him other opportunities to make up for this, e.g. counselling, contact with other siblings.

Some parents said there was nothing available where they were, and others said they didn’t know if there was any sibling support available. Those in rural areas had even less options for support.

Isolation for rural families should be addressed as most things seem to be city-centred.

Rural areas miss out. No-one wants to take on the job to advocate for us and it is left to the 24/7 carer to fight because they see a need. We are exhausted!

As mentioned in the provider survey summary, the whole situation for families with respect sibling support is very ‘hit and miss’.

Understanding by professionals

One of the factors influencing whether support services are available to siblings was the understanding by professionals with whom they had contact. Generally, respondents felt that understanding of the issues experienced by siblings could be improved across the board in schools (79.4% could be improved), disability services (58.9% could be improved) and by GPs (79.8% could be improved).

One parent was disappointed by the skills of group facilitators at a particular sibling group, whilst others highlighted the importance of schools, e.g.:

There is a definite need for schools to be educated about the role that siblings and young carers play in their families and the impacts that it can have on their schooling performance and behaviour. I have broached this topic several times with our current school but, sadly, they just bury their heads in the sand and pretend it isn’t happening.

Comment was made that the medical profession and mental health services for young people were particularly inexperienced in rural areas.

Benefits

Those who were able to access support commented on the benefits, including:

Key benefits of the program have been a break from her sister, something special just for her, and an opportunity to connect with others in somewhat similar circumstances. It helps my daughter realise she is not the only one.

My son was able to understand why his brother needs that extra attention.
Fantastic service that makes her feel special & supported. Gives her respite and the opportunity to do things she would otherwise miss out on. The friendships she has made are invaluable & they are working on educating her on her sibling’s disability & teaching her stress management and self-care skills.

siblings are now more relaxed and active within the community.

The outings were a great time for my son to enjoy himself but also to discuss any feelings he had and to hear from other siblings.

**What supports are needed?**

Respondents indicated the types of support they felt were needed. Approximately 60% of all respondents felt the following were needed:

- parent resources / training for parents on how to support siblings (64.5%)
- counselling opportunities for siblings (60.7%)
- recreational activities for siblings (60%)
- peer support for young siblings (58.7%)
- advocacy for siblings (56.7%)

Other support required included:

- support with schoolwork for young siblings (46.5%)
- information about brother’s / sister’s disability (32.9%)
- information about the NDIS (22.6%)
- online peer support (20%)
- support for adult siblings (15.5%).

**Figure 3. Supports needed**
Some parents also wished for support to enable the sibling and the child with disability to share fun activities together.

**Other comments**

There were a number of additional comments. Quite a few parents expressed thanks for the survey being offered, for ‘being asked’, and for the work Siblings Australia is doing regarding raising awareness of the issue. For example:

*Thank you for investing time and effort, and promoting, an aspect of disability care that is incredibly overlooked and taken for granted. The stresses on siblings are huge and if anything, I feel they only increase as they get older, in some respects anyway. The concerns become more long-term and life-defining.*

*Thank you for seeing that siblings are a major support and might need some extra education, support and ‘time-out from what can be a stressful family life.*

*Thank you. I finally said what I wanted to say for the last two years. Now get Malcolm on the line, he needs a good kick up the bum!*

One parent was able to say that the early intervention service they had accessed had the whole family in mind, but most of the 30 comments from parents repeated the problem that no-one had ever asked them whether their non-disabled children needed support and there was just so little available. Others reinforced that siblings were not a priority for agencies:
Service providers might have an understanding of sibling issues but providing for them is not their main priority. Consequently, very few organisations offer programs or support.

We have not been able to find any formal supports. When a diagnosis is made, information for that child is provided but nothing for the family unit or siblings.

Any attempts to find some counselling to allow the child to have someone to talk to in a supportive non-parent environment has been extremely difficult to access.

If you are not connected with some sort of agency, you won’t know what’s out there. Trying to find something for siblings and keeping them connected can be hard. Time can be consumed by the person with disability. Finances can make it difficult and travel time too as we live regionally.

Some parents made comments about the NDIS:

It feels as though the siblings have been somewhat forgotten under the changes with the NDIS. The focus is all on the child with disability and I am concerned funding for vital sibling support programs will dry up. These programs are desperately needed.

I believe siblings should be able to access groups and support through the NDIS to enhance the family unit. Particularly psychological support for siblings.

I think it’s lousy that the needs of siblings are not covered by the NDIS. They are often overlooked and help to support them should be included.

Some parents were concerned about what they saw as government attempts to prepare siblings from a young age to take over the role of carer for their brother or sister. One said:

Governments of Australia should stop ‘grooming’ siblings to be ‘informal supports’ to cost shift. It is not their fault or their responsibility.

Attachment 1 – Respondent demographics

The majority (81%) had 1 child with a disability in the family, 14% had 2 children, and less than 5% had 3 or more children with disability; 52% of respondents had 1 sibling without disability in the family; 36% had 2 siblings; 9% had 3 siblings and 3% had 4 or more siblings without disability.

Most respondents were from NSW (51%); followed by Victoria (17%), SA (13%), Queensland (10%), WA (8%) and ACT (1%). There were no responses from Tasmania and NT. There were 59% of respondents in the metropolitan area and 41% in regional / rural areas.

Nine percent spoke a language other than English; namely Chinese, Afrikaans, Turkish, Arabic, Indonesian, Filipino, Greek, Vijaya and Makaton sign language.
The most frequent age bracket of children with disability was 5-12 year olds (49.5%); followed by 13-18 year olds (20%); 0-4 year olds (16.9%) and over 18 (13.6%). Autism spectrum was the most frequent disability type (25.8%), closely followed by intellectual/ cognitive / developmental disability (24.2%). There was a relatively even spread between sensory (14.9%), physical (10.4%), complex communication (9.4%) and psychological / mental health (9%) disabilities. Other disabilities (6.3%) included global developmental delay, various chromosomal abnormalities, epilepsy, behavioural problems, ADHD, psychiatric disorders, plus medical conditions such as diabetes. Respondents were able to select as many types of disability as applied to their children.

The vast majority of children with disability lived with one or both parents (88.5%); 4.6% lived with other family members; 2.3% lived in supported accommodation and a few lived in out of home care or foster care.

The majority of siblings without disability were in the 5-12 year age bracket (51.6%); 22.3% were in the 13-18 year age bracket; 14.1% were over 18, and 11.7% were aged 0-4.
Appendix 2  Adult sibling survey report

The adult sibling survey was one of a series of three surveys; as part of a broader project intended to help understand more about where and how siblings are being supported; where the gaps are and what people believe should be happening in the area of sibling support. This survey was directed towards adult siblings to better understand what supports are available and in which areas further support is still required.

The survey was developed by the project team, and circulated widely through email listings, Facebook, Siblings Australia website and personal contacts. The survey remained open for approximately one month, and reminders were sent prior to closing.

Note re language and format. Although ‘sibling’ is a generic term, in this report the term will be used only to refer to the child without disability. Also, specific quotes from parents, providers and siblings are highlighted in italics.

Key Findings

- Survey findings
- Adult siblings report a number of challenges both as children and adults
- Many siblings have experienced health or mental health problems as a result of the stresses involved in their family situation
- Families are complicated and each sibling experience is unique, and affected by a range of variable factors
- Siblings need support to manage their own challenges, but as become older they need support to assist in their brother or sister having a ‘good life’
- Few siblings accessed specific support in childhood and a small number believed that the support had fully met their needs
- There is a lack of understanding by professionals in the disability, health and education sectors of the needs of siblings across the lifespan

Implications/why findings matter

- Siblings are a group at significant risk
- If siblings are not supported they can develop a range of health/mental health problems, with significant costs to themselves and the community
- Siblings are overlooked in policy/programs
- Many people with disability become isolated – strengthening sibling relationships should be a crucial part of any strategy to improve wellbeing for people with disability
- Support for siblings is likely to have benefits for siblings, parents, people with disability and the broader community

How issues could be addressed

- Recognition of the needs and contributions of siblings
- A true ‘family focus’ when considering the impacts of disability
- More research into ‘best practice’ models of lifetime support for siblings
- More workforce development across relevant sectors
- Policy development to ensure there is some imperative to consider siblings
Respondents
There were 106 respondents, with 90% of people who started the survey completing all questions. For details of respondents and other demographics please see Attachment 1. There were two parts to this survey, which looked at experiences and needs in both childhood and into adulthood. The report will look at these two components separately.

Challenges of being a sibling
Respondents were asked to select from a range of feelings and situations in relation to growing up with a brother or sister with disability. As the survey was focused on the availability of support for siblings, we sought information about the challenges experienced by siblings. Respondents were able to select all that applied. The top 10 responses were:

1. Family stress – 83.8%
2. Missing out on time or attention due to time required to care for sibling – 70.5%
3. Feeling isolated and that others don’t understand – 68.6%
4. Embarrassment about behaviour of their brother or sister with disability – 67.6%
5. Feelings like anger, sadness, envy, resentment, guilt – 66.7%
6. Worry about the future – 66.7%
7. Too much responsibility – 52.4%
8. Difficult relationship with brother or sister with disability – 41.9%
9. Fear of sibling being in pain / dying – 38.1%
10. Physical harm from brother or sister with disability – 37.1%

Only 4.8% of respondents indicated that they had no concerns and coped well. Further detail is provided in Figure 1 below.

Figure 1. Challenges of being a sibling
Other comments showed how complex family relationships can be. Siblings talked about being concerned for parents and needing to be extra good to make parents happy. They also mentioned the stress of witnessing multiple seizures every day, or anxiety about the safety of their brother or sister, or experiencing or witnessing aggression from their brother or sister, and worry about the future if something should happen to parents. There was often increased responsibility, e.g. ‘all through my teens’, either to care for a brother or sister or to watch out for them in case they ‘did a runner’ or got into other danger. The extra responsibility was often combined with a lack of attention from parents, or an inability to do things other families did like take holidays. In one case, the sibling felt she was the scapegoat for her parents’ anger and frustration.

**Health or mental health problems (signs of stress)**

As shown in Figure 2, many respondents had experienced some form of health or mental health problems, with more than half experiencing anxiety (65.7%), depression (53.7%) and low self-esteem (53.7%). Other issues experienced included: lack of confidence (46.1%), sleeping problems (35.3%), post-traumatic effects (20.59%), physical problems (16.7%), eating disorders (14.7%), and substance abuse (6.7%). Only 16.7% felt they had not experienced any health or mental health problems.
There were over 30 further comments giving more details of the above. A few siblings also talked about having PTSD, self-harming and suicide attempts.

**Short term high stress related to specific incidences with brother.**

*I had anxiety and depression from my teen years, likely from the emotional excess and ignorance of how to deal with [the stresses] when young. I definitely didn’t have much self-esteem or confidence.*

**Grief and loss related to having a sister with disability and highly anxious parents and increased family stress (which continues especially with the NDIS).**

*Without meaning to, when things got stressful, parents would lay blame in the heat of the moment. Some things that can’t be taken back damaged my outlook on myself. Over the years this becomes ingrained in how you view yourself. Taking on grownup responsibility as a child to help get through the day was not a deliberate request from parents; it was just easier than dealing with life getting to them. There was nowhere to turn especially when you had to keep everything ‘just in the family’. Psychologists have helped my thinking now as an adult.*

*I have experienced all of the above but these issues were put aside as the focus was on caring for my brother first.*
When I was a teenager, I self-harmed and struggled with depression/anxiety.

Seventy percent of respondents have taken medication or sought counselling to deal with these issues, with mixed results. At most, some had been seeing therapists for over 10 years, with varying degrees of success.

I am 43 years old and have spent the majority of 20 years in some form of therapy to deal with the effects of my brother’s mental health disability on me and my life. I have sought out psychology a couple of times but neither seemed interested as to why I was anxious or that I felt it related to having a sister with disability. It was unhelpful.

It is impossible to know for sure how much of these stresses/outcomes were due to being a sibling, but most siblings seemed to feel that the stresses of childhood were linked to their adult challenges. The survey asked for sibling experiences of support in both childhood and adulthood.

**Childhood**

**a. Support received**

Many respondents (approximately 50%) had been provided with some form of support in their childhood/teenage years, however 42.3% indicated that no support had been available to them. Of those that received support, the primary types were:

- informal support from extended family or friends (26.7%)
- individual counselling (21.8%)
- information about their brother’s / sister’s disability (19.8%)
- recreational activities (18.8%)
- friendship with other siblings (15.8%)
- face to face peer support (14.8%)

Many siblings reinforced that there was very little support available, that their needs were constantly overlooked by people around them (family, professionals) and the expectation was to just ‘get on with it’.

Whilst a significant number of siblings (26.7%) mentioned support from parents or from family or friends, some also said that parents would not assist in them getting support. One had accessed help through school but their parents were not supportive and had told her to ‘not tell anyone about the disability’.

I was never sent to a support system due to the fact I was a sibling of someone with a disability specifically. I was sent to the school counsellor because I attempted suicide in high school. I saw the school counsellor often "just to chat" and to cry I suppose. I didn't receive support. My family would not allow it.

Parents did not understand and were too stressed. Was seen as good and did not play up - not seen to need help.

[I] was desperate for sibling specific support but not aware of any available.
A couple of siblings talked about the benefit of receiving support from a family focused agency. Since the age of 9 (sister’s age 5) we were part of an amazing supportive family organisation that really shaped me as a well-rounded, confident individual. My family is still part of this organisation.

I was supported, nurtured by the teachers at my local country preschool, primary school, [they recognised that family life was difficult for me].

A few siblings mentioned that support came after crises, or if someone could see the family was in trouble. One mentioned that a support group, accessed in primary school, ‘just stopped’. Some showed the lack of understanding of those around them.

I had individual counselling in my later teen years after a suicide attempt (pressure to be the ‘good girl’ was too much), but for some reason I wasn't able to make the link between my depression and my living situation and the traumatic events that arose from it. It wasn't until my late 20’s that I really started to acknowledge the huge impact that my upbringing had had on me. Up until that point it was so normalised that I internalised my anxiety/feelings of isolation as being a problem within me. Now I see that my upbringing was not normal, that I had little support or understanding of what was happening to me and my family, and that a lot of what I witnessed was deeply traumatic. I managed to make it through high school, but mostly I was so exhausted that I would fall asleep in class. Again, I thought for a long time that this was a personal problem, but in hindsight I see that I was under so much stress and feeling frightened at home that I didn't have the mental energy to keep myself awake.

b. Did this support meet their needs?

Only 13.5% of respondents felt these supports had fully met their needs, while 47.2% felt their needs had been partially met; 39.3% felt their support needs were not met at all.

Psychologists seemed unconcerned about the impact of the relationship I had with my sister. I wasn't aware of any potential support until I booked an appointment to see my school counsellor in year 10. The support provided by the school counsellor was helpful, but more focused on academic related stress than the family dynamics and the challenges of being a sibling to a sister with a disability.

Although I had counselling for anxiety/depression as a child and teenager, it was not recognised that having a brother with a disability was a significant underlying cause of my symptoms.

The support kept me going but did not reduce the ongoing worry and stress [in my family]. I felt that there was something wrong with me, not that I was living in an unusual environment. I had no friends that understood what was happening in my life and so I felt completely isolated. Peer support would have been a huge help, as during teen years it can be difficult to build relationships with adults. It would have been great to know that I wasn’t the only one so that I didn’t internalise the feeling that 'there is something different or wrong about me'.
It would have been nice to be able to network with other siblings in similar situations, but at the time I did not know I wanted this.

One who accessed support said,

*It just made me feel more normal and that I wasn’t the only one in this situation.*

c. Additional support needs (gaps in support)

Nearly 80 respondents commented on extra support they would have liked as children. Many would have liked contact with other siblings, for example:

*…..to learn I am not alone and to help internalise less guilt and responsibility.*

This was mentioned as especially important for sole siblings – those who had no other brothers or sisters besides the child with disability.

*I would have loved knowing other siblings.*

Many also commented on the need for counselling or mentoring, even if there had not been signs of distress during their childhood, but more as a preventative approach to help them understand and process their feelings, and in ‘handling life’. Several felt stressed watching their parents experience stress.

Siblings said they would have liked more information about their brother or sister’s disability and its impacts on the child with disability and themselves. They also wanted more opportunities to do ‘normal’ things as a family. Some mentioned more support/information for parents on how to support siblings. Others mentioned they would have liked support to interact more positively with the child with disability. Several siblings mentioned that they wished the school had more understanding of the impacts on them. Some also wished they had had a quiet space to study at home without all the interruptions.

*[I wish there had been] recognition of the effects of having a brother with a disability had on me by my parents, friends and counsellors. [I wish there had been] professional advice for my parents regarding how to minimise the effects on me (and my other brother).*

*There was no support or understanding offered. It may have been helpful to get one on one support to understand and learn to deal with some of the issues that occurred in my family and also to be seen, heard and understood as an individual with needs and individuality of my own as well as understanding (at school etc) that the family situation had an impact on me.*

*[I wish I had had] contact with other siblings away from my sibling and parents to create a genuine friendship network with people that have similar experiences with disability. I also would have liked to see my parents receive ongoing and professional support to properly*
identify my needs and how to parent in a situation where there is high disability care happening.

[I wish I had had] someone to help me learn skills for interacting well with my sister. Some wished they had found sibling support earlier, one commented that she wished she had been encouraged to not seek out a caring career and been told that she had some choice in the amount of responsibility she had for her sister in the future. Some wished they had had support, as they became older, to think about and plan for the future.

**Adulthood**

a. Adult sibling support

Respondents also reflected on the types of support they had accessed as adults:

1. Individual counselling (43%)
2. Online peer support (33.7%)
3. Information about brother's/sister's disability (32.5%)
4. Informal friendships with other siblings (24.4%)
5. Face to face peer support (20.9%)
6. Recreational activities (17.4%)

Approximately 17% of respondents had not accessed any support as adults.

Most people (47.5%) had found out about support online (Facebook or internet search). Other sources of information included: informally from family or friends (23.7%), disability-specific organisations (16.2%), health providers (15%), sibling specific organisations (15%) and carer organisations (12.5%).

In addition to the above sources, a few had been given information about Siblings Australia, specifically, by therapists or disability agencies, or had been recommended the book *Siblings*, which had links to support but, overall, most had found through their own searches online.

Further comments showed that quite a few of the respondents were connected via Siblings Australia online or face to face support.

*Online support with other siblings, run by Siblings Australia, is the most frequent activity I engage in on a weekly basis. I once attended an art group with siblings and it had a profound impact on me. Would love to engage in more of that. Information about disability and NDIS has been hard to obtain and I have had to research. It has not been sibling specific. Individual counselling is periodic during a crisis involving my sibs.*

*I have used a Siblings Australia group online and psychologist for a few months. Learning more about my brother’s disability means I can advocate better.*

*I have seen several Counsellors, Psychologists and Psychiatrists as an adult. I read the book Siblings in about 2004-2005 which was enormously helpful.*

Again, as with parents, siblings really valued being recognised:
b. Did the support meet their needs?
Some 26.5% of respondents felt that support had met their needs as adults, while 53% felt that support had only partially met their needs; 20.5% felt support had not met their needs at all. Again the 40 or more extra comments reflected such a diverse set of experiences, but an overwhelming consistency in feeling that others, even professionals, do not understand, or ‘get it’. Whilst there are many services for parents, there are few for siblings.

Other issues that were highlighted included the extra stress brought on by the transition to the NDIS and the need to support a brother or sister with disability.

I would like to speak to someone like a psychologist who is experienced with sibling issues as I have found the whole NDIS thing so stressful – it has brought up a lot of grief and anxiety about the welfare of my sister and my parents. Particularly as I work in the area I am acutely aware of the inequities and issues.

Sometimes siblings are trying to manage their own families whilst maintaining a job and also trying to advocate for a brother/sister. If there are issues like abuse or neglect in supported accommodation, it can be very difficult ensuring the safety of a brother/sister. Some people had found that formal complaints procedures are not always effective. For some, taking on more formal roles such as guardian meant even more pressure and this could also lead to financial stresses if they had to reduce their paid work in order to meet guardianship responsibilities.

I am trying to maintain a job and my own family while advocating on their behalf. Knowing my sibling is being neglected at his supported accommodation and the negative response I have received for following formal complaints procedures is the most heartbreaking experience. I am trying to stay strong and guide my family through this.

c. Gaps in support
The adult sibling survey reinforced what parents said about the lack of specific sibling support, for both young and adult siblings. Again, the finding of support for siblings was pretty ‘hit and miss’. Previous research by Siblings Australia has also shown a gap in specific support services for adult siblings. And a past ‘phone in’ and more recent project reinforced the gaps. Siblings Australia continues to hear from adult siblings who received no support in childhood and still struggle to find it now that they are older.

Siblings maintain that there is little understanding by their families or the agencies that support people with disability about the issues faced by siblings.
Understanding by agencies

Generally, respondents felt that understanding of sibling issues could be improved across the board in schools (89.9% felt it could be improved), disability services (83.1% felt it could be improved) and by GPs (88.6% felt it could be improved).

d. Benefits

Of those who had accessed support, one of the most beneficial activities has appeared to be peer support, not only to feel less alone, but also to think through ‘what things we might be able to try in our family too, things we may not have thought of before’.

*Learning more about my brother’s disability means I can advocate better.*

Other projects/programs by Siblings Australia reinforce this. One sibling referred to the online support she received from other siblings as a ‘lifesaver’. Another sibling reconnected with her brother with severe disability (he had been very aggressive in childhood causing her to feel great anxiety around him) after gaining support from other siblings and the agency that supported her brother.

e. Would siblings like to access any other support?

Approximately 50 respondents provided many suggestions about the types of support they would like to access now as adults. Generally, they fell into two categories – support for their own experience, and support for them in their role as support person to a brother or sister with disability.

Some called for stronger advocacy for siblings so there could be greater understanding of the roles and needs of siblings. Siblings wanted to connect with other siblings to share experiences and information/support, or even just social activities. They wanted counselling by therapists who had specific training and knowledge about sibling issues, and wanted to see more preventative approaches than reactive ones. Some needed help with the financial burden of ongoing help with mental health issues. They wanted to see more understanding of the financial impact of providing support to a brother or sister and they also hoped there could be more understanding amongst employers about the impacts on siblings and the responsibilities that some have.

Several siblings wanted to see better options for their brother or sister, that is, better accommodation options, better management of such accommodation, thereby reducing the risk of abuse or neglect. Some siblings who play an active caring role just wanted a break for themselves. Others mentioned the need for a hub of information relevant to siblings, including information on the options available for people with disability, legal advice as they became more involved in support for a brother or sister.

What supports are needed?

This more general question asked what types of support siblings felt were needed to effectively support siblings across the lifespan:

1. Resources/ training for service providers – 77.7%
2. Resources/ training for parents – 74.5%
3. Advocacy for siblings – 67%
4. Counselling support – 61.7%
5. Face to face peer support for young siblings – 61.7%
6. Recreational activities – 60.6%
7. Support with schoolwork – 58.5%
8. Face to face peer support for adult siblings – 45.7%
9. Information about disability, including NDIS – 43.6%
10. Information about a brother or sister’s disability – 42.5%

Further detail is provided in Figure 3 below.

Figure 3. Support needed

Several said they were not aware of what was available now but stressed the importance of providing assistance when siblings are young. Some siblings said they were still working through issues from their childhood, and that they would need support throughout their life. They believed that counselling should be very specific to siblings by psychologists who truly ‘get’ the sibling experience and who can provide specialised supports to manage such things as anxiety and PTSD.

Several said there needed to be more emphasis on developing lasting connections and networks between siblings to counter the ‘isolation, loneliness, powerlessness’. They added that maybe there should be more opportunities for creative outlets, such as writing or art. While another said they needed support to maintain family life - not so much talking but actual services.

Activities that brought together families with a child with disability were helpful to one sibling:

They made it seem ok to have a child with disability in the family as you could see other families with similar experiences. I fear this will be lost under the NDIS, as there will not be funding for such activities and NDIS don’t care about families.

Another suggested:
Resources and training for providers and raising awareness of the unique needs of siblings. Providing advice to parents about how to support siblings and prevent longer term mental health problems.

Again, several mentioned the importance of working with schools, to increase understanding and support. One said she wished there had been greater leniency, given her family situation, regarding her inability to sometimes finish homework.

One sibling said that there ‘should be acknowledgement that the burden of care should NOT fall to siblings’. Another expressed concern about the concept of ‘young carers’, especially in relation to developing their own identity. Being referred to as a ‘young carer’ can add to the difficulty of developing an independent identity; instead this might reinforce their perception that they are a ‘helper’, ‘carer’ and that they should put their own needs behind those of others.

One sibling also said:

There needs to be a change in the prevailing attitude that family can do it – for nothing regardless of their own needs. Plus, the appalling mentality that family are going to rip off the PWD [person with disability], system, NDIS – far from truth. We give more than could ever get.

Another said:

siblings have so much insight to offer and are an untapped source of understanding. We should also be offered support and have information needed to help us through tough times.

Again, several siblings reinforced the importance of a sibling specific organisation such as Siblings Australia, describing it as a ‘vital resources’ that should be supported to continue.

Other:

Twenty-five responses were received for the final question asking for other comments, with many siblings expressing again that they felt so grateful that someone was looking at sibling issues. For example:

Thank you for caring and undertaking this research. I actually feel a bit teary thinking that ‘someone has my back’.

This survey was very supportive and helpful.

I have been attending one of the Siblings Australia face to face sib groups. For the first time I feel like there are other people who understand my situation and who offer so freely their experiences with dealing with the issues that arise – from arranging care providers, to legal matters etc. I think it is important for siblings to have an organisation as a point of contact, distribution of information etc.
I hope your study improves things. My brother’s disability and the effects it had on the family were profound and linger today. I think we would all be much happier, well-adjusted and productive if we had some support when we were younger and my parents were more aware of the impacts on their other children.

One sibling talked of only recently, at the age of 37, being open to support due to experiencing a ‘new depth to my grief’. As their parents age and the future responsibility for a brother or sister becomes more real, siblings can experience renewed anxiety about the changing landscape of disability services, as well as fear and worry about safety and vulnerability of a brother or sister.

Attachment 1 – Respondent demographics

Of the 106 respondents, 9.3% were male, 88.7% were female and 1.2% identified as other. There was a fairly even spread across respondents age ranges: under 18 (19.8%), 18-24 (16%), 25-34 (22.6%), 35-44 (19.8%), 45-54 (12.2%), 55-64 (7.6%) and over 65 (1.9%).

Most respondents were from NSW (34.6%); followed by Victoria (23.1%), Queensland (21.2%), SA (12.5%), WA (8.6%). There were no responses from ACT, Tasmania and NT. There were 69% of respondents in the metropolitan area and 31% in regional / rural areas; 3.8% identified as Aboriginal or Torres Strait Islanders. Approximately 11% percent spoke a language other than English; namely Cantonese, French, Auslan, Mandarin, Greek, Japanese, Spanish, Key word signing, Arabic.

Respondents were asked their employment status, and were asked to select all that applied (e.g. part time work and studying): 27.9% were employed full-time, 17.3% were employed part-time, 11.5% were casual employees, 9.6% were self-employed, 7.7% were volunteers, 7.7% were unemployed, 3.8% were retired, and 35.6% were studying.

The majority (80.2%) had 1 brother or sister with disability; 14.1% had 2 brothers/sisters; 1.9% had 3 brothers/sisters and 3.8% had 4 or more brothers/sisters with disability. The spread of age ranges of brothers/sisters with disability was: under 18 (24%), 18-24 (14.4%), 25-34 (25%), 35-44 (14.4%), 45-54 (10.6%) 55-64 (11.6%) and none over 65. The gender distribution of brothers/sisters was 63.2% male, 35.8% female, and 1% other.

The majority had brothers/ sisters with intellectual/ cognitive / developmental disability (80.2%), followed by physical (41.5%), autism spectrum (38.7%), psychological / mental health (22.6%), complex communication (21.7%) and sensory disability (21.7%). Other disabilities (6.6%) included Epilepsy plus medical conditions such as diabetes, gastrostomy and Cystic Fibrosis. Respondents were able to select as many types of disability as applied to their brothers or sisters.

Accommodation arrangements for respondents’ brothers/sisters were spread, with the main types being:

- With respondent and parent/s - 31.7%
- With parents (without respondent) - 26.9%
- In a group home - 14.4%
- Independently with support - 11.5%
- With respondents without parents - 3.8%
Other arrangements included: independently with no support, in aged care, hospital, foster care, mixture of arrangements. One sibling mentioned that their brother or sister with disability was deceased.
Appendix 3   Provider survey report

The service provider survey was one of a series of three surveys as part of a broader project intended to help understand more about where and how siblings of people with disability are being supported and about where the gaps are and what people believe should be happening in the area of sibling support.

This survey was directed towards service providers from organisations currently providing sibling support or organisations that had provided sibling support in the past. The survey was interested in the following types of sibling support:
1. Direct support that specifically targets and involves siblings (e.g. sibling-specific counselling or peer support programs)
2. Indirect support that addresses sibling issues, but does not directly involve siblings (e.g. advice/resources for parents on support of siblings)
3. Other broader supports that are not specifically for siblings but may still benefit them (e.g. school based resilience programs).

The survey was developed by the project team, and circulated widely through email listings, Facebook, Siblings Australia website and personal contacts. The survey remained open for approximately one month, and reminders were sent prior to closing.

Note re language and format. Although ‘sibling’ is a generic term, in this report the term will be used only to refer to the child without disability. Also, specific quotes from parents, providers and siblings are highlighted in italics.

Key Findings

<table>
<thead>
<tr>
<th>Survey findings</th>
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<tbody>
<tr>
<td>Providers report that siblings are very vulnerable but their needs are often not a priority</td>
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<tr>
<td>There are few specific sibling support services</td>
</tr>
<tr>
<td>Some carer services include siblings but these are not always relevant or appropriate for siblings</td>
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<tr>
<td>The sibling support sector is unco-ordinated and lacking in ‘best practice approaches’</td>
</tr>
<tr>
<td>There is little or no collaboration between sibling support services</td>
</tr>
<tr>
<td>Without a policy framework, there is little imperative for agencies to provide sibling services</td>
</tr>
<tr>
<td>The barriers to agencies providing sibling support services include funding, the current disability services model (NDIS), a lack of understanding by professionals regarding siblings’ contributions and needs, and lack of policy</td>
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<table>
<thead>
<tr>
<th>Implications/why findings matter</th>
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<tbody>
<tr>
<td>Many providers lack understanding of the contributions and needs of siblings</td>
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<tr>
<td>Those who do understand the risks for siblings are often unable to act on their concerns due to restrictions within their agency</td>
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<table>
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<tr>
<th>How issues could be addressed</th>
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<tr>
<td>Recognition of the needs and contributions of siblings</td>
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</table>
A true ‘family focus’ when considering the impacts of disability
More research into ‘best practice’ models of lifetime support for siblings
More workforce development across relevant sectors
Policy development to ensure there is some imperative to consider siblings

Respondents
A total of 75 responses were received. However, 27 of these only completed the first 2-3 answers and so cannot be included in the overall findings. There were 48 other responses, but several did not complete the whole survey so there are different response rates to different questions in the information that follows. (See Tables 1 and 2 below for detail).

A majority completed the survey on behalf of their organisation; a small number were sole-practitioners; the remainder were clinicians, caseworkers or advocates. Providers of disability services were the largest group (30% of respondents) with people working in other sectors (health services, mental health services, education, community services, family support, carer support) each representing less than 10% of respondents.

Of the 48 responses, 30 indicated they provide direct support, 18 provide indirect support and 3 of the 48 indicating they provide broader or other support.5

Table 1. Summary of respondents indicating they provide direct support (30 total responses)
(numbers indicate the number of people who answered each question listed)

<table>
<thead>
<tr>
<th>Role of respondent</th>
<th>Agency focus</th>
<th>Strategies to support siblings</th>
<th>Has program been evaluated?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sole practitioner</td>
<td>Disability</td>
<td>11 Face to face peer support</td>
<td>15 Yes</td>
</tr>
<tr>
<td>Organisation rep</td>
<td>Health</td>
<td>1 Individual therapy</td>
<td>3 No</td>
</tr>
<tr>
<td>Other</td>
<td>Mental health</td>
<td>3 One-day event annually</td>
<td>2 Unsure</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>4 Camp (2 with children with disability)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Community services</td>
<td>3 Adult sib info re NDIS</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>2 Young Carer</td>
<td>3</td>
</tr>
</tbody>
</table>

5 Direct support that specifically targets and involves siblings, e.g. sibling-specific counselling or peer support programs; this may also sometimes include young carer and carer programs, if they accept siblings; indirect support that addresses sibling issues, but does not directly involve siblings, e.g. advice/resources for parents on support of siblings, respite care for person with disability so parents can spend time with sibling; broader supports that are not specifically for siblings but may still benefit them, e.g. school based resilience programs, community based mental health programs
<table>
<thead>
<tr>
<th>Role of respondent</th>
<th>Agency focus</th>
<th>Program benefit to siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sole practitioner</td>
<td>Disability</td>
<td>12 Info for parents</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Organisation rep</td>
<td>Health</td>
<td>1 Parent counselling</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>Mental health</td>
<td>0 Family events</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>Part of carer program</td>
</tr>
<tr>
<td>Community services</td>
<td>1</td>
<td>Respite care</td>
</tr>
<tr>
<td>Family support</td>
<td>0</td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Carer support</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL RESPONSES</strong></td>
<td><strong>14</strong></td>
<td><strong>15</strong></td>
</tr>
</tbody>
</table>

*The response numbers do not total 15, as people could choose as many responses as applied*

**Table 2. Summary of respondents indicating they provide indirect support (15 responses)**
(numbers indicate the number of people who answered each question listed)

1. **Agencies providing direct support for siblings (30 responses)**

The main findings in relation to direct sibling support indicated that most services do not seek to target specific cultural or language groups. Some only include siblings of people with a particular disability; most commonly these are autism and intellectual disability, and are targeted at primary and high school aged children. Face-to-face peer support is the type of support most commonly offered.

Further detail is provided in Table 3 below.
Table 3. Direct sibling support provision.

<table>
<thead>
<tr>
<th>Specific target groups</th>
<th>Most services (69%) do not seek to include any specific groups (such as Aboriginal and Torres Strait Islanders, or culturally and linguistically diverse groups). Some agencies indicate that they focus specifically on siblings experiencing such things as social isolation, others include only siblings of people with a particular disability and one agency focuses on siblings who identify as LGBTIQ.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability type</td>
<td>Many programs cover siblings in relation to any disability type; predominant are programs for siblings of people with autism (68%), intellectual disability (65%), physical disability (59%), sensory disability (50%), mental health (41%) and chronic illness (15%)(^6).</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>Eligibility is generally determined by being part of a client’s family (41%), which means that the sibling program is restricted and is not open to the general community. Living locally is the other key eligibility criteria (35%).</td>
</tr>
<tr>
<td>Target age group</td>
<td>The most common target age group for siblings’ programs is children aged 5-12 years (83%), followed by teens aged 13-17 years (60%). Infant and toddler, and young adult siblings’ programs represent approximately 20% each of programs offered.</td>
</tr>
<tr>
<td>Type of program</td>
<td>Just over half of the organisations (55.6%) providing direct sibling support did so via face-to-face peer support. Other types of support included individual therapy/counselling (30.6%), group therapy/counselling (22.2%), and camps (most including the child with disability) (33.3%).</td>
</tr>
</tbody>
</table>

Other support provided included young carer programs and retreats (which siblings can usually access), family-based support such as family based treatment programs for a specific illness, school holiday programs, after school activities, annual events or fun days, specific therapies and parenting programs. It is difficult to know how specific these activities are to siblings.

The following agencies are the main ones to provide direct specific sibling support programs:

- Direct, specific, sibling support programs – open to anyone in their local area – 3 agencies (one in each of WA, SA and NSW). (In total they support about 120 siblings across the age ranges 5-12 years and 12-17 years).
- Direct, specific, sibling support programs – open only to siblings of their clients – 5 agencies (2 in Victoria, 2 in NSW and one in Tasmania) (150 children/teens).
- One off events for siblings (1-2 per year and client family only) – 2 in NSW. (50-100 children/teens)
- Two schools (one mainstream, one special) indicated that they provide sib support via formal programs, one during the year based on Sibworks, and the other an annual event (30-50 children)

\(^6\) These percentages do not total 100% as respondents could tick all responses which applied to their situation.
• Three sole practitioners responded to the survey – two provide counselling/therapy for all ages; the other indicated they provide creative expression workshops for children and teens (approx. 30 across all ages).
• Three agencies run programs that are combined for both the sibling and the child with disability – day activities or camps.
• Some carer agencies provided ‘young carer’ programs.

While difficult to ascertain from the survey answers the detail of the programs offered, the general structure included social and recreational activities, as mentioned earlier. Some organisations used a specific model such as Sibworks (13%); others offered an in-house developed model (58%). One agency offered a modified version of the SibShops model developed in the US. The remainder offered an adaptation of Sibworks, something more informal, or were unsure of the model offered. The programs, Fun Friends and Friends for Life were mentioned by one provider and mindfulness, compassion focused therapy and CBT by another.

Some activities for siblings were provided as part of more general family support e.g. family camps, or part of a more specific treatment program for a particular illness. One program was a combined social and recreational program for children with a particular disability and the sibling(s).

The timing of these programs is quite variable – weekly, monthly, fortnightly, annually, school holidays, on request or referral, 6-week programs, camps over 2-3 days.

As highlighted above, the number of siblings taking part annually in such programs was difficult to determine as numbers provided were approximate. The survey indicated that 40% of programs involved some 20-50 siblings, 34% involved 10-20 siblings and 12.5% of programs involved either less than 10 participants or more than 50). However, when follow up enquiries were made it was apparent these were only estimates, and some programs had in fact ceased, and historical attendance numbers had been provided.

Most programs have been running for longer than 5 years (55%), with approximately 20% running for 2-5 years, 13% running for 1-2 years, and 13% for 1 year or less. Most programs (69%) are delivered in the local area, with 19% delivered regionally, and 12% run state-wide. Several indicated that they used to run programs but are no longer able to due to NDIS, lack of funding or staff skills.

Funding for siblings’ programs was variable, with some organisations combining funding from different avenues. More than half the agencies (53%) provide funding from their own budgets. Other key funding came from:
• Commonwealth government funding (30% of organisations),
• State government funding (43.3%),
• Family pays a fee (20%)
• Other sources (40%)

Some had a mix of sources. Also, it is not known however how much of this funding is specifically for sibling programs and how much is for general services.
As shown in Figure 1 the main **desired outcomes** for direct programs included: less isolation among siblings (93.8%); support for siblings (87.5%); improved mental health among siblings (84.4%); skills to deal with experiences (81.3%); relationship between siblings and their brother/sister (65.6%); information re sector to better support brother/sister (25%); and understanding NDIS (15%). Comments under ‘other’ were variations on these themes, although one mentioned support for young carers to remain at school.

**Figure 1. Desired outcomes for the program.**

Approximately half of the respondents did not know if the program they offered was evidence-based. Only 11% indicated that the program they offered had undergone a formal evaluation. Evaluation strategies included evaluation forms/exit surveys, and informal discussions about the benefits. The evaluations indicated that siblings show an increased understanding of the different roles that siblings can play; they provide a safe place to express feelings and emotions; and that siblings gain from meeting other siblings and knowing they’re not alone.

The survey confirmed that there has been little formal evaluation of the programs being used to support siblings. Those who have done some evaluation still appeared to have focused on how the children/parents feel about the program, rather than measurable outcomes. A few evaluations have used other tools (some standardised) to measure reduction in symptoms such as anxiety or depression, level of connection to community or functioning at school. The Sibworks program has been evaluated using a controlled study.7

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Very few agencies work in collaboration with others (10 respondents); the focus of this interagency work is identification of siblings, supporting families, use of local facilities, and contact between similar services which are government funded across different agencies.

2. Agencies providing **indirect support for siblings** (15 responses)

Agencies providing indirect support focussed on providing information for parents on the needs of siblings (53%), parent counselling (47%), respite care for family member with disability (40%) and family events/activities (33%). Other types of support included strategies to address conflict between siblings, relaxation, psychology support, presentations at seminars about sibling issues and providing information about available sibling support. Agencies providing indirect support did not collect data on how many siblings benefited from their support.

3. Agencies providing **broader support for siblings** (3 responses)

Although there were 3 responses to this section, further details were not given, meaning that a detailed analysis is not possible.

**Barriers to implementation of sibling programs**

A small number of respondents (4) indicated they had previously provided sibling specific programs but no longer did so. Lack of funding and the introduction of the NDIS were cited as the reasons for this.

> Unfortunately, the shift in funding due to NDIS has meant that services that we could previously offer are no longer viable. This change in community services in general to a business model has meant that we have lost many valuable community services, and in our case, this has significantly affected sibling and family support. It also means that experience in this area is lost as staff are not given the opportunity to be involved in any of the sibling groups and camps that we used to offer in the past.

The barriers to implementing specific services for siblings included lack of funding, not being in the agency’s strategic direction, sibling support being seen as a lower priority, and lack of staff knowledge and skills.

> Lack of priority [for sibling support] which leads to a lesser focus and given the current market environment where everything is equated to the cost. This is everybody's business and needs to be prioritised.

Responses to the question ‘what would help’ focused on further funding and a change in agency goals and/or purpose. One response commented that further funding for sibling specific programs would be a way to highlight sibling issues as a priority.

**Referrals**

Only 8 responses were received to the question about whether they refer to other agencies, with 4 saying they did. No further information was given about these referrals. Part of the difficulty at present is the lack of sibling support services available to refer to.
**Needs and gaps**

Many of the providers (41), responded to the question about sibling needs and gaps in their support. They talked about siblings being very vulnerable to a range of emotional, behavioural and psychological difficulties, but that their needs are often not a priority. Whilst many providers highlighted these needs, they indicated their organisation didn’t necessarily have the capacity to address them. Sibling needs mentioned included:

- support to manage mixed and difficult feelings;
- assistance in asking for help;
- information to help them better understand what is happening in their family;
- time with parents;
- help to develop their own identity and to feel valued;
- tools to build resilience and social skills;
- support to feel less isolated; and
- support to work out what roles they might play and manage extra responsibility.

Ultimately the view from service providers was that siblings need to maintain their own life needs and goals whilst also supporting their brother or sister with disability. They thought that sometimes siblings need help to strengthen the relationship with their brother or sister with disability, while others may need help to manage the difficult or aggressive behaviour of a brother or sister. Additionally, they said that some need help to manage the bullying by other children of themselves or their brother or sister.

Providers stressed the importance of providing support to siblings. A variety of support strategies were mentioned, including:

- Contact with other siblings to:
  - share experiences and learn from each other,
  - relax and have fun,
  - build friendships,
  - learn they are not alone;
- Respite from the stresses of home.
- Parenting programs to assist parents in understanding the needs of siblings.

One provider (see Attachment 1) talked about the dangers of taking a view that ‘fun time out’ was enough; that this may not be effective in all cases and that siblings might need other supports. This reinforces the need for some best practice guidelines to be developed that can have some flexibility for different needs.

Responses indicated multiple gaps including a lack of sibling support, particularly peer support programs and specialist counselling, especially for teen and early adult siblings. They also said there is a gap in awareness of the needs of siblings and in information about what programs might be available. As one provider said,

*There is not much mention of siblings in relation to disability at all. This includes kids and adults. The NDIS has ignored the needs of siblings*
Others pointed out that some programs have stopped or will soon stop due to a lack of flexibility in funding since the introduction of the NDIS. Some agencies feel that ‘carer’ support is sufficient but as one provider said, this approach does not always meet sibling needs. It was suggested that ‘more pro-active education from Siblings Australia is obviously needed’, but it was also recognised that funding was limited.

It was also suggested that schools needed to have more awareness of the needs of siblings and have a big responsibility to identify the links between sibling issues and their behaviour/performance at school.

The full list of comments to this question can be viewed below.

Please add any comments about what you see as the most important needs of young or adult siblings, and what gaps you see in their support (N=41)

- Support around frustrations, being targeted and bullied at school because of the behaviours of a sibling - to be themselves and not being the sibling of ‘that kid’ as was stated to me recently by a sibling who had a trip to Sydney and felt that no-one knew them.
- Some families who are involved in various disability support programs provided by our organisation have expressed the lack of supports for siblings of the child with a disability. Numerous times families tell of the sibling(s) spending time in their bedroom to avoid aggressive behaviour of the sibling with disability.
- For them to be listened to and to spend time with them doing activities they enjoy
- Young carers need support they are growing up with their needs given less priority in their family than their sibling. They move into the world of recognising they are going to be the person responsible for their sibling and struggle to make sense of what they need to do. There are many unmet needs and young people are extremely vulnerable
- Specific avenues to voice their feelings, concerns and needs. Contact with other families in similar circumstances.
- Lack of sibling programs for families to access. Limited availability of funds to expand program. Lack of specific specialist counselling services.
- The parents of children with a disability tend to spend a lot more time with the child who has extra needs. This can lead to resentment from the typical child. Or the typical child is missing out on ‘normal life’ due to the extra needs of a child with a disability.
- To have their own identity in the family and community and is not just a sibling
- Places where kids can get together and do activities that don’t revolve around their siblings. Meeting other siblings so that they are aware that they are not the only ones and have the opportunity to ‘normalise’ their situation.
- I think there is a gap in support for the older group and we are looking at the options to better engage Siblings 16-25.
- Information, mental health support, peer support, respite care for sibling with a disability to enable quality time with parents
- Support groups with other siblings in similar situations are needed on a regular basis. Sibling education on coping strategies and empowerment, to assist strengthening the sibling relationship, to ensure lifelong informal support. Sibling outlets for siblings to feel important also and focus specifically on their needs. Programs for parents to highlight the impact on siblings when caring for a child with disability/ special needs.
• Education, social living skills.
• Creating a sense of belonging - to generate a sense of you are not alone. 2. Social - creating fun social opportunities for siblings to relate to other siblings, to build friendships. From friendships created sharing of experiences can occur over time. 3. Voice for Siblings to create awareness amongst community on the experiences of siblings.
• Acknowledgement of their role, a sense of self, peer support network to break down their feelings of isolation. There are gaps in support due to lack of and sensitivity around identification, especially when it involves the role of a young carer.
• Very little support available and no funding for that support
• Peer support programs for siblings
• No more neglect. Siblings are the best
• Online presence is very important
• Young and older siblings have needs for acknowledgement and support. They have a greater risk of emotional, behavioural and psychological difficulties. They can benefit from meeting others in the same situation and sharing feelings and experiences as well as identifying strategies for coping with the pressure. There are many gaps in this area. The NDIS has ignored the needs of siblings.
• Time is what is missing. Time away from the stressful situations, understanding about the impact that is on their lives, time to be themselves and opportunities to be with others that completely understand what they are going through. I believe schools have a bigger responsibility to recognise the links between sibling issues and behaviour/performance at school. We need more frequent siblings only events.
• Support, understanding, tool kit to build resilience and problem solve, build social skills
• Support is not easy to find or automatic so sibs can fall through the cracks very easily.
• Early intervention for siblings as children to ensure needs are being met - reduced isolation, connecting with others, support to manage emotions and challenging situations, respite.
• Not enough information out there on what sibling groups are available. I have considered this type of service, however, have not had the resources to take this forward at this time. Happy to collaborate where appropriate/needed.
• I am currently working with a family who are very involved in a support organisation for their child with a disability but who had never heard of Siblings Australia until I advised them. More proactive education from Siblings Australia is obviously needed (subject of course to resources)
• I live in a regional area. Here there are 'traditional' disability related supports available (such as therapy or support work), but less support for the more nuanced needs of people with disability and their families. There is little support for siblings, no sibling program, not much mention of siblings in relation to disability at all. This includes kids and adults. For adults, it can be hard for them to feel included in conversations about the NDIS and what it means for their family member. Community based groups for siblings in relation to working through the NDIS would be very useful at this point in time. I believe kids who are siblings always benefit from a sibling’s program if it is well designed. Neither of these things are available
• To maintain their own life needs and goals as well as accessing support as needed to assist in care for sibling/s
• We focus on giving siblings the opportunity to relax, have fun and just be kids. Most kids generally have a positive relationship with their brother or sister who has a disability but there are tough times too and our program is a safe space to meet others who have an idea
of what that is like. We come across a range of kids from varying socio-economic backgrounds and it would be great to ensure all children regardless of their family's financial circumstances were able to access our program.

- A safe place for them to express their feelings. Engaging in fun and therapeutic activities with others who share a similar lived experience. Having a break away from their sibling to explore their individual interests. Being valued as an individual who is valuable.

- Due to current funding, we may lose funding for our SIB group with the NDIS. Currently seeking other avenues of funding, however there will be a massive gap in services and experiences provided for siblings if this funding is not secured. We also see a massive gap in support provided for children in high school or over 12 who cannot access our group.

- For young children, the family are often busy focusing on the needs of the child who has a disability and or illnesses. Helping the family see the needs of the whole family is essential for the whole family to adjust.

- Continually raising siblings’ issues and their need for support/resources and acknowledgement is an ongoing issue amongst Health and education staff. We have a commitment to providing some level of support/resources for siblings. Some agencies feel that providing "carer" support is sufficient and do not always target siblings. We have a commitment to siblings and will continue to provide at least an annual event just for siblings.

- For us, the most important support is for siblings to have one-on-one time with parents, as there is often a necessary focus on the child with chronic illness - hospital appointments/admissions etc. Gaps are opportunities for peer interaction with other siblings in similar situation, especially away from the family - e.g. camps with professionals who can structure appropriately. We used to organise these but can no longer afford them. We offer day trips for sibs and parents just to have fun.

- Have run annual siblings’ groups in the past but due to restrictions of NDIA funding we no longer provide these highly needed (and well loved) groups

- Our program works because I know the siblings’ brothers and sisters within the school, and so understand their individual circumstances. The program also helps break down some of the fear and confusion that attending a special school can cause them. They also become more included in the school community, so that when they attend school functions they know other siblings. I get interest from non-school siblings to attend, but feel this will water down the benefits and feedback available through the program.

- They need access to information that can support them in their roles as siblings, and connection with others in the same situation for moral support. Importantly they need to be taught to recognise when to ask for help and how to access that support. They need to recognise that their feelings are normal, and that those feeling can be expressed in a safe environment.

- Education and awareness of supports this needs to start in school

- For young children/teenagers to have the option to link up with other young children/teenagers to share about individual challenges, to build resilience and to have that sense of "I'm not the only one going through this".

- Awareness; respite; social care for sibling; school building resilience program
Attachment 1 – Input from social worker

Jane works as a Social Worker at a DSU which sees approx. 200 children per year as part of a Disability Diagnostic and Assessment Unit within Sydney. She offers the following input:

Parents (and I) show frustration that sibling programs that do exist are mainly recreation focussed, providing time out and fun. Whilst these do serve some purpose parents are really wanting programs that allow for more connections, conversations with other sibs etc. They feel that the recreational programs cater more for a higher socio-economic group.

An estimated 90% of parents seen at the Unit are after support that allows children to learn more strategies, be able to vent, access counselling etc. They often feel considerable guilt because they are unable to give enough to the sibling(s). Other concerns include how they share the diagnosis with the sibling(s), how they manage the sibling’s behaviour, including when they copy the behaviour of the child with disability.

The issue of family therapy has been raised – this model would be a good support for families especially if there were some focus on the sibling(s).

Funding is a huge barrier but also the lack of staff knowledge around sibling theory/evidence and what the needs truly are can be very significant. My question to service providers is why parent support is so strong, and well executed, but sibling support is less understood. Sometimes the answer is that the parent has the task of raising the sibling and therefore the necessary support can be provided to the parent for this... but I worry this doesn’t allow a thorough enough systemic lens ... I do refer to the early intervention services sibling days. Often their support or keyworker programs will consider sibling issues (e.g.: within behaviour management). I also refer to Siblings Australia website and print out material from there to give to parents to raise their awareness about sibling issues and support.

I worry that if siblings needs are solely addressed within a ‘fun time out’ framework then this undermines the family system, and risks creating two systems in which there is a ‘normal’ child raising environment and a ‘special needs’ child raising environment. I do completely agree with respite and time out, but it is just that in this case it is pitched as the most important sibling need, which it might not be.
Appendix 4  Siblings Australia

Siblings Australia was established in 1999 with a focus on siblings of children and adults with disability or chronic illness. Over a period of 18+ years Siblings Australia has developed a national and international reputation for its work with families and professionals. It aims to create connections between siblings, between parents and siblings, and between families and professionals, with a focus on strengthening families. The organisation’s Mission is a simple one: Siblings: Acknowledged, Connected, Resilient.

Siblings Australia has built relationships with family, mental health, youth, education and disability agencies, in an attempt 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. Further links to what the organisation does can be found here, including a guest editorial, published in 2008 in the Australian e-Journal on the Advancement of Mental Health.

Workshops

Workshops have been run for thousands of siblings, parents and service providers all around Australia (in both metropolitan 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 completely stopped.

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 at no cost via the website, which also includes a range of information and networking opportunities. 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) generated very powerful responses from around Australia and overseas. It has also been published in the US, the UK, and translated into Korean.

**Research**

The organisation has played an important role in areas of research to inform social policy makers about the needs of siblings. These can be viewed on the website here.

**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, through various advocacy papers. 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 (Towards improved recognition and support for siblings of those with a chronic condition: A report on consultations) by Families Australia and Siblings 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, this was not taken up by government.

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 that the value of Siblings Australia may not be sustained into the future, including through a petition in 2008, forwarded to government when funding was lost, and another in 2015. Comments from some of the signatories for these petitions can be viewed via the advocacy link above.

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Appendix 5  Evaluation of project outcomes

This project clearly met the stated outcome of ‘understanding the current situation for support for siblings of PWD, including mapping of current supports, needs and gaps.’ Through this project, Siblings Australia has confirmed previous knowledge in relation to the significant needs of many siblings of PWD, and the gaps in service provision which currently exist.

The response rate for the three surveys (75 service providers [only 48 completed beyond first 2-3 questions]; 198 parents; 106 adult siblings) provided ample data for understanding the current sibling situation nationally. The completion rate for the service provider survey was lower than the project team would have liked (only 64% answered beyond the first 3 questions). However, this may be because question 3 specified the types of sibling support in which the survey was interested, and some respondents may have felt that their services did not fall into these categories, and so discontinued the survey.

An evaluation of each of the seven project objectives is outlined below.

1. Develop Activity Work Plan outlining activity requirements and deliverables
   Completed within agreed timeframes

2. Establish national Consultation Group, including Terms of Reference, with representatives across Australia to seek input and share information
   As sibling issues are not core business for organisations, potential group members were unable to commit to the time involved, and it was not possible to convene a consultation group which met regularly. However, to ensure representation of siblings’ voices, siblings were invited to be involved in a more ad hoc manner. A university researcher experienced in sibling issues acted as an expert adviser; two siblings were amongst the group that developed the project plan and the surveys, and there was a sibling represented in the small consultancy group. Other researchers from organisations with relevant expertise provided feedback on request on aspects of survey development.

3. Develop an agreed mapping approach
   The agreed mapping approach of separate surveys for providers, parents and siblings was a successful methodology. The provider survey included coverage of direct sibling services, indirect services and other broader services that might not be specifically for siblings but may benefit them. This was complemented by phone follow up and direct interviews with selected respondents. Surveys were circulated via Siblings Australia e-mail list (1300 contacts); Siblings Australia Facebook page (2800 likes); purchasers of the Sibworks peer support program and SibChat members (online chat group (360 members).

4. Review Activity milestones and progress to date, and submit Progress Report to NDIA
   Completed within agreed timeframes

5. Finalise online directory of supports/services for siblings
   Through the survey results and follow up discussion with survey providers, it became apparent that there are limited (3-4) sibling support services open to the general public. Services, where they exist,
are mainly directed to siblings of existing clients accessing specific disability services. With such limited services to direct people to, creating an online directory was not feasible or useful for the target group it was intended to assist. Instead, Siblings Australia refers people to the few available services, if people in the appropriate geographical areas make inquiries. Currently, Siblings Australia receives an average of 1-2 inquiries a week from parents requesting referrals for support, with very limited services to direct them to.

6. **Gather feedback from online directory users to review its effectiveness**
   Siblings Australia reviewed the online directory, and found that most of those services previously listed were no longer available, and unable to provide any further services. The new website does not include a directory as too few sibling services are available.

7. **Evaluate outcomes in Final report, including analysis of mapping and illustrative case study/ies (if required) for NDIA to review**
   Evaluation completed. Stories from service providers, parents, and siblings have been included in the body of this report.