Supporting Siblings of Children with Special Needs

Report

Sibling Support in Australia – Scoping Project

August 2009

Funded by
Department of Families, Housing, Community Services and Indigenous Affairs

By Siblings Australia
23A King William Road
Unley SA 5061
Phone: (08) 83571214
Fax: (08) 83571216
info@siblingsaustralia.org.au
Acknowledgements

Siblings Australia would like to thank all the people and organisations who took the time to complete the online survey. In addition, Siblings Australia would like to acknowledge the support of the following people for their involvement in and support of this project:

**Rebecca Paior**
Project Officer
Siblings Australia Inc

**Kate Strohm**
Executive Director
Siblings Australia Inc

**Project Consultation Group**
**Ben Holt**
Sibs Squad Coordinator
Xavier Children’s Support Network

**Camille Heagney**
Intake & Assessment Manager
Family Support Team
Very Special Kids

**Sandra DeMarchi**
Social Worker
Tumbatin Clinic
Sydney Children’s Community Centre

**Emily Caska**
Senior Policy and Projects Officer
National Disability Services - NSW

The work detailed in this report was supported by funding from the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). The views expressed herein do not necessarily represent the views of FaHCSIA. Whilst all reasonable care has been taken in the preparation of the Report, no liability is assumed for any errors or omissions.
# Contents

Acknowledgements........................................................................................................... 2  
Contents ................................................................................................................................ 3  
List of Tables ......................................................................................................................... 4  
Executive Summary................................................................................................................ 5  
  Methodology.......................................................................................................................... 5  
  Selected Project Findings .................................................................................................... 5  
  Recommendations .............................................................................................................. 6  
Introduction............................................................................................................................ 7  
  Background ........................................................................................................................... 7  
  Siblings Australia ................................................................................................................ 7  
  Project Brief ........................................................................................................................ 7  
Literature review..................................................................................................................... 8  
  Methodology.......................................................................................................................... 9  
  Project team ........................................................................................................................ 9  
  Project Consultation Group ................................................................................................. 9  
  Methodology.......................................................................................................................... 9  
Results................................................................................................................................... 10  
  Organisations not currently providing sibling support services ....................................... 10  
  Organisations providing sibling support services ............................................................. 11  
  Challenges and Gaps ........................................................................................................... 16  
Discussion............................................................................................................................... 19  
  Current Sibling Support Programs in Australia .................................................................... 19  
  Program Models and Evaluation Practice ......................................................................... 20  
  Gaps in Supporting Siblings .............................................................................................. 20  
Issues..................................................................................................................................... 22  
  Recommendations .............................................................................................................. 23  
References.............................................................................................................................. 26  
Appendix 1: Survey Questions .............................................................................................. 27  
Appendix 2: Directory of Services ......................................................................................... 32  
Appendix 3: Verbal responses to gap in services which should be provided to siblings ....... 41
List of Tables

Table 1: Breakdown of respondents per state ................................................................. 10

Table 2: The reasons for not providing sibling support program .............................. 11

Table 3: Strategies which the program uses to provide support to siblings of people with special needs ................................................................. 11

Table 3A: Strategies which the program uses to provide support to siblings of people with special needs (Sibling Only Support) ......................................................................... 12

Table 4: The main outcome that the sibling program seeks to address ...................... 13

Table 5: Models the programs’ use .............................................................................. 13

Table 6: Incidence of research evidence provided against the program model used by respondents .............................................................................. 14

Table 7: Funding for Sibling Programs .......................................................................... 15

Table 8: Funding for Sibling Programs broken down per state ................................... 15

Table 8A: Funding for Sibling Programs broken down per state (Sibling Only Support) ............. 15

Table 9: The main barriers to the implementation of specific services for siblings .......... 16

Table 10: Actions which would assist the organisation to implement more sibling support services ................................................................. 17

Table 11: What is the most important gap in service which should be provided for siblings? 18
Executive Summary

Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Support for siblings allows them to feel less isolated and helps them build resilience. As a result, they will be more likely to develop to their full potential and also to contribute to the quality of life of their brother or sister with special needs. Sibling support also enables the whole family to function more positively.

This is the report of a scoping project on sibling support in Australia. It was funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and carried out by Siblings Australia over the period April to September 2009.

The aim of this project was to:

1. Map the current practices around Australia undertaken by the various organisations involved in sibling support programs.
2. Understand the approaches and models currently being used and the evaluation practices and measures.
3. Identify what are the current gaps and the reasons for these gaps in supporting siblings in Australia.

The results of this project are detailed in this report, and will be presented at the Siblings Australia: Creating Connections Conference (19-20 November 2009). Also, they have been used to build a directory of services for siblings which is available on Siblings Australia’s website. (http://www.siblingsaustralia.org.au)

Methodology

The intention was to contact as many organisations as possible who are providing sibling support and it was determined that the fastest and most effective way to reach these organisations was to use an online survey and communicate via email.

The survey was developed, with reference to a previous scoping study on support programs for Children of Parents with Mental Illness (Australian Infant, Child, Adolescent and Family Mental Health Association 2001) and previous Sibling Australia Service Provider surveys. A total of 90 completed responses were received. It is recognised that this is not an exhaustive list due to the challenges in identification of providers of sibling programs, and reliance on responses from these organisations. However, a large amount of useful information was collected and enabled identification of issues and recommendations to be made.

Selected Project Findings

The project found that the most common form of sibling support is a support group program for the 5-12 year old age group. These support programs are formed with the intention to reduce feelings of isolation experienced by siblings and to improve their level of support.

The scoping project highlighted the challenge of funding for many sibling programs in Australia, with generally little specific funding allocated to sibling support. This lack of funding is the greatest barrier to organisations continuing or establishing new sibling programs. Further collaboration and additional trained staff and resources would also enable more sibling programs to be developed and facilitated.

The project also found that the program models used, level of research evidence, and evaluation measures, varies greatly. Over half the organisations had developed their own in-house program model. It was also identified that there is limited evaluation currently being completed within the sibling programs. The lack of evaluation makes it difficult to determine the quality and effectiveness of these programs.
Respondents identified that awareness of the needs of siblings is still minimal in many groups. Additionally, consistency and the availability of support for siblings, particularly those based in rural areas, are matters which are not currently being addressed in Australia.

**Recommendations**

Based on the information collected, some recommendations have been developed by the project team.

**Recommendation 1: Support for Siblings**

1.1 Policy
Siblings of children with special needs should be recognised within government policy as an ‘at risk’ group and their needs acknowledged accordingly.

1.2 Awareness Program
There should be an awareness program developed that will build understanding of the needs of siblings of children with special needs from childhood to adulthood.

1.3 Rural Support
There are very limited opportunities for siblings who are living in rural or remote areas of Australia to receive support. It is recommended that the needs of these siblings should be explored further and a rural support program developed.

**Recommendation 2: Standards of Practice**

2.1 National Reference Group
A National Reference Group for Sibling Support made up of service providers who have, or who are intending to have, sibling programs within Australia should be established.

2.2 Evaluation
Appropriate evaluation measures to ensure best practice sibling support should be developed.

2.3 Standards of Practice
Sibling Support policies and principles should be developed to ensure the different sibling programs meet best practice.

2.4 Communication
Promotion and dissemination of evaluation practices and standards of practice generated by the National Reference Group should be carried out.

**Recommendation 3: Support for Organisations**

3.1 Siblings Australia
Resources should be allocated to Siblings Australia to enable them to take a leadership role in developing tools and facilitating this support.

3.2 Collaboration Framework for Organisations
A review and the development of a collaborative framework for organisations supporting siblings should be instigated.

3.3 Professional development
The development and implementation of a Workforce Training Strategic Plan should be funded to provide guidance for training and supporting organisations that come in contact with families who have a child with special needs.

3.4 Directory of Services
The sibling support program directory of services should be maintained to provide up-to-date opportunities for families to find nearby programs and for organisations to refer siblings to.
Introduction

Background
The relationship that all siblings share is one of the longest and literally lasts a lifetime. Siblings who have brothers or sisters with special needs such as disability, chronic illness or mental illness can face additional challenges and often grow up in a situation of considerable stress, without the cognitive and emotional maturity to understand the mix of feelings they experience.

In Australia there are over 200,000 young people with a severe or profound disability or chronic illness (not including mental illnesses). In addition, we can assume each young person with special needs would have an average of one sibling. Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Understandably, significant resources are spent addressing the needs of the child with special needs. By the same token, research has now substantiated the fact that siblings of these children may themselves experience significant long-term physical and mental health problems such as anxiety, depression, low self-esteem and relationship difficulties if their needs are left unaddressed. These problems are exacerbated by limited access and availability of appropriate services and the practicalities of family life where the needs of a brother or sister take greater priority. Without support, these siblings are at risk of developing longer-term physical, emotional and psychological problems.

Support for siblings allows them to feel less isolated and helps them build resilience. As a result, they will be more likely to develop to their full potential and also to contribute to the quality of life of their brother or sister with special needs. Sibling support also enables the whole family to function more positively.

Sibling Australia
Sibling Australia is a unique national organisation committed to enhancing the wellbeing of siblings of children and adults with special needs; including chronic illness, disability and mental health issues. It is our mission to assist siblings to become acknowledged, connected and more resilient. We provide workshops and networking opportunities for families and providers across Australia and overseas.

Project Brief
The aim of this scoping project was to:
1. Map the current practices around Australia undertaken by the various organisations involved in sibling support programs.
2. Understand the approaches and models currently being used and the evaluation practices and measures.
3. Identify what are the current gaps and the reasons for these gaps in supporting siblings in Australia.

The results of the scoping project are to be:
- Documented in this report
- Presented at the 2009 Siblings Australia Conference: Creating Connections (19-20 November 2009)
- Contribute to a Directory of Services which is available from the Siblings Australia website.
Literature review

The sibling relationship is often the longest of any. This relationship is crucial in the emotional development of children as it allows children to openly express feelings (both positive and negative), gain companionship, learn social skills and influence a developing identity (Young 2007) (Brody 2004) (Banje, et al. 2004) (Azmitia 1993). Family relationships are important to the development of individuals, with sibling relationships among the most enduring with ongoing effects over the lifespan (Young 2007) (Banje, et al. 2004).

Brothers and sisters of children with disability often face a family situation which involves considerable stress, but without the understanding, emotional maturity and coping skills required to deal with their experiences. Research and anecdotal evidence substantiates that siblings are at an increased risk of physical (Hogan, Park and Goldscheider 2003) and mental health issues, including anxiety, depression and low self esteem (Lamorey 1999) (Houtzager, Grootenhuis and Last 2001). It is also suggested that these issues become more difficult as the individual with special needs gets older (Cuskelly 1999).

There have been a number of studies into the effect that sibling support programs 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. Siblings gain a better understanding of the special 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).

While the effects of other 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.

Sibling support programs have been run for many years overseas particularly in the US and UK. In the UK, legislation recognises these children. 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 should not be overlooked. In Australia, some organisations have been providing sibling programs for considerable time, but this project is the first time there has been an attempt to map what has been or is happening.
Methodology

The aim of this project has been detailed above. The intention was to contact as many organisations as possible who are providing sibling support, however it is recognised that this is not an exhaustive list due to the challenges in identification of providers of sibling programs, and reliance on responses from these organisations.

Project team

The project team consisted of a part-time project officer who was employed to carry out project tasks, Siblings Australia’s Executive Director who provided guidance and direction, and a Project Consultation Group. Details of the project team are included in the acknowledgements.

Project Consultation Group

The role of the Project Consultation Group was to provide feedback and guidance. The Project Consultation Group was formed from known service providers who have sibling programs.

Methodology

It was determined that the most effective way to reach as many organisations as possible was to use an online survey.

A survey was developed (through Survey Monkey), with reference to a previous scoping study on support programs for Children of Parents with Mental Illness (Australian Infant, Child, Adolescent and Family Mental Health Association 2001) and previous Sibling Australia Service Provider surveys. The link to the survey, as well as information regarding this project was sent out to 1500 contacts (including siblings, parents and service providers) as part of Sibling Australia’s newsletter on 28 April 2009. A follow up message was sent on 1 June 2009 encouraging further participation.

Additional specific target emails were sent to:

- Organisations who have previously provided sibling programs which were listed on Siblings Australia’s website
- Organisations who are known to be providing sibling support programs as identified via internet searches
- Organisations who started the survey but didn’t complete it
Results

As detailed above in the Methodology, information regarding sibling programs in Australia for this project was collected via an online survey. It is difficult to identify the total number of organisations who received survey details due to the methods of communication. There were 90 completed responses submitted and received.

The respondents came from all across Australia, with organisations that are currently providing sibling support in all States. Table 1 shows the breakdown of the respondents per state.

<table>
<thead>
<tr>
<th>State</th>
<th>Providing sibling support</th>
<th>Not providing sibling support</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>NSW</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>NT</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>QLD</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>SA</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>TAS</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>VIC</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>WA</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>National</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Not Provided</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>59</strong></td>
<td><strong>31</strong></td>
</tr>
</tbody>
</table>

Information on organisations that are currently providing sibling support is included in Appendix 2, and this information has also been made available on the Siblings Australia website. Those organisations that declined to provide their contact details gave reasons for this including, currently unable to meet demand, limited resources, only providing program to existing client base, program still in developmental stage.

Organisations not currently providing sibling support services

Although one of the main aims of this project was to map those services which are currently being offered, the reasons why sibling programs are not offered is also crucial in understanding the gaps in the support for siblings. As the majority of organisations were contacted through Siblings Australia networks, it is reasonable to assume that they have some interest in sibling support.

Of the 90 organisations who responded, 31 identified themselves as not currently providing any sibling support services. Eighteen (58.1%) indicated that, whilst they were not currently, they intended to provide a support program to siblings in the future.

Respondents who indicated that they were not providing support were asked if they were able to refer siblings to alternative support programs. Just under half of these organisations (48.4% N=15) indicated that they did not refer siblings to other organisations. Although a reason for not referring siblings was not required a number of organisations noted that a lack of knowledge of what support was available to siblings in other organisations as a barrier to providing these referrals. Additionally, others noted the challenges that rural organisations and siblings face due to the lack of available support. Of those who do refer siblings to alternative support programs,
six listed Siblings Australia as one of the organisations referred to. This was the most commonly referred to organisation.

Respondents were asked the main reasons why they were currently not providing a sibling support program (Table 2). The main reasons which organisations listed for not providing support or stopping a previous program were lack of funding and inadequate resources. Those who selected “Other” listed additional reasons including; not in their inclusion support guidelines or core business, currently in the process of reviewing their program offering, and difficulty in providing support due to the wide area covered by their client base.

Table 2: The reasons for not providing sibling support program

<table>
<thead>
<tr>
<th>Reason</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of funding</td>
<td>71.0%</td>
<td>22</td>
</tr>
<tr>
<td>Inadequate resources</td>
<td>48.4%</td>
<td>15</td>
</tr>
<tr>
<td>Inadequate staff skills/training</td>
<td>22.6%</td>
<td>7</td>
</tr>
<tr>
<td>Lack of interest/participants</td>
<td>9.7%</td>
<td>3</td>
</tr>
<tr>
<td>Turnover of staff members</td>
<td>6.5%</td>
<td>2</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>16.1%</td>
<td>5</td>
</tr>
</tbody>
</table>

answered question 31

Organisations providing sibling support services
Fifty nine organisations indicated that they were currently providing a sibling support program. The following results relate to their responses.

Strategies used to provide sibling support
Respondents were asked to identify the strategies used to provide this support. Table 3 details their responses. The results show that support groups were generally the most common strategy provided to siblings, with camps and individual counselling for parents the next most common.

Table 3: Strategies which the program uses to provide support to siblings of people with special needs

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response %</th>
<th>Response Count</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>QLD</th>
<th>SA</th>
<th>TAS</th>
<th>VIC</th>
<th>WA</th>
<th>National</th>
<th>Not Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support groups for siblings</td>
<td>71.2%</td>
<td>42</td>
<td>0</td>
<td>14</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>4</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Camps for siblings</td>
<td>44.1%</td>
<td>26</td>
<td>1</td>
<td>6</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Individual counselling with parents regarding issues arising for siblings of a child with special needs</td>
<td>42.4%</td>
<td>25</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Individual counselling with siblings regarding issues arising from having a sibling with special needs</td>
<td>28.8%</td>
<td>17</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Workshops for parents on the needs of siblings and how to support them</td>
<td>27.1%</td>
<td>16</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>37.3%</td>
<td>22</td>
<td>2</td>
<td>10</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

answered question 59 2 19 1 5 5 2 8 7 1 9
Of those organisations who selected “Other”; ten (16.9%) provided day excursions and activities for siblings often held in school holidays, three maintained online services for siblings, and two provided respite options.

Respondents also provided further description of the programs which they provided.

Although the survey did specifically question whether the program was for siblings only or a combined care program with parents and/or special needs child, further questioning and investigation identified that 51 organisations were providing sibling only programs. Table 3A below provides information on the strategies used for programs which are provided for siblings only. There is a noticeable difference in the amount of support available in South Australia when ‘siblings only’ programs are explored.

The other eight programs which provided a combined care program were camps for children with a disability or chronic illness and their siblings, or family centred approach program.

| Table 4A: Strategies which the program uses to provide support to siblings of people with special needs (Sibling Only Support) |
|---|---|---|---|---|---|---|---|---|---|---|
| Answer Options | Response % | Response Count | ACT | NSW | NT | QLD | SA | TAS | VIC | WA | National | Not Provided |
| Support groups for siblings | 80.4% | 41 | 0 | 14 | 1 | 3 | 2 | 6 | 4 | 1 | 8 |
| Camps for siblings | 43.1% | 22 | 1 | 6 | 0 | 3 | 1 | 1 | 1 | 5 | 1 | 3 |
| Individual counselling with parents regarding issues arising for siblings of a child with special needs | 41.2% | 21 | 0 | 7 | 1 | 3 | 1 | 0 | 3 | 3 | 0 | 3 |
| Individual counselling with siblings regarding issues arising from having a sibling with special needs | 29.4% | 15 | 0 | 5 | 1 | 3 | 1 | 0 | 2 | 2 | 0 | 1 |
| Workshops for parents on the needs of siblings and how to support them | 27.5% | 14 | 0 | 5 | 0 | 1 | 0 | 0 | 2 | 2 | 0 | 4 |
| Other (please specify) | 43.1% | 22 | 2 | 10 | 1 | 1 | 1 | 0 | 4 | 1 | 0 | 2 |

answered question: 51

Additionally, there were two which clarified that their program was designed for carers (although siblings may be welcome).

**Target Age Groups**

Respondents were also asked to indicate their target age groups for the program from a selection of Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years), Young adults (18-25 years), Adults (25 years and older). The majority indicated children (89.8%) and young people (71.2%) with many verbal comments identifying their main target group as 5-12 years as their main target age group. Overall, all age groups were represented, however in many states, it appears that support for the less common age groups; infants, young adults and adults is not available.

The majority of programs for siblings are local (55.9%), with state-wide and national programs combined totalling 27.1% (16 N-59). Regional programs made up the remaining difference of 16.9%.
Program Outcomes

Table 5 details what the respondents believe to be the main outcome that their program seeks to address for siblings. The most common outcomes for siblings programs are to reduce the feelings of isolation amongst siblings (40.7%), and to improve the support for siblings (32.2%). Of those respondents who selected “Other”, four felt that their program addressed all five outcomes equally. The other two stated their main program outcomes as building siblings skill in dealing with people with special needs, and providing respite for sibling.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced feelings of isolation amongst siblings of people with special needs</td>
<td>40.7%</td>
<td>24</td>
</tr>
<tr>
<td>Improved support for siblings of people with special needs</td>
<td>32.2%</td>
<td>19</td>
</tr>
<tr>
<td>Skills development for siblings to be able to better deal with experiences</td>
<td>8.5%</td>
<td>5</td>
</tr>
<tr>
<td>Increased knowledge and understanding by siblings of their brother/sisters special needs</td>
<td>6.8%</td>
<td>4</td>
</tr>
<tr>
<td>Improved mental health among siblings of people with special needs</td>
<td>1.7%</td>
<td>1</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>10.2%</td>
<td>6</td>
</tr>
</tbody>
</table>

answered question 59

Program Models

The majority of programs are based on some form of a program model (88.1%), with many organisations developing and using their own in-house models. A number of respondents who were using in-house models indicated that they had designed these from adapted SibworkS (5) and Sibshops (2) models. Table 6 shows a breakdown of the models currently being used. Organisations who selected “Other” listed the following additional models; Applied Behaviour Analysis, Granting Dreams for Siblings, various counselling models, peer support model, and one was unsure of the model they were currently using.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-house developed model</td>
<td>57.6%</td>
<td>34</td>
</tr>
<tr>
<td>SibworkS (Siblings Australia 6 week peer support program)</td>
<td>22.0%</td>
<td>13</td>
</tr>
<tr>
<td>Sibshop (Don Meyer’s program from United States)</td>
<td>10.2%</td>
<td>6</td>
</tr>
<tr>
<td>Noah’s Ark Sibling model</td>
<td>1.7%</td>
<td>1</td>
</tr>
<tr>
<td>Seasons of Growth Model</td>
<td>1.7%</td>
<td>1</td>
</tr>
<tr>
<td>No model</td>
<td>11.9%</td>
<td>7</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>8.5%</td>
<td>5</td>
</tr>
</tbody>
</table>

answered question 59

Research Evidence

Respondents were asked to detail the research evidence that underpins their programs; this information was then reviewed and grouped into broad categories. Forty Two provided a response to this question and the level of research varied noticeably. One organisation, Canteen, has an internal research team which has completed an extensive needs analysis for both siblings and bereaved siblings. At the other end, five organisations stated that they were unsure of the research evidence that was used to start the program or stated that their program
was not based on research evidence. The majority of respondents, (59.5% N=25) indicated that their research had been based around literature on sibling issues. Many referred to Kate Strohm’s book “Siblings: Brothers and Sisters of Children with Special Needs” (Wakefield Press 2002), SibworkS and/or Siblings Australia (44% N=11). Additional sources of literature which were referred to included Don Myer’s work and Sibshops (2), Michael Guralnick (1), and the Carer Life Course (1). Five respondents stated that the research evidence for their program was based on previous experience and the ongoing feedback of participants and facilitators. Others did not refer to any existing literature or experience but stated that the organisational view was that sibling programs have an important role in supporting families with children who have special needs (11.9%).

Table 7 shows these results cross-referenced by the program models.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percentage</th>
<th>Provided reference to research evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-house developed model</td>
<td>64.7%</td>
<td>22/34</td>
</tr>
<tr>
<td>SibworkS (Siblings Australia 6 week peer support program)</td>
<td>84.6%</td>
<td>11/13</td>
</tr>
<tr>
<td>Sibshop (Don Meyer’s program from United States)</td>
<td>83.3%</td>
<td>5/6</td>
</tr>
<tr>
<td>Noah’s Ark Sibling model</td>
<td>100%</td>
<td>1/1</td>
</tr>
<tr>
<td>Seasons of Growth Model</td>
<td>100%</td>
<td>1/1</td>
</tr>
<tr>
<td>No model</td>
<td>28.6%</td>
<td>2/7</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>60.0%</td>
<td>3/5</td>
</tr>
</tbody>
</table>

Program Evaluation

Nineteen programs (31.7%) stated that their programs have been formally evaluated. The most common form of evaluation was through written and verbal feedback via a questionnaire or feedback form (15). Of those who were using this type of evaluation process, most sought feedback from the participants, however some also extended this to include parent and facilitator feedback in their evaluation. Two programs stated that they have an external review process for evaluation.

Funding

Most organisations fund their sibling programs through multiple funding channels. Many commented that there is often no specific funding provided for siblings, so organisations must use existing resources or incorporate costs into overall program budgets. Table 8 details the sources of funding.

In addition to the government and organisation support detailed in the above table, “Other” support was through: staff volunteering their time (5), donations (5), grants (5), fundraising (3), and having siblings/parents paying for the cost of the program (3).
A further breakdown of this information per state is provided in Table 9. State government funding for sibling programs is most common in New South Wales. The majority of programs receive no government support; this is more apparent again when we look at the programs which are providing support for siblings only (Table 8A).

Most organisations are able to provide sibling programs without cost for participation (69.5%). Of those who do pass on some cost, most charge less than $20 (27.1%) and no organisations required more than $100 for siblings to participate in their programs.

**Collaboration between agencies**

Of the 59 organisations, 21 (35.6%) indicated that they collaborated with other agencies to deliver their program. Four indicated that this collaboration focused on ensuring the needs of siblings are met through interagency discussion (resourcing), six indicated that this collaboration focussed on the identification of siblings and nine indicated that their focus was both. Additionally, respondents identified that their collaboration was through information exchange, physical assistance, joint run programs, and shared training.
Challenges and Gaps

The following responses include both those organisations currently providing sibling support programs and those who are not.

Barriers to implementation of specific services for siblings

Respondents were asked to indicate what they saw as the main barriers to implementation of specific services for siblings. Table 11: The main barriers to the implementation of specific services for siblingsTable 11 below shows the breakup of the responses, with an additional breakdown of these responses against organisations that are providing sibling programs, and whether organisations are working collaboratively with other agencies.

Funding was indicated by the majority of respondents (80%) as the main barrier to implementing sibling services. A closer analysis of the responses regarding funding, shows that there is a notable difference of 12.6% between those organisations who have indicated that they work collaboratively with other agencies and those not working with others. Those not working with other agencies were also more likely to see lack of staff knowledge/skills as a barrier.

Secondary to funding, insufficient human resources was also seen as a barrier to implementation. This was most common with those organisations that were not currently providing a sibling program (58.1%). These organisations were also more likely to see a lack of staff knowledge/skills as a barrier compared to those who were providing a sibling program, with a difference of 23.3% of responses.

Table 11: The main barriers to the implementation of specific services for siblings

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Total Response Percent</th>
<th>Total Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>80.0%</td>
<td>72</td>
</tr>
<tr>
<td>Insufficient human resources</td>
<td>45.5%</td>
<td>41</td>
</tr>
<tr>
<td>Lack of understanding of sibling needs</td>
<td>18.9%</td>
<td>17</td>
</tr>
<tr>
<td>Lack of staff knowledge/skills in implementation of sibling support services</td>
<td>26.7%</td>
<td>24</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>12.2%</td>
<td>11</td>
</tr>
<tr>
<td>No perceived barrier</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3x Lack of Parental Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2x Lack of Sibling time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding competition between organisations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No perceived barrier</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

answered question 90
**Actions which would assist in the implementation of more sibling support services**

Similar to the barriers which prevent implementation, 83.3% of respondents indicated that additional funding would enable them to implement services for siblings (Table 12).

Forty two respondents, who indicated that staff training and development would assist their organisation to implement more sibling support services, were asked to clarify the type of training which would be most useful. In-house training by an external consultant was the most common preferred training process (42.9% N=18). Second to that were the provision of resources such as printed training manuals, or a DVD (26.2% N=11), followed by online training (23.8% N=10).

**Table 12: Actions which would assist the organisation to implement more sibling support services**

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Total Response Percent</th>
<th>Total Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>83.3%</td>
<td>75</td>
</tr>
<tr>
<td>Extra staff numbers</td>
<td>51.1%</td>
<td>46</td>
</tr>
<tr>
<td>Staff training/development</td>
<td>46.7%</td>
<td>42</td>
</tr>
<tr>
<td>Collaboration with other organisations</td>
<td>61.1%</td>
<td>55</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>5.5%</td>
<td>5</td>
</tr>
<tr>
<td>Making Sibling Support a core component of service provision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Larger pool of siblings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More time to evaluate programs and find out what siblings want</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better awareness of sibling issues in the community to generate more support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better awareness that our organisation covers siblings as well as members (Canteen)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*answered question* 90

**SibServices Forum**

All respondents were asked whether they would be interested in joining the Siblings Australia discussion forum, SibServices. This is a web based forum for providers involved in sibling support to enable the sharing of resources and experiences. It is one indicator of the willingness of organisations to collaborate. Eighty indicated that they would join this type of forum. Of the ten who responded that they would not join, six had indicated that they saw collaboration with other organisations as something which would assist them to deliver more sibling services.

**Gaps in the services for siblings**

Respondents were asked what they saw as being the most important gap in services which should be provided for siblings of people with special needs. Seventy eight provided a response to this question, and these responses were then reviewed and collated. From this process, it was identified that the responses provided an insight both into the gap areas for sibling support and also the actions necessary to address these gaps. Table 13 and Table A detail the collated responses. The verbatim comments are located under Appendix 3.

Respondents identified the main gap in sibling support services was a need for additional support. This support was generally described as time with peers in a similar sibling situation, emotional support, consistency of activities, and better support for siblings in rural areas. One respondent provided the following comments that reflect this theme: “... *Resilience comes from externalizing and getting out in the world and getting on with things rather than introspection and by learning some strategies to work in teams and identify with others in the same position,*
we can help our siblings to be more resilient, not only to cope themselves but to be role models/teachers for their parents who bear a very different burden of grief ...”

To address this gap, respondents again commented on the need for additional funding: “…There is very little funding given to services to work with families, and even less to support the siblings. If you are not funded to work in that way it can be very difficult to provide any service to siblings...”. Additionally, the challenge of locating information regarding sibling support programs so as to link siblings to the right support services, and collaboration between organisations were also seen as significant issues and contribute to the gaps in sibling service.

Finally, the other area that respondents commented on regarding the gaps in support for siblings of people with special needs was a need for a broader awareness and recognition of the needs and challenges that siblings face by government, by policy makers and the general community. Some challenged the approaches which have been used in the past so as to better treat and support the family as a whole.

### Table 13: What is the most important gap in service which should be provided for siblings?

<table>
<thead>
<tr>
<th>Themes</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling Services</td>
<td></td>
</tr>
<tr>
<td>Additional Support</td>
<td>18</td>
</tr>
<tr>
<td>Social (peer) groups</td>
<td></td>
</tr>
<tr>
<td>Respite</td>
<td>7</td>
</tr>
<tr>
<td>Access to sibling support</td>
<td>4</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>4</td>
</tr>
<tr>
<td>More frequent activities</td>
<td>4</td>
</tr>
<tr>
<td>Consistency</td>
<td>3</td>
</tr>
<tr>
<td>Rural support</td>
<td>3</td>
</tr>
</tbody>
</table>

### Table 11A: Actions needed to address the gaps in sibling support

<table>
<thead>
<tr>
<th>Themes</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisational Challenges</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>12</td>
</tr>
<tr>
<td>Information about Sibling Support</td>
<td>10</td>
</tr>
<tr>
<td>Collaboration</td>
<td>8</td>
</tr>
<tr>
<td>Resources</td>
<td>4</td>
</tr>
<tr>
<td>Evidence based program</td>
<td>1</td>
</tr>
<tr>
<td>Additional training for organisations</td>
<td>1</td>
</tr>
<tr>
<td>Overall Awareness</td>
<td></td>
</tr>
<tr>
<td>Community Awareness</td>
<td>9</td>
</tr>
<tr>
<td>Parent Education regarding needs of siblings</td>
<td>6</td>
</tr>
<tr>
<td>Holistic Approach to support services to include siblings</td>
<td>5</td>
</tr>
<tr>
<td>Government recognition that siblings need support</td>
<td>3</td>
</tr>
<tr>
<td>School based awareness and support</td>
<td>2</td>
</tr>
<tr>
<td>Understanding of sibling needs</td>
<td>2</td>
</tr>
<tr>
<td>Options across all age groups</td>
<td>2</td>
</tr>
<tr>
<td>Parent (carer) needs not being met</td>
<td>1</td>
</tr>
<tr>
<td>Needs further discussion</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Recognition of siblings as part of carers group</td>
<td>1</td>
</tr>
</tbody>
</table>
Discussion

The aim of this scoping project was to map the current practices around Australia undertaken by the various organisations involved in sibling support programs. The project sought to understand the approaches and models currently being used and the evaluation practices and measures. Additionally, the project was to identify what are the current gaps and the reasons for these gaps in supporting siblings in Australia.

The project’s methodology was effective, with the process enabling communication to and participation by many service organisations regarding the project and survey quickly and economically and it has enabled the development of a directory of services for sibling programs within Australia. However, there are likely to be organisations that did not participate in this survey. Some of these organisations may have been aware of the project but chose not to participate for a variety of reasons and others may not be contactable by the chosen communication methods. That noted, a large amount of useful information has been collected, enabling the identification of issues and recommendations to be made.

Current Sibling Support Programs in Australia

This project found that the most common form of sibling support is a support group program for the 5-12 year old age group. Second to the support groups in Australia are camps for siblings, closely followed by counselling for parents regarding sibling issues. These support programs are formed with the intention to reduce feelings of isolation experienced by siblings and, in addition, to improve their level of support.

It is interesting that camps are so common, particularly given respondents also raised that regular consistent support for siblings is a gap in the current support available. One possibility for this could be the challenge of distinguishing sibling only specific support from combined services such as camps for children with a disability or chronic illness and their siblings. This project had difficulty distinguishing those programs which combined their support from those providing sibling only support. It is acknowledged that there are benefits to both types of programs for different children.

Similarly, respondents also raised the issue of a perceived lack of parental awareness and support of sibling issues. Given the counselling for parents regarding sibling issues was the third most common support provided it would appear that the message is still not getting through and further education and support regarding sibling issues for parents is needed.

Another challenge to sibling support in Australia is the distinction between sibling programs and carer programs. Carers in Australia are generally defined as people who are providing unpaid care and support to family members or friends with special needs. Within families, many siblings will take on caring responsibilities for a brother or sister with special needs. However, they are rarely identified as carers as in most cases the parent is identified as the primary carer. Some siblings do not want to be identified as carers, but instead prefer to be a brother or sister to the child with special needs. Even if siblings do not provide any ‘hands on’ caring, there can still be considerable challenges and support is still very important. Two respondents clarified in their survey that their programs were designed for carers although siblings may be welcomed.

There is some form of sibling program in every State across Australia, however many programs may not be available to everyone as these programs are often only available to siblings of the organisations’ clients and are limited in participant places due to funding and resource constraints. These restrictions were voiced by a number of respondents. New South Wales has the largest number of sibling programs in Australia, and the greatest number across each of the sibling support strategies. This leap in support for siblings by New South Wales may reflect, to some extent the commitment of the State government to sibling needs. For example, the
Support Networks Program which was developed in 2007 by the Department of Ageing, Disability and Homecare specifically includes support for siblings in both rural and metropolitan areas. (Department of Ageing, Disability & Home Care June 2007)

Funding for sibling programs in Australia is a key challenge for many organisations. It was difficult to get a clear picture on the sources of funding due to varied interpretations of the question. In addition, it became very apparent that there is generally little specific funding for sibling support, with organisations funding their programs through a range of sources and with some organisations redirecting funds or including sibling programs into other grants. Where organisations said that their programs were funded by government, in some cases, this meant the whole organisation, and not specific sibling programs. Generally, organisations do not pass on the costs of these programs to siblings. Organisations are additionally often reliant on volunteer support to facilitate these programs. A lack of funding and inadequate resources are the two main reasons that organisations do not develop or commence new sibling programs or are required to discontinue their existing sibling programs.

Given the common challenges that organisations face regarding funding, the reasons why organisations do not collaborate more often to provide these services requires further investigation. Over 60% of organisations recognised that further collaboration would be an enabler for them to provide additional sibling services, but only 23% are actually currently collaborating with other organisations. The lack of opportunities for collaboration and communication between organisations was seen to also contribute to the difficulty in identification of these programs and engagement in this project.

**Program Models and Evaluation Practice**

This project found that over half the organisations that provide a sibling program have developed their own in-house program model. These programs are a result of development over time from feedback of participants and facilitators, or where organisations have found that the existing models did not match their needs or desired timeframes for the sibling programs.

Many of the sibling programs had some level of research evidence; however the level of detail regarding the research evidence differed greatly. Additionally, the variation in organisations that were able to provide detail of the research evidence of their programs differed significantly. Those who follow existing program models were more likely to cite research evidence and organisations that were using an in-house model were less likely to have research evidence underpinning their program.

Finally, the project found that there was a low level of evaluation completed within the sibling programs. Within those who are evaluating their program, many are using a feedback form only and may not be formally capturing the benefits of their sibling support. The project did not find any evidence of formal quantitative evaluation which include randomised control trials.

The results of these findings indicate that there is a great level of inconsistency across the sibling programs available in Australia. In-house models alone can be a great solution for organisations, however, with little research evidence or ongoing evaluation to back up a sibling program, the quality and effectiveness of these programs is questionable.

**Gaps in Supporting Siblings**

This project looked at the gaps in supporting siblings from two perspectives. Firstly, it explored the challenges which organisations face in providing support for siblings. Secondly, it looked at the gaps in the delivery of services to meet the needs of siblings.

From an organisational perspective, as anticipated, the results found that respondents felt funding for sibling programs was the greatest gap in providing support. The challenge of funding in general is common for most non-profit organisations and one which is unlikely to diminish in
the future. Whilst the ideal solution to this gap would be to direct sufficient additional funding to all of these programs, it is not a realistic solution given the current lack of coordinated efforts. However, from the results it can be concluded that some organisations are attempting to meet this challenge through collaboration with other organisations. Those organisations who work collaboratively with other agencies were less likely to see funding as a barrier. Collaboration appears to be a key opportunity for organisations to manage these programs with limited funding.

Organisations also indicated that an additional gap in the provision of sibling support was insufficient resources, both human and technical (staff skill sets). For some, this gap is due to sibling support not being included in their service provision. The project also noted that respondents indicated they felt awareness of sibling issues is low across community, families and government. An education campaign to ensure that policy and decision makers are aware of the impact on, and support needs of, siblings within families with children who have special needs would assist in addressing this gap, and increasing the likelihood of extra funding, and subsequent human resources, in this area.

Additionally, to address the need for technical resources, although the response was lower than other options, 46.7% of respondents felt that additional staff training and development would assist them in providing sibling support programs. Currently, where many support programs are based on an in-house model, a common training support option is difficult. However, a collaborative approach with a consistent base practice model would make additional training across multiple organisations more economical and effective.

Respondents highlighted the gaps in sibling support and stressed that siblings needed more opportunities to mix with peers in social groups, access respite, attend camps, etc. Additionally noted was the importance of this support being consistent. Linking this back to the challenge of funding, it highlights the importance of funding availability and ongoing grants for support of these programs. The opportunities to address these gaps in support for siblings, lie very much with addressing the needs and gaps of organisations.

Finally, some respondents also noted the importance of addressing the challenge for rural sibling support. Whilst a relatively low number 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 need to be reviewed to assist in addressing this challenge.
Issues

The information collected as part of this scoping project highlighted a number of recurring themes. These themes are important and are listed as follows:

- Funding is a common challenge for sibling programs
- There needs to be a greater awareness at a government, community and family level of sibling issues
- Sibling programs are difficult to define
- Sibling support is often included with other family or child with special needs activities, rather than the provision of sibling only support.
- The role of sibling and carer can be confused
- It is not clear what type of organisation should be responsible for sibling support, whether it belongs through a carer program or disability etc. services.
- Collaboration is seen by many to be an opportunity to further sibling programs however many organisations are not currently utilising these opportunities.
- Research evidence supporting sibling programs is limited, organisations need to be provided with additional information/research to assist them to ensure that their programs best meet the needs of siblings
- There is currently very limited evaluation occurring on the existing programs, making it difficult to identify the relative success and benefits of a program.
- There are no standards to identify “good” sibling support
- There are very few support services to rural based siblings
Recommendations
Based on the information collected, some recommendations have been developed by the project team. These recommendations have been grouped under the following headings:

1. Support for Siblings
2. Standards of Practice
3. Support for Organisations

Recommendation 1: Support for Siblings
The project found that awareness of the needs of siblings is still minimal in many groups including parents, government and community. In addition, consistency and the availability of support for siblings particularly those based in rural areas are key areas which are not being addressed.

1.1 Policy
Siblings of children with special needs should be recognised within government policy as an ‘at risk’ group and their needs acknowledged accordingly. This project recommends the development of appropriate policy and in doing so, the appropriate government body responsible for this group should also be identified.

1.2 Awareness Program
There should be an awareness program developed that will build understanding of the needs of siblings of children with special needs from childhood to adulthood. The program should be delivered to key groups including; Parents, Government, Community.

1.3 Rural Support
There are very limited opportunities for siblings who are living in rural or remote areas of Australia to receive support. It is recommended that the needs of these siblings should be explored further and a rural support program developed.

Recommendation 2: Standards of Practice
The scoping project highlighted that of the sibling support programs currently available in Australia the program models used and level of research evidence varies greatly. In addition, it was found that limited evaluation of these programs has been completed to ensure that the programs are achieving the desired outcomes. The following recommendations seek to address these issues.

2.1 National Reference Group
A National Reference Group for Sibling Support made up of service providers who have, or who are intending to have, sibling programs within Australia should be established. The objectives of this group should be to:
- Promote the needs of siblings within the government and community
- Develop and facilitate a collaborative framework for organisations
- Sharing of evaluative measures and results

The project found that there was a need and desire for a greater level of collaboration between organisations. As many organisations are locally based and have limited time, a National Reference Group will facilitate this collaboration faster and more efficiently.

2.2 Evaluation
Appropriate evaluation measures to ensure best practice sibling support should be developed.
It is very important to ensure that sibling programs in Australia are formally evaluated, so as to ensure that they are achieving the desired outcomes. Evaluation will enable comparison of programs and better understanding of what models work for whom.

2.3 Standards of Practice
Sibling Support policies and principles should be developed to ensure the different sibling programs meet best practice.

These standards will assist in the definition of what sibling support programs are (and are not), provide guidelines for responding to situations such as options where child is not suitable for program, requires additional support, or provides information which needs to be reported to other agencies.

2.4 Communication
Promotion and dissemination of evaluation practices and standards of practice generated by the National Reference Group should be carried out.

To ensure that the above evaluation measures and standards of practice are taken up across Australia a communication strategy must be developed and implemented.

Recommendation 3: Support for Organisations
The project found that funding, collaboration and additional trained staff and resources would enable more sibling programs to be developed and facilitated. Additional funding of programs without the tools developed under Recommendations 2.2 and 2.3 may not be effective. Additional support for organisations through assisting with collaboration, staff training and resources is sought.

3.1 Siblings Australia
Resources should be allocated to Siblings Australia to enable them to take a leadership role in developing tools and facilitating this support.

Siblings Australia is the only organisation in Australia which is committed to addressing the needs of brothers and sisters of people with special needs. They have developed a national and international reputation for their work with families and professionals. Siblings Australia is well placed for this role as they have provided workshops, print, web-based resources and networking opportunities. In addition, they have previously presented extensive training for service providers from a variety of sectors including disability, health, education and community services.

3.2 Collaboration Framework for Organisations
A review and the development of a collaborative framework for organisations supporting siblings should be instigated.

Recommendation 2.1 which supports the establishment of a National Reference Group will play a role in developing these collaborative frameworks, exploring opportunities for organisations to work more closely together and share knowledge and skills regarding sibling programs. One tool for facilitating this may be the existing online SibServices Forum.

3.3 Professional development
The development and implementation of a Workforce Training Strategic Plan should be funded to provide guidance for training and supporting organisations that come in contact with families who have a child with special needs.
This project highlighted that additional staff training would aid in the delivery of sibling programs. The strategic plan will take into consideration information and highlighted needs gathered from this scoping project and the Siblings Australia: Creating Connections conference.

3.4 Directory of Services
The sibling support program directory of services should be maintained to provide up-to-date opportunities for families to find nearby programs and for organisations to refer siblings to.

As part of this scoping project a directory of services has been created and updated. The ongoing maintenance of this resource is essential to ensure that it remains relevant and utilised.
References


Siblings Australia Inc. “SibworkS; A quantitative analysis of a program for siblings of children with special needs.” 2007.


Strohm, Kate, Director, Siblings Australia Inc. “Inquiry into better support for carers - Submission No. 701.” *Submission to Standing Committee on Family, Community, Housing and Youth*. June 2008.

Appendix 1: Survey Questions

Australian Siblings Scoping Project – Survey

OVERVIEW and INTRODUCTION
Siblings Australia is a national organisation committed to providing support for brothers and sisters of people with special needs; including disability, chronic illness and mental health issues.

The purpose of this survey is to research what is happening now in terms of sibling support around Australia in order to
- develop greater knowledge about approaches and models currently being used
- develop greater knowledge about what evaluation has been done and the measures used
- identify gaps
- provide a resource for families and providers to use to access sibling support

The results of this research will be presented at the Siblings Australia ‘Creating Connections’ Conference, which will be held in November 2009. Additionally, a directory of current sibling programs will be placed on the Siblings Australia website as a resource for other service organisations, parents and siblings.

It is also hoped that this research will lead to development of standard evaluation measures for sibling support programs, shared policies and procedures, and the development of ‘best practice’ guidelines.

The survey will take approximately 20 mins to complete and your participation is greatly appreciated.

CONTACT DETAILS

<table>
<thead>
<tr>
<th>Contact Person</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td></td>
</tr>
<tr>
<td>Organisation</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
</tbody>
</table>

Would you like to join our email mailing list?
- Yes
- No

Are you happy for Siblings Australia to publish the program’s details on our website Directory of Services?
- Yes
- No

If No, please explain _____________________________________________________
Please provide public access contact details for your organisation which may be published on the Siblings Australia website

<table>
<thead>
<tr>
<th>Address</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Suburb</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td></td>
</tr>
<tr>
<td>Postcode</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
<tr>
<td>Fax</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>Website</td>
<td></td>
</tr>
</tbody>
</table>

**SIBLING PROGRAMS**

1. Is your organisation currently providing a program that directly addresses the needs of siblings of people with special needs?
   - Yes – please go to question 5
   - No

2. Do you have any plans to offer a program to support siblings in the future?
   - Yes
   - No

3. Do you refer siblings to organisations around you that do provide support for the needs of siblings of people with special needs?
   - Yes
   - No
   If yes, please detail __________________________________________________

4. What are the reasons for not providing support or stopping this program?
   - Lack of funding
   - Lack of interest/participants
   - Turnover of staff members
   - Inadequate staff skills/training
   - Inadequate resources
   - Other - Please detail ________________________________________________
   * Please go to question 19

5. What strategies does the program use to provide support to siblings of people with special needs?
   - Support groups for siblings
   - Camps for siblings
   - Workshops for parents on the needs of siblings and how to support them
   - Individual counselling with parents regarding issues arising for siblings of a child with special needs
   - Individual counselling with siblings regarding issues arising from having a sibling with special needs
   - Other – Please detail _______________________________________________

6. Please describe the program
   ____________________________________________________________________
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>Who are the programs’ target groups?</td>
</tr>
<tr>
<td></td>
<td>□ Infants and toddlers aged 0-4 years</td>
</tr>
<tr>
<td></td>
<td>□ Children aged 5-11 years</td>
</tr>
<tr>
<td></td>
<td>□ Young people aged 12-17 years</td>
</tr>
<tr>
<td></td>
<td>□ Young adults aged 18-25 years</td>
</tr>
<tr>
<td></td>
<td>□ Adults</td>
</tr>
<tr>
<td></td>
<td>□ Other – Please detail ____________________________</td>
</tr>
</tbody>
</table>

| 8. | Is your program |
|    | □ Local |
|    | □ Regional |
|    | □ State-wide |
|    | □ National |

| 9. | What is the main outcome that the program seeks to address? |
|    | □ Improved support for siblings of people with special needs |
|    | □ Improved mental health among siblings of people with special needs |
|    | □ Increased knowledge and understanding by siblings of their brother/sisters special needs |
|    | □ Reduced feelings of isolation amongst siblings of people with special needs |
|    | □ Skills development for siblings to be able to better deal with experiences |
|    | □ Other – Please detail ____________________________ |

| 10. | What models does the program use |
|     | □ SibworkS (Siblings Australia 6 week peer support program) |
|     | □ Sibshop (Don Meyer’s program from United States) |
|     | □ Noah’s Ark Sibling model |
|     | □ Seasons of Growth Model |
|     | □ In-house developed model |
|     | □ Other – Please detail ____________________________ |

<p>| 11. | If your program is based on the SibworkS model (the Siblings Australia group program) would you be interested in contributing to a review of the resource, based on your own experiences? |
|     | □ Yes |
|     | □ No |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.</td>
<td>Please briefly describe the research evidence that underpins your program.</td>
</tr>
</tbody>
</table>
| 13.      | Has your program been formally evaluated?  
|          | □ Yes  
|          | □ No – Please go to question 15. |
| 14.      | Please describe what evaluation strategies/measures are used |
| 15.      | Is there a cost for siblings to participate?  
|          | □ Yes – Greater than $100  
|          | □ Yes – Greater than $20  
|          | □ Yes – Less than $20  
|          | □ No |
| 16.      | Who funds the program?  
|          | □ Commonwealth Government  
|          | □ State Government  
|          | □ Local Government  
|          | □ Non-Government body  
|          | □ Private body  
|          | □ Other – Please detail |
| 17.      | Do you work with other agencies to deliver your program  
|          | □ Yes  
|          | □ No – Please go to question 19. |
| 18.      | Does the collaboration focus on  
|          | □ Ensuring the needs of siblings are met through interagency discussion (resourcing)  
|          | □ Identification of siblings of people with special needs  
|          | □ Other – Please detail |
19. Which of the following are the main barriers to the implementation of specific services for siblings?
- Funding
- Insufficient human resources
- Lack of understanding of sibling needs
- Lack of staff knowledge/skills in implementation of sibling support services
- Other (please specify): ________________________________________

20. Which of the following would help your organisation to implement more sibling support services?
- Funding
- Extra staff numbers
- Staff training/development
- Collaboration with other organisations
- Other (please specify): ________________________________________

21. If you indicated that staff training would help the organisation to implement sibling support services which of the following would be most useful?
- In-house training by external consultant
- On-line training in sibling issues and support
- Resources eg print, DVD
- Other (please specify): ________________________________________

22. Siblings Australia has established a web based discussion forum (SibServices) for providers who are involved in sibling support, in order to share resources and experiences. Would you join such a forum?
- Yes
- No

23. What do you see as being the most important gap in services which should be provided for siblings of people with special needs?
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Thank you for taking the time to complete this survey
Appendix 2: Directory of Services

Association for Children with a Disability
Suite 2, 98 Morang Rd Hawthorn VIC 3122
03 9818 2000
http://www.acd.org.au
mail@acd.org.au
Type of Support: Individual Counselling, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years), Young adults (18-25 years)
We provide information and support for parents, siblings and service providers as to how siblings can be better supported. Our organisation also runs two websites, www.yourshout.org.au and www.siblink.org.au which provide an online outlet for siblings to write stories and connect with others.

Autism Behavioural Intervention NSW
Suite 202, 35 Doody Street Alexandria NSW 2015
02 9669 2250
http://www.abinsw.org.au
info@abinsw.org.au
Type of Support: Individual Counselling, Other
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years), Young adults (18-25 years)
We have a family focused model of intervention and often program for siblings of children with special needs. Siblings are an integral part to our service often involved in therapy session to work on play and social skills and equip siblings with behavioural strategies

Autism Queensland
437 Hellawell Road Sunnybank Hills, Brisbane QLD 4109
07 3271 0000
http://www.autismqld.com.au
Type of Support: Camp, Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years)

Autism Spectrum Australia
PO Box 361 Forestville NSW 2087
02 8977 8300
http://www.autismspectrum.org.au
infoline@autismspectrum.org.au
Type of Support: Camp
Age Group: Children (5-11 years), Young people (12-17 years)

Bradfield Park Wellbeing Centre Carers Program
Cnr. Burton and Alfred Sts. Milsons Pt. NSW 2061
02 8920 0675
http://www.kncsydney.org
Type of Support: Individual Counselling, Support Group
Age Group: Children (5-11 years), Young people (12-17 years), Young adults (18-25 years), Adults
Our service offers support and respite for carers of people with a mental illness - siblings are welcome in all our programs. We also run holiday programs for young carers, and a variety or respite programs for carers.

**CanTeen**
GPO Box 3821 Sydney NSW 2001
02 9262 1022
http://www.canteen.org.au

Type of Support: Camp, Other, Support Group
Age Group: Young people (12-17 years), Young adults (18-25 years)
Online Services - www.nowwhat.org.au.
Resource - "Now What? Dealing with your brother or sister's cancer"

**Carers NT**
PO Box 1861 Darwin NT 0801
08 8948 4877
http://www.carersaustralia.com.au
carersnt@carersnt.asn.au

Type of Support: Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years)
Crocshops are fun 6 hour workshops over one day that are based around themes such as:
'Feelings' - it is an important component of being healthy – good health is about being at ease in both mind and body. 'Me, Myself & I' - to assist young carers begin to recognise the impact caring has on their lives and the importance of taking time to ‘do things’ for themselves.

**Centacare**
25 - 27 Auburn Street Wollongong NSW 2500
02 4227 1122
http://www.centacare.woll.catholic.org.au
enquiries@centacare.woll.catholic.org.au

Type of Support: Camp, Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years)
Program focuses primarily on siblings aged between 5 and 12 years.

**Cystic Fibrosis NSW**
51 Wicks Road North Ryde NSW 2113
02 9878 2075
http://www.cysticfibrosis.org.au
general@cysticfibrosisnsw.org.au

Type of Support: Camp, Individual Counselling, Other
Age Group: Children (5-11 years), Young people (12-17 years)
Also provide Day Outing programs for siblings in school holidays.
Cystic Fibrosis Queensland
31 Kate St Kedron QLD 4031
acity (3359 8000
http://www.cfqld.org.au
admin@cfqld.org.au
Type of Support: Camp, Individual Counselling
Age Group: Children (5-11 years), Young people (12-17 years)
Provide Sibling Activity Days for siblings of CF clients aged between 7 and 15 years.

Cystic Fibrosis WA
The Niche Building, 11 Aberdare Road Nedlands WA 6009
acity (9346 7333
http://www.cysticfibrosis.org.au
socialworker@cysticfibrosiswa.org
Type of Support: Camp
Age Group: Children (5-11 years), Young people (12-17 years)

Department of Ageing Disability & Homecare
140 William Street Bathurst NSW 2795
acity (6339 5811
http://www.dadhc.nsw.gov.au
Type of Support: Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
We are currently trialling this program in the DADHC Western Region.

Department of Ageing, Disability, & Homecare
PO Box 1805 Burwood NSW 2134
acity (9701 6300
http://www.dadhc.nsw.gov.au
Type of Support: Support Group
Age Group: Children (5-11 years)
3 day sibling group program run twice yearly in school holidays (usually January and July).
Program is primarily social and fun based, but also provides information re: disability and coping mechanisms for siblings.

Disability SA
57 Park Tce Salisbury SA 5108
acity (8182 1560
Type of Support: Camp, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
"Time for Me" sibling program for siblings of clients of Disability SA (aged approx 11-14 years old) - comprises of 9 weekly group sessions and a weekend camp combination.Recreation based
program facilitated by Disability SA and Northern Carers Network staff.

**Disability Services**  
19 George Street Maroochydore QLD 4558  
07 5459 9630  
Type of Support: Individual Counselling, Support Group  
Age Group: Children (5-11 years)

**District Council of Mount Barker**  
6 Dutton Road Mount Barker SA 5251  
08 8391 7227  
[iroberts@dcmtbarker.sa.gov.au](mailto:iroberts@dcmtbarker.sa.gov.au)  
Type of Support: Camp, Individual Counselling  
Age Group: Children (5-11 years), Young people (12-17 years)  
A yearly Siblings Retreat for children and parents of children with a disability.

**Giant Steps Sydney**  
23 Punt Rd Gladesville NSW 2111  
02 9879 4971  
[http://www.giantsteps.net.au](http://www.giantsteps.net.au)  
[helen.appleton@giantsteps.net.au](mailto:helen.appleton@giantsteps.net.au)  
Type of Support: Support Group, Workshop for Parents  
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)  
The Giant Steps Siblings Program runs over 3 groups and focuses giving the siblings access to fun activities they might not ordinarily get to participate in. The groups also include group discussion around emotions, understanding autism and dealing with public perceptions of autism.

**Haemophilia Foundation Australia**  
1624 High St Glen Iris VIC 3146  
03 9885 7800  
[hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
Type of Support: Camp, Support Group, Workshop for Parents  
Age Group: Children (5-11 years), Young people (12-17 years), Young adults (18-25 years)  
These peer support programs are offered from time to time and not on a regular basis through our member foundations

**HeartKids SA**  
PO Box 364 North Adelaide SA 5006  
0406 165 111  
[mail@heartkidssa.org.au](mailto:mail@heartkidssa.org.au)  
Type of Support: Other  
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years), Young adults (18-25 years)  
HKSA organise special events for children with childhood heart disease and their siblings such as a playgroups, Christmas party, teenage pizza nights, movie days, ball room parties.
I.d.entitywa
47 David Street Kensington WA 6151
  08 9474 3303
  http://www.identitywa.com.au
  reception@identitywa.com.au
Type of Support: Camp, Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years)
- Sibling day activities for 6-9yrs, 9-12yrs & 13-15yrs olds. It is a group therapeutic activity and day outing.
- Sibling camp 3days Sept/Oct holidays.

Interaction Disability Services Ltd
B2/11 Hudson Ave Castle Hill NSW 2154
  1300 668 123
  http://www.interactiondisability.com
  admin@interactiondisability.com
Type of Support: Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years)
Support groups for children aged 8-13 years

Koorana Child and Family Centre
1a Cleary Ave Belmore NSW 2192
  02 9750 4100
  http://www.koorana.org.au
Type of Support: Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years)
Koorana runs Sibs Club during school term on a weekly basis. Sibs Club is for children between the ages of 7-11yrs.

Kurrajong Early Intervention Service
2 Grampian Place Wagga Wagga NSW 2650
  02 6926 2466
  http://www.kurrajongwaratah.org.au
  keis@kurrajongwaratah.org.au
Type of Support: Individual Counselling, Support Group
Age Group: Children (5-11 years)

Landsdale Family Support Association Inc
80 Landsdale Road Darch WA 6065
  08 9303 4660
  http://www.lfsa.org.au
  support@lfsa.org.au
Type of Support: Camp
Age Group: Children (5-11 years), Young people (12-17 years)
2 camps per year for approximately 25 children per camp. Children engaged in fun activities while getting to know other children with siblings with disabilities. Counsellor available to discuss issues with children.

Lifestart Co-operative Ltd
Building 25 /92 Seven Hills Rd Baulkham Hills NSW 2153
Type of Support: Support Group
Age Group: Children (5-11 years)

Little Dreamers Australia Pty Ltd
PO Box 2035 Wattletree Road LPO East Malvern VIC 3145
0433 818 212
http://www.littledreamersonline.com
littledreamers272@hotmail.com
Type of Support: Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
Little Dreamers Australia provides "dream experiences" for the siblings and young carers providing them with some temporary respite from their burdens at home.

Marymead Child and Family Centre
255 Goyder Street Narrabundah ACT 2604
02 6162 5800
programs@marymead.org.au
Type of Support: Other
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)
Provides respite care for siblings in families affected by disabilities. There are three types of care;
1. Individual respite with volunteer carer
2. Group respite fortnightly for two hours
3. School holiday program - one day per week

Melbourne City Mission
123 Albion Street Brunswick VIC 3051
03 9385 3211
siblingprogram@mcm.org.au
Type of Support: Other, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
TIME Out” stands for “This Is Me Everybody !” We run groups, workshops and excursions for children and young people who have a brother or a sister with a disability, and also run activities for young carers. The groups provide a fun, safe environment in which to meet other siblings and say: “T.I.M.E. Out - THIS IS ME EVERYBODY !” There are 2 regular activities running in 2009:
• fortnightly groups for 8 – 13 year olds, on Tuesday afternoons, at Brunswick and at Broadmeadows throughout the school term
• “Give Me 5” - a teen sibling and young carer group for 12 – 18 year olds, which runs on the last Thursday of every month, from 4.30 to 7.30 pm, in Reservoir
We also run a variety of other services and activities:
• school holiday excursions
• young carer workshops
• family support
• referral and information about sibling and young carer issues

Muscular Dystrophy Association
36 - 38 Henley Beach Road Mile End SA 5353
08 82345266
Type of Support: Camp, Individual Counselling
Age Group: Children (5-11 years), Young people (12-17 years), Young adults (18-25 years), Adults
A camp for people 5 to 25 years of age with neuromuscular disorders and their siblings is held annually. Counselling is available for individuals with disorders and their families and carers.

Northcott Disability Services
1 Fennell Street North Parramatta NSW 2151
02 9890 0100
http://www.northcott.com.au
Type of Support: Camp, Other, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
Also provide day trips for siblings in the school holidays

Northcott Disability Services
147 Goonoo Goonoo Road Tamworth NSW 2340
02 6762 4902
tamworthoffice@northcott.com.au
Type of Support: Camp, Other, Support Group, Workshop for Parents
Age Group: Children (5-11 years), Young people (12-17 years), Adults
Additionally provides support through Mothers and Fathers weekends Young Carers and Siblings Support network (Group of service providers who get together to provide sibling and young carer support)

Novita Children's Services
171 Days Road Regency Park SA 5010
08 8243 8243
http://www.novita.org.au
enquiries@novita.org.au
Type of Support: Individual Counselling, Support Group
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)

Pinarc Support Services
20 King St Nth Ballarat VIC 3350
03 5329 1300
http://www.pinarc.org.au
admin@pinarc.org.au
Type of Support: Individual Counselling, Support Group, Workshop for Parents
Age Group: Children (5-11 years)

Recreation Sports and Aquatics Club
PO Box 120 Bankstown NSW 1885
02 9790 5001
http://www.disabledsportrsac.org.au
RSAClub@bigpond.net.au
Type of Support: Other
Age Group: Children (5-11 years), Young people (12-17 years), Young adults (18-25 years), Adults
integrated programs that include siblings and family holidays camps etc where they can interact with their siblings and others who have a sibling with a disability

**Senses Foundation**
11 Kitchener Ave Burswood WA 6149
08 9473 5400
http://www.senses.asn.au

Type of Support: Other, Support Group, Workshop for Parents
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)
Additionally run Family Fun Days

**St Giles Society Inc.**
65 Amy Road Newstead TAS 7250
03 63442451
http://www.stgiles.org.au
familysupport@stgiles.org.au

Type of Support: Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
We have run two six week groups using the Siblings Australia program for 8 - 13 year olds. We have just commenced meeting monthly for an activity night with these young people and also have a 'day out' each school holidays. We are planning a teen group to run at the end of this year.

**Sunspec Support Group for Families/Carers of People with Disabilities Inc.**
5B/36 Macedon Street Sunbury VIC 3429
03 9740 5155
sunspecinc@bigpond.com

Type of Support: Support Group
Age Group: Young people (12-17 years)
The program provides a range of social and recreational activities for siblings during school holidays.

**Tascare Society for Children**
231 Main Road Derwent Park TAS 7009
03 6272 8265
http://www.tascare.asn.au
eo@tascare.asn.au

Type of Support: Camp, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)

**The Brain Injury Service**
The Children's Hospital at Westmead Westmead NSW 2145
02 9845 2821
http://www.chw.edu.au/rehab
martines@chw.edu.au

Type of Support: Individual Counselling, Support Group
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)
The Brain Injury Service offers a two day group day for primary school aged children aged 8 - 12 years. The Senior Clinical Psychologist and Senior Social Worker in the team offer counselling/therapy to all family members regarding sibling adjustment issues.

**The Centre for Cerebral Palsy**
Type of Support: Individual Counselling, Support Group
Age Group: Infants and toddlers (0-4 years), Children (5-11 years), Young people (12-17 years)

The Junction Works
2 Littimer Way Ambarvale NSW 2179
02 4625 7333
http://www.thejunctionworks.org
siblingsupport@thejunctionworks.org
Type of Support: Camp, Individual Counselling, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
Age Group is 8-17 years.

The Spastic Centre
PO 184 Brookvale NSW 2100
1300 888 378
http://www.thespasticcentre.org.au
Type of Support: Individual Counselling, Other
Age Group: Children (5-11 years)

Tumbatin Clinic, Sydney Children's Hospital
High Street Randwick NSW 2031
02 9382 8189
http://www.tccp.com.au
Type of Support: Individual Counselling, Support Group
Age Group: Children (5-11 years)
Also provides presentations to allied health professionals and community health doctors on the needs of siblings and information and resources available for professionals and siblings

Xavier Children's Support Network
284 Pine Mountain Road Mount Gravatt East QLD 4122
07 3216 8811
http://www.xcsn.org
Type of Support: Camp, Support Group
Age Group: Children (5-11 years), Young people (12-17 years)
Xavier also refers families on to specialist providers in the case of workshops for parents and individual counselling if required.
The Xavier Sibs Squad operates a monthly outing for 20 children (aged between 7-14 years old) from families across Brisbane. An annual camp is also held over one weekend per year.
The focus of the program is fun-based socialisation with the opportunity to share anything the children want to discuss.
Appendix 3: Verbal responses to gap in services which should be provided to siblings

What do you see as being the most important gap in services which should be provided for siblings of people with special needs?

- Free activities and camps for siblings to give them a break from their families.
- Ongoing and consistent family support, including groups and information for siblings and parents.
- The fact that very few organisations accept that siblings needs are paramount. Plus the lack of knowledge and training for workers around working with siblings, particularly younger siblings and adolescents.
- Support for siblings in general - particularly young people aged 12 years +
- Services that work with the whole family as the client. So whilst implementing programs for the child with ASD also incorporating siblings issues
- Resources Including Staff and funding
- Consistency. There are a number of services that provide sibs programs but they run infrequently and therefore don't really provide siblings with the opportunities and support they need.
- Emotional support
- Rural and regional areas are severely lacking in disability supports of any kind, especially where carers and siblings are involved. There is no support for siblings in country areas if Victoria.
- Support groups.
- Somewhere they can find out information easily to support their sibling with a disability - services, long term supports such as accommodation and physical assistance
- Ongoing funding
- Parent education re the effect on siblings of having a child in the family with special needs.
-Support for families in the early days to help development of the same kinds of positive relationships that other siblings have.
- Adequate staff and locations for programs
- There is very little funding given to services to work with families, and even less to support the siblings. If you are not funded to work in that way it can be very difficult to provide any service to siblings.
- We're a big country. Most of our stakeholders are spread around the nation and they should be connected online for intermittent fellowship and counselling and have an annual camp for face to face contact and formal group therapy or acknowledgement of the fact that they grieve in their own way and require support. My adult sons as young children only attended one weekend workshop which was led at the time as rural outreach through the Cerebral Palsy league (other disorders catered to by their service in that region at the time were included). They attended that workshop of fellowship and craft activities that were geared towards building self esteem and acknowledging their grief and their feelings and they had such a positive experience. Their disabled sibling attended with them at that time but at least they were included and acknowledged as carers, as support for their sibling, as stoic little people who knew the meaning of sacrifice etc. I should think that such services were provided more regularly - as I say this was a one-off opportunity for my children in rural Queensland. As a university student, my now psych graduated, parole officer son attended specific sibling camps with younger children as a facilitator and he recounted to me some cathartic group discussions with these children. Resilience comes from externalizing and getting out in the world and getting on with things rather than introspection and by learning some strategies to work in teams and identify with others in the same position, we can help our siblings to be more resilient, not only to cope themselves but to be role models/teachers for their parents who bear a very different burden of grief (as my unaffected sons have been).
- Lack of support/counselling
- Deficit re time out opportunities
- More time out for siblings either by the family having more Respite or the Sibling being taken out of the home.
- The client group that DADHC provide services to is very broad, and this target group is
growing...maybe we could discuss gaps at our next meeting.

- Support groups for the siblings.
  Understanding by parents of the siblings needs to be supported.
- Funding for more intensive work such as individual counselling or group work.
- Information and access to sibling services
- Knowledge of the needs of siblings of people with special needs.
  Following a family centred practice framework
- Support and information
- There are just not enough services around
- Funding and recognition of need, it may be that siblings of children with a sensory impairment do not see the need as quite as high as other disability groups. We are concerned about the support for CODAS but that is largely around their language development as well as the issues that surround CODA children i.e. responsibility for communication for Deaf family members
- More that it should be easier to work together with other agencies.
- Opportunities to be with other kids in the same boat and counselling
- networking opportunities
- knowledge and information resources
- Consistent support
- Specific support and awareness raising about the issues that face siblings everyday
- Lack of awareness by parents and sibs of the relevant issues and needs and the supports available.
- Community awareness may help to let people know that these could be a possibility?
- lack of services due to no funding
- Recognition of siblings as being a subset of a larger group known as young carers thereby combing our efforts to improve services for all
- Service providers understanding sibling needs
- Education and support for siblings at school and in community activities.
- Giving siblings some attention and respite while developing their own capacity to live fulfilling lives within their family
- being able to run regular activities, groups for sibs
- Information sharing
- Carer’s i.e. parents needs are not being met especially with children with Epilepsy so that they don’t have time for their other children. Epilepsy is often a frightening experience. Funding for time for siblings is minimal and often not acknowledged
- Ongoing, regular groups, not just time limited, or occasional weekends or school holidays. Transport is always an issue. Consistency with facilitators, and good relationships with the whole family is essential. DHS should see sibling support as an integral part of Disability Services and fund it alongside other case management and respite services to fully support each person in the family.
- Peer support and opportunities for networking, forums and information
- Siblings groups and camps to provide emotional and social support for siblings and prevent social isolation
- Firstly that Siblings are not acknowledged as part of the client base and therefore their needs not recognised. Services fail to have a holistic approach when working with families. I also feel services need to network together in a regionally based approach and pool resources and skills and perhaps offer a general support service which ensures strong participation.
  FUNDING!!!!!!!!!!
- Education ,for carers ,about the impact of having a child with a disability on the siblings. Also support services to enable parents to be able to focus more on siblings needs - e.g. respite services
- opportunity to participate in programs specifically designed for siblings in our local area
- FINDING A WAY TO GET THROUGH TO PARENTS THAT THIS AREA IS IMPORTANT AND REQUIRES THEIR ATTENTION!
- Limited social support services and specific counselling services.
- Currently ‘family centred practice’ does not in real terms support siblings due to the absence of funding for sibling support services.
- group work, information, workshops, camps (opportunities for siblings to meet one another)
- School based awareness and support
- Support to reduce the feelings of isolation
Strategies to cope with the extra pressure on their role
Education for parents on recognising the siblings' special needs and having strategies to help them

- Community Awareness of the needs of families caring for a child with a disability, and the pressures/concerns of other children in these families.
- Social groups to provide peer support and opportunity to work through issues they face
- Allocated funding to ensure that siblings services are a core component of any agency who is providing services for families who have a child with special needs. Ongoing training of broader community services in regards to siblings needs/issues
- Raising awareness of issues with service providers and with siblings.
  Funding to run programmes
- childcare support
- An acknowledgement of the issues that Siblings face and the impact the unwell siblings journey has on them.
- Access and information about services applicable to siblings.
- a service orientation that includes siblings in its thinking, planning and responding to families where there is a member with a disability.
- Specific targeted services for siblings of people with special needs
- Know that such services are available and approachable
- Access to Siblings Support - we receive many referrals to access our program but we can only support 20 children. Either more funding to current programs to expand or more specific funding to more service providers to increase Sibs programs/awareness across all organisations.
- Many of the Sibling group models target siblings aged 8-12 years old. There are hardly any groups targeting young people above 12 years old.
- Government acknowledgement, funding via disability or youth or health sectors, national policy, ongoing groups - year long across every region as a collaborative effort, transition options from a primary aged service to teen to young adult services
- Linking siblings into existing services, need more support groups for children and young people, creating community awareness of challenges experienced by siblings. Outreach to young people and children.
- frequency of events
- Lack of funding
- a proper evidence based program formation and discussion on this
- Respite.
- Raising awareness of the impact of being a sibling in a family where there is someone with a disability.
- Increased access to programs in Regional Victoria
- Access