

ARACY ARC/NHMRC Network Encouragement Grant

**Support for the siblings of children with disabilities or chronic illness:
Needs, services and research approaches**

REPORT ON THE PROCESS OF COLLABORATION

Prepared by:

**Dr Rebecca Giallo (Parenting Research Centre)
and
Kate Strohm (Siblings Australia)**

Convenor:

Associate Professor Susana Gavidia-Payne (RMIT University)

Correspondence to:

Dr Rebecca Giallo

24 Drummond St

Carlton 3053

Ph: 8660 3500

Email: rgiallo@parentingrc.org.au

Contents

Introduction

Background to the Collaboration

Forming the Collaboration

Developing the Collaboration Activity: The Forum

What Worked Well

Challenges to Collaboration

Conclusion

Introduction

A collaborative research network of researchers, service providers, and family members of children with a disability whose interest focuses on the health, wellbeing and supports of siblings of children with a disability, life-threatening, or chronic illness, was formed.

The expected outcomes of the collaboration included:

1. The establishment of ongoing partnership and collaboration among researchers, service providers, policy makers and consumers interested in siblings of children/people with a disability/illness
2. Preliminary mapping of sibling research and services across Australia
3. The establishment of several collaborative groups with mutual interests around issues relevant to siblings of children with a disability/illness, with the view to submit an application to the ARC or NHMRC for future research.

As part of the ARACY Encouragement Grant, a 2-day forum to connect 20 researchers, service providers, siblings and family members of children with a disability, chronic illness, or life threatening illness took place on the 22nd and 23rd May, 2008 in Melbourne.

The present report describes the process involved in the initiation and formation of the collaboration, development of the collaboration activity, the learnings, and challenges faced.

Background to the Collaboration

Kate Strohm from Siblings Australia initiated the process to submit an application to ARACY to establish a collaboration of researchers and service providers whose interest focuses on the health, wellbeing and supports of siblings of children with a disability, life-threatening, or chronic illness. Through her role with Siblings Australia over many years, Kate had come into contact with many providers and researchers. Through these connections, it became evident that there was a lack of communication and collaboration between researchers conducting sibling related research in Australia. More salient was the lack of collaborative efforts between researchers and practitioners supporting siblings and families. These links continue to be viewed as critical in developing research directions that contribute to a greater understanding of sibling issues, evidence-based practice in supporting siblings, and knowledge generation that may be required by governments to influence policy development in this area.

Siblings Australia hosted a conference on sibling issues which attracted 140 attendees (10 from overseas) in 2004. The conference program included a session on research of sibling issues. The intention was to develop a research network from the conference but, without specific resources, this proved challenging. Because researchers were spread around Australia, co-ordination of the networking process once people returned to their own workplace was seen as paramount to its development. Unfortunately, Siblings Australia did not have the resources to accomplish this task.

Forming the Collaboration

In 2007, Siblings Australia, under the direction of Kate Strohm, became aware of the ARACY New Collaboration grants and contacted several researchers and practitioners, with whom she had maintained contact, to gauge interest in developing a proposal for funding. This took place over several months, during

which Kate Strohm collated information on those people who were interested, and developed an email distribution group for the group to be kept in touch.

Initially, there had been about 20 people who showed interest. As the proposal gained momentum, this number reduced to about 10. Again, it was very difficult to have the group communicate with each other via email. People were busy and it became increasingly challenging to gain responses. A small group worked on an initial draft which was then circulated to the rest of the group for further development and comment. Associate Professor Susana Gavidia-Payne from RMIT University was nominated as the Convenor, and Dr Rebecca Giallo, an early career researcher to be involved. The proposal was submitted to ARACY and was successful in attracting an 'encouragement grant'.

Developing the Collaboration Activity: The Forum

In order to coordinate the collaboration activity of a forum, Dr Rebecca Giallo was employed and mentored by the Convenor, Associate Professor Gavidia-Payne. Details pertaining to the dates, location, format, and content of the forum were developed in consultation with the members of the collaboration group. Members were asked to nominate their preferences for location and offer dates of availability. At this point, several members, detailed in the original submission, indicated that they were no longer able to attend a forum. The primary reason being a change in employment, which sibling research or service provision was no longer within the scope of their role. One member was unable to attend as they were out of the country at the time of the forum. Of the original group 14 indicated that they would still like to be involved in some way.

During the lead up to the forum, a further 11 participants were invited to attend the forum. These participants were identified by members of the collaboration, and represented a mix of service providers, parents, siblings, and student researchers. Given that the initial members of the collaboration were primarily researchers, the involvement of service providers, parents and siblings was seen as a critical element of establishing a collaboration representing a broad range of perspectives and insights from different sectors and backgrounds. All invited participants attended the forum. Once dates and location of the 2-day forum were set, members of the group were asked to provide ideas and suggestions for the forum format. These included presentations by individuals, discussion of key issues in sibling research and service provision, and starting work on submission for an ARC grant or other funding opportunity. Participants were also asked to submit an abstract outlining their research or service provision activities, interest areas in sibling research and support, and some key questions or issues they would like to see discussed at the forum. These were grouped according to themes and formed the structure of discussion sessions for the forum (see Figure 1).

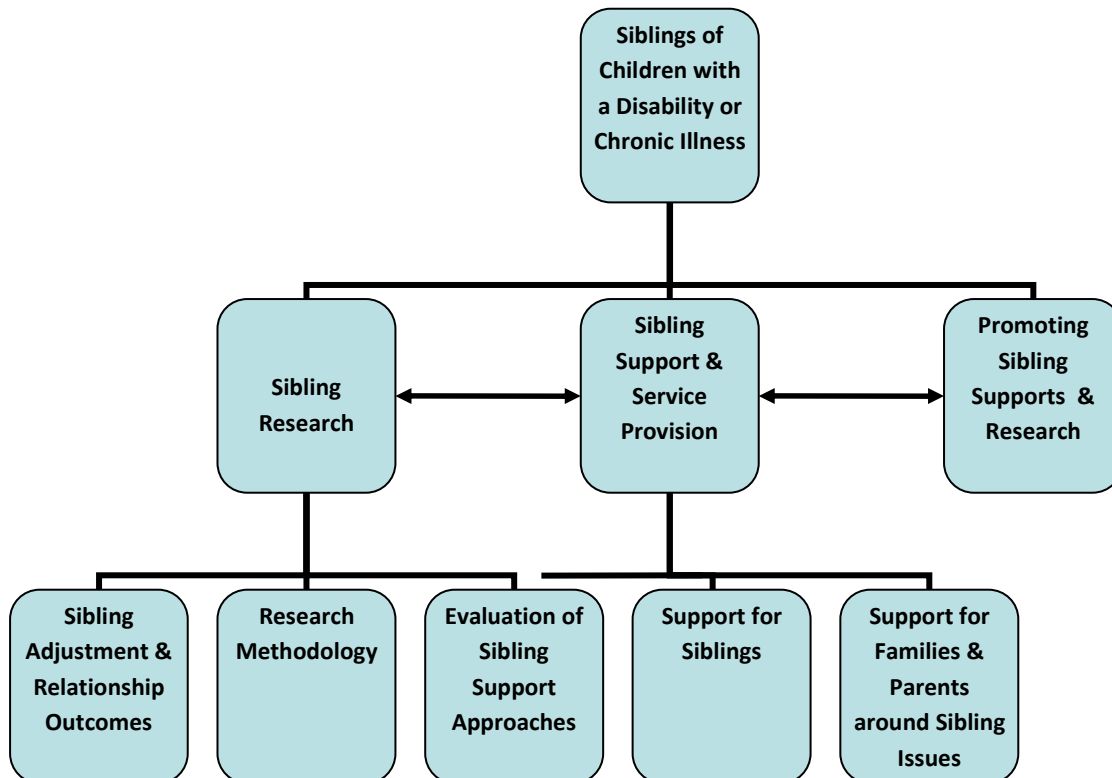


Figure 1: Thematic map of discussion questions submitted by participants

What Worked Well

We have identified several factors associated with the successful development of this collaboration, and participation in the forum. These include:

- The funding support from ARACY enabled researchers and service providers from all over Australia to come together to share their research knowledge, insights from service provision, and experiences in living with and supporting a family member with a disability or illness;
- The involvement of a key person with existing links and relationships with researchers and service providers in the area;
- For the provision of a forum framework and organisation of activities prior, during and after the forum, the involvement of a paid coordinator who had both practitioner and researcher knowledge in the siblings area;
- A forum provided members with an opportunity to meet people in person, to establish connections and discuss opportunities for future work.

A noteworthy factor contributing to the success of the forum was the involvement of researchers, service providers, siblings and parents who each offered diverse perspectives on sibling issues and key questions for future research.

We are anticipating that this will inform the development of evidence-based information, resources and support for siblings. Comments from several participants highlight the value in this:

“A rich opportunity which highlighted great potential for collaboration between researchers and providers, in an area which warrants far more focus – the sibling experience.”

“Having both researchers and practitioners from different disciplines was extremely powerful, and provided a nice bridge between evidence based practices and also the delivery of service to families and siblings of children with special needs. The day was enriching and has inspired me to carry out my research to my greatest potential in order to inform myself, other practitioners and families how to best support siblings of children with disabilities. I hope a forum like this is able to continue in order for me to share my knowledge and also learn from others in such an empowering experience.”

“The forum was informative and a wonderful opportunity to network with both sibling researchers and those working in sibling support. From the perspective of a researcher, it was extremely valuable to make connections with others who are researching in this area & to hear about the programs that are in place for supporting siblings. As a sibling, it was also wonderful to meet so many others who were siblings and working in the field (both research, or service provision).”

“I walked away from the forum feeling energised about the way forward for sibling research. A number of us have been working away in this area for the past decade in relative isolation and it was wonderful to get together with like-minded people who share a passion for helping siblings. It was also exciting to have researchers and service providers alongside each other agreeing that sound research is an integral part of improving how we assist siblings and working more effectively alongside families. Thank you and I look forward to helping to keep the momentum going!”

Challenges to Collaboration

Several challenges during the process were identified:

- Throughout the different stages of the collaboration, some members were more actively engaged in the process than others.
- For some members, changes in employment meant that this work was now outside the scope of their current role.
- There was no representation from government or policy level stakeholders engaged in the process. This would be essential if more work is to be done through the collaboration.
- Maintenance of the momentum gained during the forum, and how this could be developed further considering participants’ employment positions and workloads, not to mention the vast geographical distances among them. It is clear that progress is most likely when resources are available to employ someone to co-ordinate efforts.

Conclusion

We have successfully hosted a 2-day forum in which researchers, practitioners, siblings and family members were able to come together to share their research knowledge, insights from service provision, and experiences in living with and supporting a family member with a disability or illness.

Most importantly, we have now formed a national network of researchers, practitioners, policy-makers, siblings and family members who will work together to enhance our knowledge of how to best support

siblings of children with a disability, chronic illness, life-threatening (bereaved and non-bereaved), and mental illness.

We would like to acknowledge and extend our gratitude to ARACY for the Encouragement Award which has enabled us to bring together a diverse group of people to share our knowledge and experiences, stimulate our thinking, and form a collaboration committed to working together in the future.

It is imperative that further resources are found to meaningfully develop the outcomes of the forum, and to incorporate them into clear policy directions. This would ensure an ideal combination of research, service provision and policy.