



*Services for brothers and sisters  
of children with special needs.*

## SibworkS; A quantitative analysis of a program for siblings of children with special needs

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This report was completed by Siblings Australia Inc, in partnership with  
the Commonwealth Department of Health and Ageing, Canberra.

December, 2007

# Siblings Australia

## About Us

Siblings Australia is a unique national organisation committed to providing support for brothers and sisters of people with special needs (disability, chronic illness and/or 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.

## Our Story

The program developed from the concern of an experienced health professional and journalist, Kate Strohm, who grew up in a family with a sister with cerebral palsy.

From her own experiences, and then through talking with other siblings and service providers, Kate understood the need to develop supports for siblings of children with special needs as they move through to adulthood. In 1999 she established the Sibling Project within the Department of Psychological Medicine, at the Women's and Children's Hospital in Adelaide.

In 2003 a national incorporated body developed from this project and since then Kate has been the Executive Director of Siblings Australia Inc. In 2002, her book, *Siblings: Brothers and Sisters of Children with Special Needs* was published in Australia by Wakefield Press and, in 2005, it was published in the US and UK.

## Why siblings need support

Research and anecdotal evidence supports the view that illness and disability affects the lives of all family members. Brothers and sisters of children with special needs often face a family situation which involves considerable stress, but without the understanding, emotional maturity and coping skills required to deal with their experiences. They can feel isolated and confused and become 'at risk' for a range of emotional, mental and physical health problems, which can continue into adulthood. Yet siblings are regularly overlooked both within their family and by agencies, even though they are likely to have the longest relationship of anyone with the person with special needs.

## Creating Connections

Siblings Australia aims to create connections between siblings, between parents and siblings, and between families and professionals. Our focus is on strengthening families. Consequently, we aim to increase the availability of information and support services for siblings of people with special needs, through increasing awareness, understanding, skills and capabilities at two levels:

- direct support to siblings
- working with parents and service providers who, in turn, offer support to siblings

We also play an important role in areas of research and advocacy to inform social policy makers about the needs of siblings.

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## Abstract

The current study examined the effectiveness of SibworkS, a support program for siblings of children with special needs. Participants were 11 siblings of children with special needs (including Autism Spectrum Disorder, Down Syndrome, Juvenile Arthritis and other disorders) between the ages of eight and 11 years who completed the six week group intervention. Questionnaires evaluating siblings emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour were administered to both the siblings and their parents before the first group session (pre-test) and during the last group session (post-test). Results indicated that no significant differences were found, however there was a decrease in total difficulties for siblings and an increase in scores on the Parent Checklist which partially support the hypotheses. Directions for future research are discussed.

# Introduction

## Siblings

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; Azmita & Hesser, 1993; Jones, Welsh, Glassmire & Tavegia, 2006). 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). According to the Australian Institute of Health and Welfare, there are over 200,000 young people in Australia with a severe or profound disability or chronic illness and many more with a mental illness. It can be assumed that most have a sibling and when one (or more) sibling has special needs, the family dynamic alters dramatically. Changes to an older sibling's lifestyle and parental relationship often occur and modelling of social behaviour in younger siblings is nonexistent with some special needs (Brody, 2004).

The needs of brothers and sisters of children with special needs are often overlooked. Services are commonly directed towards the child with special needs, as often they require more attention. Research and anecdotal evidence also substantiates that siblings are at an increased risk of physical (Hogan, Park & Goldscheider, 2003) and mental health issues, including anxiety, depression and low self esteem (Lamorey, 1999). It is also suggested that these issues become more difficult as the individual with special needs gets older (Cuskelly, 1999).

Research also supports the view that illness and disability affect the lives of all family members. 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. They can feel isolated and confused and become 'at risk' for a range of emotional, mental and physical health problems, which can continue into adulthood. Yet siblings are regularly overlooked both within their family and by agencies, even though they are likely to have the longest relationship of anyone with the person with disability (Young, 2007).

Effects on the siblings can differ tremendously according to the special need of the sibling, for example, siblings of children with Attention Deficit Hyperactivity Disorder reported higher levels of trait anger (Jones, Welsh, Glassmire & Tavegia, 2006) while siblings of children with Autism Spectrum Disorder have reported greater behavioural problems (Rodrigue, Geffken & Morgan, 1993) and siblings of children with Down Syndrome have reported increased anti-social behaviour (Gath, 1972). While the issues can be quite different between siblings, it must be emphasised that the treatment can be the same.

Support for siblings allows them to feel empowered and less isolated, and it helps them build resilience. As a result, not only will they be more likely to develop to their full potential, but also more likely to contribute support to their brother or sister with special needs. Siblings are too important to ignore.

## Sibling Groups

Sibling groups aim to provide support, build resilience and improve the siblings understanding of their brother or sister's disability. Sibling groups discuss problems and issues that siblings may encounter and suggest adaptive ways of coping. Groups also encourage an environment where siblings are able to express their emotions, both positive and negative, openly.

Groups vary in format from highly structured group sessions which use role plays, activities and craft, to unstructured sessions where the group has control over the content and leads most of the discussion. Unstructured groups tend to have higher success rates with teen and adult siblings, where structured groups with lots of smaller activities are more suitable for siblings under 12 years.

Sibling groups also provide families and more specifically siblings, with a social network outside of the home, which is crucial as some families may have restricted social activities due to the special needs of one (or more) family member.

## SibworkS

SibworkS was written by Kate Strohm (Siblings Australia Inc) and Dr. Monique Nesa (Curtin University). SibworkS is a highly structured six week group-based program for siblings of children with special needs aged eight to 12 years.

The program aims to increase participants' emotional capacities, help to understand the special needs and increase their communication with family and friends. Children are able to ask questions about their siblings' special needs as well as participate in fun activities. The group aims to increase participants' support network and provide a comfortable and safe environment where siblings can share feelings and experiences. Over six weeks, participants discuss topics such as problem solving, understanding feelings and coping techniques.

## Aims/Hypotheses

The main objective of this study was to assess the effectiveness of the SibworkS group in siblings of children with disabilities aged eight to 12 years. It was therefore predicted that (1) siblings would increase their strengths and decrease their difficulties scores post completion of the group; and (2) parents would report positive changes to sibling's behaviour towards their families (especially the child with special needs). Further evaluations would also be conducted on the subjective feedback provided by the siblings, parents and facilitators.

# Method

## Design

The quantitative study used an experimental design which scored siblings pre and post completion of the SibworkS group. Measures of siblings' emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour were administered to both the siblings and their parents before the first group session (pre-test) and during the last group session (post-test).

## Participants

Participants (N=11) included siblings of children with special needs (five brothers, six sisters), with the special needs including Autism Spectrum Disorder, Down Syndrome, Cerebral Palsy, Juvenile Arthritis, Arthrogrypsis, and other undiagnosed disabilities. Seven of the siblings were older than the child with special needs and four were younger. Participants ranged from eight to 11 years for both males and females (M=8.82, SD=0.98).

Families were recruited by advertising the SibworkS program via email (Appendix A) through the Siblings Australia network (including members, parents, schools, government departments, service providers and other interested parties), via posting an article in the monthly Auseinet online newsletter (Appendix B) and via referral from service providers around Adelaide.

## Materials and Procedure

### *Procedure*

Families who met the criteria (sibling aged between eight and 12) were then sent two letters; one addressed to the parents describing the aims of the group and what the group involved (Appendix C) and secondly; a letter addressed to the sibling inviting them to participate (Appendix D). Families were then required to reply with their acceptance via phone or email. Once confirmed, families were then invited to participate in an interview with two facilitators to complete the pre-tests. Parental consent was obtained for siblings to participate in the SibworkS group as well as the research component to assess the program's effectiveness. Siblings completed the Strengths and Difficulties Questionnaire (SDQ) while parents completed the Parent Checklist (PCL). Siblings then met once a week for six weeks. In the last session, siblings completed feedback sheets and the SDQ again (post-tests). Parents were also invited to complete feedback and the PCL (post tests) in the last session.

### *Sibling Measurement*

Sibling relationships, emotions and behaviours can be operationalised in many ways. As there is no one tool directly related to measuring these aspects in siblings, the Strengths and Difficulties Questionnaire (SDQ) was used (Goodman, 1999). Mathai, Anderson and Bourne (2002) found that the SDQ was sensitive to detecting emotional and behavioural problems in children and adolescence and was therefore relevant to the sample tested in this study. The validity and reliability of the SDQ also make it a useful tool to measure adjustment and well-being (Goodman, 2001). The Cronbach's

Alpha level (reliability) for the SDQ pre-test was 0.44 and post-test was 0.28, which is extremely poor; this however could be explained by the size of the sample group.

The SDQ consists of 25 items which are rated on a three point scale ('not true', 'kind of true' and 'very true') and are divided into five scales; hyperactivity/inattention, emotional symptoms, conduct problems, peer relationship problems and prosocial behaviours. For each scale, scores can range from zero to 10 with a total *difficulties* score ranging from zero to 40, derived from adding all scales except for prosocial behaviour, which is the *strength* score, ranging from zero to 10. The SDQ was administered pre and post participation in the group (see Appendix E for a copy of the SDQ).

#### *Parent Checklist*

The Parent Checklist (PCL) was developed to evaluate sibling adjustment and the parents' perceived understanding of the siblings' relationships, emotions and behaviours. Parents were required to complete the measure during the pre-test interview and again on completion of the group. The Cronbach's Alpha level (reliability) for the PCL pre-test was 0.61 and post-test was 0.81, which is high given the sample size. Further analysis of the data revealed three questions with significantly low correlations to the measure (questions two, eight and 11), which with further evaluation would increase the reliability of the tool further.

The Parent Checklist consists of 15 items which are rated on a 5 point scale (from '1=Not True' to '5=Very True'). Scores from each scale are then added to give a total sibling score ranging from 15 to 75 (see Appendix F for a copy of the PCL).

Parents were also asked to complete a survey at the end of the program which asked them to provide feedback on the group and identify any changes in their child. Parents were given the survey during the last session of the program and were asked to send it back to Siblings Australia via post.

## Results

### Sibling Measurement

The Strengths and Difficulties Questionnaire (SDQ) was used to measure sibling emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour. In most cases, high scores indicated high symptomatology, except for prosocial behaviour for which the opposite is correct. Emotional symptoms, conduct problems, hyperactivity and peer problems were summed to give a total difficulties score. Table 1 also indicates the normal, borderline and abnormal scores for results on the SDQ.

**Table 1**

*Descriptive Statistics and scoring for the Strengths and Difficulties Questionnaire*

Measure	Mean (SD)	Minimum	Maximum	Normal	Borderline	Abnormal
<i>Pre-Test</i>						
Emotional Symptoms	2.55 (1.64)	0	5	0-5	6	7-10
Conduct Problems	2.45 (1.44)	0	5	0-3	4	5-10
Hyperactivity	3.00 (2.37)	0	8	0-5	6	7-10
Peer Problems	3.18 (1.99)	0	7	0-3	4-5	6-10
Prosocial Behaviour	8.64 (1.03)	7	10	6-10	5	0-4
Total Difficulties	11.18 (4.4)	4	18	0-15	16-19	20-40
<i>Post-Test</i>						
Emotional Symptoms	2.6 (2.12)	0	5	0-5	6	7-10
Conduct Problems	2.0 (2.11)	0	7	0-3	4	5-10
Hyperactivity	2.5 (1.27)	0	4	0-5	6	7-10
Peer Problems	3.3 (1.42)	1	5	0-3	4-5	6-10
Prosocial Behaviour	8.6 (1.51)	6	10	6-10	5	0-4
Total Difficulties	10.40 (4.6)	3	19	0-15	16-19	20-40

*Note: High scores indicate increased difficulties, except for Prosocial Behaviour where high scores indicate increased strength scores*

As can be seen in Table 1, scores ranged slightly from pre to post tests, with the biggest differences appearing in the total difficulties and hyperactivity scores. Peer problem scores for pre (3.18) and post (3.3) were outside the 'normal' range. A number of individual borderline and abnormal scores were recorded, including conduct problems, hyperactivity and peer problems pre test and conduct and peer problems post test, however, most average scores fell between the normal range.

### Parent Checklist

The Parent Checklist (PCL) was used to measure sibling adjustment. High scores indicate greater adjustment. Whilst scores on the PCL improved slightly from pre to post testing as indicated in Table 2, these changes were not significant.

**Table 2**

*Descriptive Statistics for the Parent Checklist*

Parent Checklist	Mean (SD)	Minimum	Maximum
Pre-Test	52.3 (7.1)	45	69
Post-Test	55.8(8.94)	41	71

## Hypothesis Testing

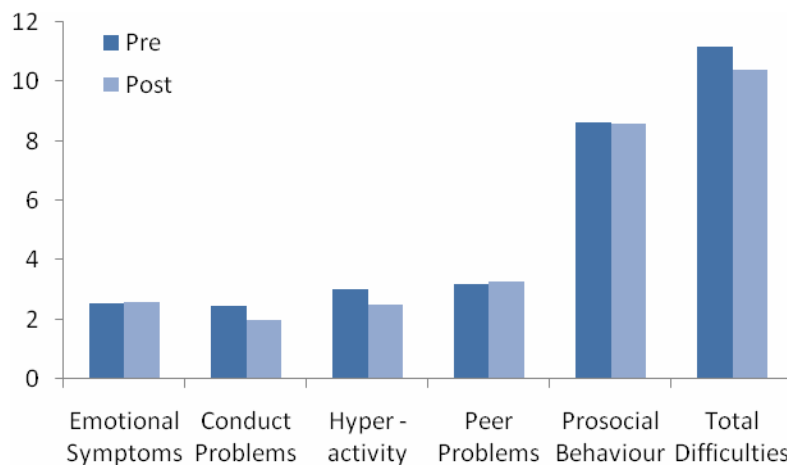
### **Hypothesis One:** Siblings would significantly increase their strengths and decrease their difficulties scores post completing the group

To investigate the effects of the SibworkS program, siblings completed the SDQ pre and post conclusion of the group. Paired Samples t-tests were used to compare scores and descriptive statistics are displayed above in Table 1.

No significant differences were found for any scores on the SDQ from pre to post testing. Although there was no significant differences in the total difficulties score,  $t=0.79$ ;  $df=9$ ;  $p=0.45$ , there was a small decrease in scores from pre to post.

**Figure 1**

*Strength and Difficulties Questionnaire Pre and Post Scores*



*Note: High scores indicate increased difficulties, except for Prosocial Behaviour where high scores indicate increased strength scores. Significant differences were found in Hyperactivity and Total Difficulties.*

### **Hypothesis Two:** Parents would report positive changes to sibling's behaviour towards their families (especially the child with special needs).

To investigate the effects of the SibworkS program, parents completed the PCL pre and post conclusion of the group. Paired Samples t-tests were used to compare scores and descriptive statistics are displayed above in Table 2.

There was a decrease in PCL scores from pre to post testing, this was however, not significant  $t=-2.107$   $df=9$   $p=.06$ .

## Post Hoc Testing

Further investigation into the relationship between the SDQ (total difficulties) and the PCL revealed no significant correlation pre test,  $r(11)=-.03$ ,  $p=0.93$  or post test  $r(9)=-.59$ ,  $p=0.09$ .

# Feedback

## Sibling Feedback

Ten out of the 11 participants completed the feedback form. Results varied, but the general response was positive towards the program. Above all, most children enjoyed the program and all children said they would recommend SibworkS to other siblings.

See Appendix G for more details.

## Parent Feedback

All parents completed the feedback form. Responses show that while most parents reported positive changes in their child and that the child gained enjoyment out of the group, over half of the parents reported that the child did not want to talk about the group with them or their family.

See Appendix H for more details.

## Facilitator Feedback

All facilitators completed feedback on the SibworkS program. Overwhelmingly, responses included the need for more training in behavioural management and more preparation at the beginning of the program about the roles and responsibilities of all involved.

See Appendix I for more details.

# Discussion

## Overview

Subjective reporting from the siblings and their families indicated improved understanding and behaviour as a result of the SibworkS group. This finding, however, was not supported in the data analysis. Limitations existed around the sample size of the study which therefore restricts the integrity of the data and the quality of the conclusions that can be drawn. However, as a pilot study for a program designed for siblings of children with special needs, the results allow for directions to be pursued and more thorough investigations to be made in the future.

## Strengths and Difficulties Questionnaire

It was hypothesised that siblings would experience positive changes in their strengths and difficulties after completing the SibworkS program. Although there were no significant results found, there was a decrease in *total difficulties* post completion of the program, which supports the original prediction. The sensitivity of the Strengths and Difficulties Questionnaire (SDQ), specifically the tool's ability to identify subtle changes in responses around sibling issues is problematic. The changes in sibling behaviour should also include changes to their understanding of their siblings' special needs and this was not assessed using the SDQ. It would be suggested that if the SDQ was used in future as an assessment tool for a sibling program, that it be adapted slightly to allow specific sibling issues to be assessed.

Honesty and concentration from the children is important when assessing siblings and the post evaluation setting may not have been ideal in that facilitators assessed siblings during the last group. Although it was a private conversation, there were a number of distractions that may have reduced the integrity of participants' answers. Also, siblings are well versed at hiding problems and acting in a way that will not create issues within the family environment, so honesty around these sorts of concepts will always be a dilemma.

## Parent Checklist

Overall, the results indicated that parents saw improvement in their children. For the most part, parents indicated positive changes in their subjective feedback to the program but this, however, was not reflected in the results for the Parent Checklist (PCL). Again, with a larger sample size, the results might be vastly different. The PCL itself requires further development, with investigations into specific questions (as suggested in the methods section) in order to increase the reliability of the assessment tool. These initial results are encouraging and spark interest for further research in this area.

## Future Directions

Whilst inroads were made in the initial assessment of SibworkS, more research is necessary to qualitatively evaluate the program. As this was the first time the program was run by Siblings Australia, elements to the induction procedures (both for facilitators and for families) need to be reviewed. More information around the social, emotional and behavioural skills of the children from their parents needs to be gathered during the screening process in order to evaluate whether a

group therapy situation will be suitable for each individual. This particular group displayed a number of difficult behavioural problems that, with a more stringent screening process in place, may not have been suitable for the group. This screening process would lead to clearer guidelines on which siblings may be more suitable for the program and in turn gain more benefit. More information about behavioural management and a formal induction procedure also needs to be implemented for facilitators.

It is also clear that further modifications need to be made on the current assessment tools, not only to make them more relevant (for example, provide a specific sibling section in the SDQ), but to increase the correlations between the two. An increased correlation between the tools would indicate a stronger linear relationship between the two variables being measured (siblings and parents).

Feedback and responses from parents and facilitators have suggested improvements to the program and together with a more sensitive and concise sibling and parent measure (and possibly a satisfaction measure), further studies could evaluate SibworkS more thoroughly.

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## Appendices

<i>Appendix A</i>	SibworkS Advertisement
<i>Appendix B</i>	Auseinet Alert: 28 <sup>th</sup> June 2007
<i>Appendix C</i>	Parent Introduction Letter
<i>Appendix D</i>	Sibling Introduction Letter
<i>Appendix E</i>	Strengths and Difficulties Questionnaire (SDQ)
<i>Appendix F</i>	Parent Checklist (PCL)
<i>Appendix G</i>	Sibling Feedback Overview
<i>Appendix H</i>	Parent Feedback Overview
<i>Appendix I</i>	Facilitator Feedback Overview

## Appendix A - Sibworks Advertisement

# Sibworks

groups for siblings of children with special needs

Are you a sibling of someone with special needs?  
Are between 8 and 12 years old?  
Do you want to have some **FUN**?

If you have said YES! to all of the questions above, then we want to hear from you! *Sibworks* is a place where you can come and share with other siblings of kids with special needs. Siblings Australia will be running *Sibworks* groups throughout Term 3. The groups will be held after school, and will include FUN, FOOD and FANTASTIC NEW FRIENDS!

Please call Jade on 83618361 or email [jade@siblingsaustralia.org.au](mailto:jade@siblingsaustralia.org.au) if you



**Siblings**  
AUSTRALIA INC

Level 1  
77 King William Rd  
North Adelaide SA 5006

p (08) 8361 8361  
e [info@siblingsaustralia.org.au](mailto:info@siblingsaustralia.org.au)



## Appendix B - Auseinet Alert: 28th June 2007

<http://www.auseinet.com/stateinfo/wotru/index.php?loc=SA#3>

### SibworkS: For siblings of kids with special needs

SibworkS are groups for siblings of children with special needs. The program was developed and written by Kate Strohm (Executive Director, Siblings Australia) and Dr Monique Nesa (Curtin University, WA).

At this stage, we will be running one program for 8-12 year olds at Fullarton Park Community Centre starting on Tuesday 21st of August. The program will run for 6 weeks – every Tuesday at 4-6pm.

We envision running more programs all over Adelaide in 2008, both for 8-12 year olds and for teens, so if you are unable to make it to this group please call and register your details for programs next year.

*Address:*

Level 1

77 King William Rd

North Adelaide, SA 5006

Phone: 08 8361 8361

Email: [info@siblingsaustralia.org.au](mailto:info@siblingsaustralia.org.au)

Website: <http://www.siblingsaustralia.org.au>

## Appendix C – Parent Introduction Letter

[Name]  
[Address]  
[Suburb] [SA] [PC]

[Date]

Dear [Name],

Thank you for signing up for the upcoming *Sibworks* program.

The program will run from 4-6pm every Tuesday over 6 weeks at the Fullarton Park Community Centre (411 Fullarton Rd, Fullarton). The dates are:

1. Tuesday 21<sup>st</sup> August
2. Tuesday 28<sup>th</sup> August
3. Tuesday 4<sup>th</sup> September
4. Tuesday 11<sup>th</sup> September
5. Tuesday 18<sup>th</sup> September
6. Tuesday 25<sup>th</sup> September

These weeks coincide with the last 6 weeks of Term 3 of the school year. Siblings Australia staff will be onsite from 3:30pm, so if you need to drop your child off straight after school, there will be someone present.

Each *Sibworks* session includes a parent information session. We are still exploring the best way to implement these sessions, but at this stage what we propose is that it will commence at 5:40pm and go for approximately 15-20 minutes. It will include a review of the day's activities as well as opportunities for you to ask any questions or queries. It is important parents participate in this session as it will enable you to offer increased support for your child and family. If coming along to these sessions are going to be an issue (i.e., childcare etc), please let us know when you ring in to book in your interview and we will be able to organise something else.

Before we start the program, we would like to invite you and your child in for an interview. This interview will be used to complete the registration forms, provide further program information and complete a small pre-program questionnaire. Times are fairly flexible, so can you please have a look at the schedule of times then phone the office to confirm your session.

### Proposed Times

<i>Week Starting:</i>	<i>6th Aug</i>	<i>13th Aug</i>
<i>Monday</i>	3:30-5pm	3:30-5pm
<i>Tuesday</i>	3:30-5:30pm	3:30-5:30pm
<i>Wednesday</i>	3:30-5pm	3:30-5pm
<i>Thursday</i>	3:30-5:30pm	3:30-5:30pm

*\* Please allow 1 hour for your session.*

We will be following up this letter with a phone call if you have not booked in your interview by Friday 17<sup>th</sup> July. We look forward to hearing from you soon.

Regards,

Jade Keightley  
*Sibworks* Facilitator

## Appendix D – Sibling Introduction Letter

[Name]

[Address]

[Suburb], [SA] [PC]

[Date]

Hi [Name]!



My name is Jade and I work for Siblings Australia.

I'm really excited to invite you along to our fun after-school program that will run during Term 3. You are one of only 12 lucky kids to be invited along!



This program was created just for you! We think you are very special and we would like to get to know you and your family a bit better.



The program will run on Tuesday afternoons for 6 weeks and we will do things like play games, make crafts and you will be able to spend time with other kids who have a brother or sister with special needs.

If you would like to come along, please give me a call on 83618361 or email me at [jade@siblingsaustralia.org.au](mailto:jade@siblingsaustralia.org.au).

I can't WAIT to hear from you!!!



Jade Keightley

## Appendix E – Strengths and Difficulties Questionnaire (SDQ)

For each item, please answer each question by marking the box with either **Not True**, **Somewhat True** or **Certainly True**. It would help us if you answered all the items as best you can even if you are not absolutely certain. Please give your answers on the bases of how things have been for you **over the last 3 months**.

Your Name: \_\_\_\_\_

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Male/Female

	Not True	Kind of True	Definitely True
I try to be nice to other people, I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others, for example CDs, games, food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would rather be alone than with other people my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people to what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, depressed or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on my or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get along better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

## Appendix F – Parent Checklist (PCL)

For each item, please answer each question by circling the number which is **most right for you**. It would help us if you answered all the items as best you can even if you are not absolutely certain. Please give your answers on the bases of how things have been for your son/daughter in **the past 3 months**.

	Not True	2	3	4	Very True
Understands brother/sister's special needs	1	2	3	4	5
Responds appropriately to questions about brother/sister	1	2	3	4	5
Express a range of feelings towards and about brother/sister	1	2	3	4	5
<b>Sometimes</b> chooses to include brother/sister in family or friend activities	1	2	3	4	5
Does not take on too much responsibility	1	2	3	4	5
Is not the 'good child' all the time	1	2	3	4	5
Free from ongoing physical complaints (eg stomach or headaches)	1	2	3	4	5
Free from sleeping problems	1	2	3	4	5
Does not show anxiety or seem withdrawn	1	2	3	4	5
Does not show behavioural problems	1	2	3	4	5
Spends time with parents alone	1	2	3	4	5
Has contact with other siblings	1	2	3	4	5
Involved in activities outside home, has friends	1	2	3	4	5
Enjoys school; progresses well at school	1	2	3	4	5
Invites friends over to your house	1	2	3	4	5

*Thank you.*

## Appendix G - Sibling Feedback Overview

### 1. Circle the face, or draw your own, that shows how you feel about today's group

Happy	8
Indifferent	1
Sad	1
Other	

### 2. Circle the face, or draw your own, that shows how you feel about the group

Happy	6
Indifferent	3
Sad	
Other – cheeky smile	1

### 3. What did you like about the group?

- Learning about how to deal with problems
- Games
- Craft
- Friendly people
- Liked games and making new friends
- I like working
- Everything
- Workers helped me understand
- Games, prizes and it was really fun

### 4. What did you not like about the group?

- Boring, sit for too long, too much work
- Nothing (x4)
- Distractions
- Doing the work, thought it would be more fun
- Some people talked when I was meant to
- Writing exercises, like problem solving

### 5. What did you learn?

- Most of the stuff I already know
- Learning about lots of things, learning about others and about how other people have a sib with special needs
- Quite a lot
- It's alright to have a sib
- To walk away and ignore my brother with special needs
- We learnt what special needs are
- How to control feelings and how others have different abilities and lots of others have brothers and sisters with special needs
- About disabilities
- Lots, how to cope with things
- I don't know

**6. What could have been different?**

- I don't know
- Would like to have done it on my own , without my sister
- Food, had cake and chippies
- No
- Nothing
- More fun to keep the kids active
- Brothers and sisters with special needs come, would like
- Making crafts every week, checklist for people to mark when arrive/leave, go to the toilet etc.
- We could to more fun games
- More art

**7. Would you like to come to another sibling group?**

Yes	7
No	2
Unsure	1

**8. Do you think other kids who have brothers and sisters with special needs would like to go to a group like this?**

- Yes, some.
- Yes, definitely
- Yes (x2)
- Yes, my friend would like it
- Yes, because it's a very good and fun group and you can learn lots from this group. Good and kind teachers.
- Yes, because they can play and do things with the group.
- Yes, because it's fun, get to do lots of things and learn heaps
- Yes, talking about siblings is a good thing
- Yes, because it's fun and they can spend time by themselves and with other kids who don't have special needs

**9. Is there anything else you want to say?**

- No (x3)
- Some kids can be mean, but we'll ignore that!

## Appendix H - Parent Feedback Overview

1. **Has your child talked about what happened at the sibling group?**
  - Not a lot, I have asked her, however she usually will not tell me much
  - Yes, they talked a bit. I think they talk to each other more than they talk to me
  - Yes, sort of. Not in great detail though, he mainly talked about what he ate
  - No (x2)
  - No, not really. I'd ask and she would say that it is a private matter
  - Yes, she has talked about other disabilities, things the other siblings do
  - Yes, talks about other kids
  - Yes, at the time
  - Yes, talked about the group when asked, did not volunteer much about the program
  
2. **Did they seem to enjoy the group?**
  - Sometimes, especially in the last 3 sessions, was really more happy about the program
  - Yes, they were always very refreshed and happy after the sessions, very kind and loving to each other and their siblings
  - No, but we think yes! We say no because that is what he was telling us but compared to other activities he truly did not enjoy it was almost that he didn't want to succumb to the fact he actually enjoyed going. He certainly seemed happy after the sessions
  - Yes, always looked forward to Tuesdays
  - Yes, loved the idea of meeting friends on Tuesdays.
  - Yes, she really looked forward to Tuesday evenings. Enjoyed filling in her sib work book
  - Yes, she talked about her friend, she really loved spending time with the adults in the group
  - Yes, loved the games. Did seem apprehensive one week about going? Challenged by talking
  - Yes
  - Yes, always happy when picked up
  
3. **Have you noticed any changes in your child (eg willingness to discuss feelings, interaction with their sibling etc)**
  - Yes, has talked about how she feels more especially after the 4<sup>th</sup> session. Continues to interact with her sibling
  - Yes, a few more questions, not a great deal of difference
  - Yes, before he did not seem to realise that his sibling was different because of his disability. A few times since we have seen him take a step back at times and really look at what is happening. He has shown more compassion to his sibling too
  - No (x3)
  - No, does not discuss any feelings and treats her sibling as she did before
  - Yes, she comments on her sib's moods – tells others why her sib does certain things – “That's [sib]'s Aspergers that makes him do that”
  - Yes, able to verbalise some of feelings toward sib and about special need
  - Yes and no, can discuss feelings when asked, but again, does not volunteer
  
4. **Would you like your child to participate in another sibling group sometime?**
  - Yes, I feel my daughter has absorbed a lot of information and it would be great to have a continuum of this and how things are progressing
  - Yes, meeting friends and lovely leaders who worked together was rewarding
  - Yes (x6)

- Yes, if we are around, don't know where we are shifting to next year
  - Yes, probably in a couple of years
- 5. Do you have any suggestions about how we could improve the groups in the future?**
- Discuss opening more about the content of the program. My daughter loves art and creativity to help her share her feelings
  - Although it all comes down to funding, having excursions type activities would be great
  - For children who have done a workshop previously, maybe more informal gatherings
  - I think in this case, to work in a smaller group in her age category. Not to have siblings together. May open up more!
  - Age, she felt a little old for the group she was in. She said she would have loved to talk to someone her age
  - Perhaps use a venue that the parents could have a coffee and chat
  - Group was great, I think she found it interesting hearing about sibling issues
- 6. Any other comments?**
- Perhaps make a group art project or do more art? I would be happy to pay extra for art of music or drama component. To get a list of contacts, so that siblings can stay in touch with each other, as my daughter likes to write letters to her friends instead of using email. Or perhaps have a milkshake group once a month for those who would like to catch up
  - We really appreciate the time that was put into the group and especially the acknowledgement of each sibling and their completely difference approach to the group. He REALLY benefitted from talking to Jade in the interview prior to the group
  - Giving permission to tell us about what the group was doing. I did not want to ask and when I did she would say it was a private matter

## Appendix I - Facilitator Feedback Overview

### What did you think of the Induction Process for SibworkS?

- I have some concerns that it did not highlight children who were not really suited to a group setting – maybe we need to do more re that aspect?
- I think that you were extremely organised in the induction that we had, but now having been a part of a group, I think that a full days training is important. As the main facilitator you need to know that your support staff are fully capable of dealing with most situations. I think that it would be beneficial to have training in the area of
  - behaviour management
  - running activities
  - the purpose and expected outcomes of SibworkS
  - group dynamic and working with children
- What was covered in the Induction process was important. However, behaviour management, and the six sessions should be covered in more detail, such as the activities and who will be responsible for leading the activity. The role of co-facilitators should be more clearly outlined. All facilitators (including co-facilitators) should meet the children and parents before the sessions begin

### Did you enjoy the groups?

- Yes
- I really liked being a part of a Team and seeing the subtle changes in the children. I was not sure what to expect so I had an advantage of being able to observe what happens rather than assume that it should 'be' a certain way. I learnt a lot and I am grateful for having the opportunity to participate
- Yes, I enjoyed the groups. I liked the children, and participating in the activities

### What were your highlights of the group?

- Certain children revealing their feelings about being a sib, the feelings session in general, 'Sib1' coming to some greater understanding of his brother, 'Sib2's' response to a firm approach, the connections between some of the children and the certificates and photos!
- 'Sib2' not rejecting me long term. Observing and learning from the children in the group – seeing how they accept other children's experiences and respond to their own. Learning about the sibling experiences and how the children view their experiences. Observing how you and Kate related to the children and kept to the program objectives. Learning about how to work with children in a group
- My highlights of SibworkS were meeting all the children, and watching the children have fun and learn more about their feelings about their brothers/sisters

### What did you find most challenging?

- Behaviour management of certain children
- Not knowing how to operate effectively during the groups. Unsure of my role? My thoughts about the fairness of some children's behaviour removing our attention from the rest of the group. Lack of resources. Making do! Facility not being large enough when we used the original room. I think that the noise level was disruptive to other people using the facility and the children were not able to freely move around. I found 'me' in the experience challenging
- Knowing my role as a co-facilitator, and managing some of the children's behaviour

**What do you think could have been done differently?**

- Maybe more careful selection process, some of the activities a bit too school-like (although I do think some of these would have worked much better with a different group of children), more fun activities
- Waiting to start the program time. Suggest that children know that it is free play and eat time and have enough staff on hand to start games etc. but then a definite point of session starting? Stress Management session. Not sure if children would use the meditation so if we are skilling children in stress management then we need to work out what suits the individual children so that there would be a greater chance of them using the tool.
- All facilitators (including co-facilitators) should meet the children and parents before the sessions begin; make sure the children want to participate in SibworkS before attending the sessions; if a child is thought to be overly disruptive or a bully they should not be allowed to attend the sessions (as they may spoil the sessions for the other children); and the consequences for bad behaviour should be followed. When outlining the 'expectations' and 'objectives' – maybe use language the children are more familiar with (such as 'rules' and 'goals').

**What, if anything, can you suggest as an improvement for the groups?**

- Most definitely ensure that the facility is suitable. To me this is crucial otherwise we create unnecessary barriers for the sake of (in my opinion) minimal amount of money. I know that we work on a budget but cut the expenses in some other area – the important factor to me is the experience that the children leave with and the facility impacts on this
- Have an even number of children participant (eg 12) and even number of each gender (eg 6 boys and 6 girls). Focus more on exploring feelings and allowing children to ask questions about their brother/sister's disabilities (as these activities worked well). Also, include more games as all the children enjoyed these and some do not get much of an opportunity to play games with other kids their age

**Did you find the 'de-brief' at the end of the sessions useful?**

- Yes
- I loved it as I was able to express my thoughts but then see the same situation from another person's perspective. It also gave me a sense of being an equal member of a team – I felt included and listened to regardless of if I was 'right' or 'wrong' in my view. Note: Well done to you and Kate as this is not easy to achieve
- Yes, the 'de-brief' at the end of the sessions were useful; as it gave the facilitators a chance to reflect on each session, and offer their different perspectives/thoughts/feelings about the children and sessions. Furthermore, the 'de-brief' highlighted the changes the children made over the course of the six sessions

**Would you like to participate in another group?**

- Yes
- If I can, I would be honoured to be a part of it
- Yes, I thought the overall program (SibworkS) was excellent, and would like to participate in future groups