

## Evaluation of a Family-Based Program to Support Siblings & Parents of Children with a Disability or Chronic Illness

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## Overview

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- Aims of the Pilot Study
- Background & Rationale for supporting siblings
- The SIBSTARS Program
- Method
- Results
- Implications

## Aims of the Pilot Study

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- To develop and evaluate the effectiveness of a family-based program, SIBSTARS, for siblings and parents of children with a disability or chronic illness.

## Why support siblings?

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- 8% of children (<14yrs) have a physical, sensory, intellectual, emotional or behavioural disability or health condition (ABS, 2004).
- 4% of children - significant impact on their daily functioning, communication, mobility and self-care, or learning abilities (ABS, 2004).
- Living and caring for a person with a disability or illness can have an impact on the whole family system
- Siblings may grow up in stressful family environments

## Experiences of Siblings

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(Giallo & Gavidia-Payne, 2003)

- Worries & Concerns about parents
  - 'Mum made me worry a bit today. She was not well, & I was worried about how she would get on with the kids. I didn't want to leave her. I didn't want to go to school' (Female, 16 y.o)
- Interruption to daily activities
  - 'Usually when I am trying to watch TV, talk to mum or trying to do anything, he makes constant noises, blows raspberries, ... it can get annoying' (Female, 13 y.o).

## Experiences of Siblings

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(Giallo & Gavidia-Payne, 2003)

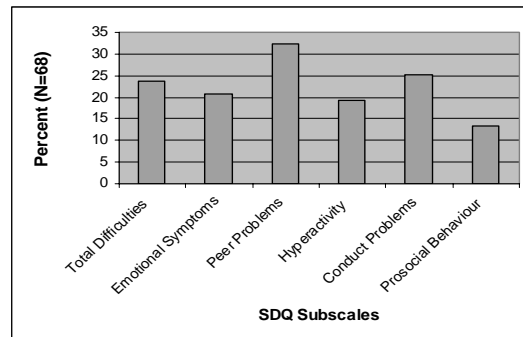
- Restrictions on sibling behaviour to pacify the child with a disability
  - M. decided to chase me around the house hitting me, because I turned the volume down on the TV. I often feel like I can't do what I want to do. I have a limit about what I can do without upsetting M'. (16 y.o. female).
- Incidents involving others
  - When I found out M was autistic I lost all my friends, they didn't know how to support me.' (Female, 16 y.o).

## Sibling Adjustment Problems

- Depression
- Anxiety and Worries
- Behaviour difficulties
- Health complaints
- Over-sensitivity to conflict in the family
- Poor family relationships
- Poor functioning at school
- Poor peer relationships

(Brosseau, Woltzman & Morsberger, 1981; Brosseau & Prubucki, 1987; Cadman, et al., 1988; Cuskelly & Gurn, 1993; Deal & MacLean, 1995; Farrari, 1984; Faxe, 1993; Giamble & McHale, 1989; Haverman & Eisler, 1994; Janus & Goldberg, 1995; Labato, et al., 1987; McHale & Harris, 1992; McHale & Pawlko, 1992; Newachock & Taylor, 1992; Roe & Plummer, 1987; Skopir & White, 1996; Spinetta & Deasy Spinetta, 1981).

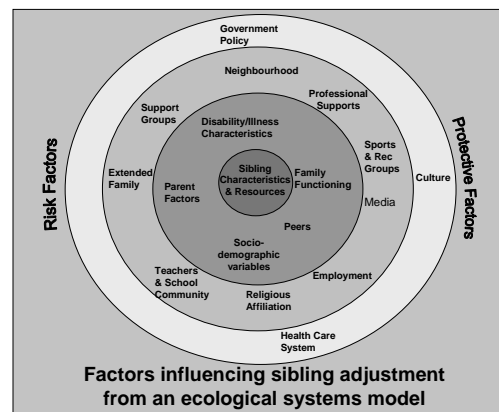
**% of siblings with difficulties in the at risk and clinical ranges**  
(Giallo & Gavidia-Payne, 2004)



## Positive Outcomes for Siblings

- Increased empathy, compassion & tolerance
- Better social competence & prosocial skills than peers
- Increased support & acceptance in the sibling relationship.
- Positive family interactions

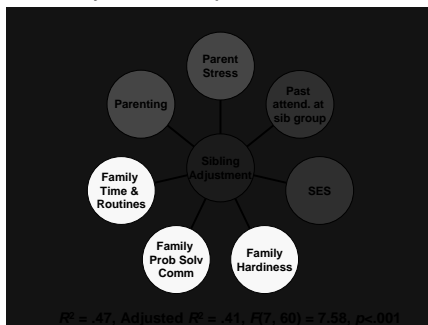
(Abramovitch, et al., 1987; Farrari, 1984; Fineman Kramer, 1984; Horvitz & Kazar, 1990; Havermans & Eisler, 1994; McHale et al., 1986; Stoneman, Brody, Davis & Crapps, 1989)



## Predictors of Sibling Adjustment

(Giallo & Gavidia-Payne, 2004)

- Parent & family factors are important determinants of sib adjustment



## Addressing Parenting Concerns

(Giallo & Gavidia-Payne, 2004)

- Sibling behaviour and adjustment issues
- Impact of lack of parental time and attention on siblings
- How to talk to siblings about disability/illness
- Dealing with sibling relationship problems
- Dealing with sibling embarrassment
- Dealing with interruptions to family life and inability to do other things families do
- Dealing with hospitalisations

## Aims of SIBSTARS

- To assist both parents and siblings develop and strengthen their coping skills to deal with daily stress encountered in the family environment.
- To assist parents to develop and strengthen their coping and parenting skills that will enable them to provide support to siblings and other members of the family.
- To assist families to work together as a team to support one another by strengthening their communication and problem-solving skills.

## SIBSTARS

- 6-7 week program
- Pre-program interview & assessment
- Written information (5 booklets each for parents & siblings)
- Practice activities
- Weekly telephone support
- Post-program interview & assessment
- 3 month follow-up

## Sibling Booklets



## Parent Booklets

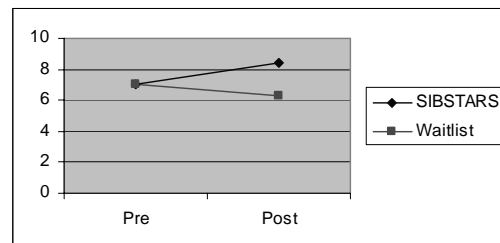


## Method

- SIBSTARS (n=8)
- Waitlist Control (n=7)
- Siblings:
  - 9-16 years (M=12 yrs, SD = 2.48)
  - Female (n=10); Male (n=5)
  - Older than child with disability/illness (n=11); Younger (n=4)
  - 66.7% - Received sibling support in the past
- Parents:
  - All biological mothers
  - Age: 42.93 years (SD=6.42)
- Disability/Illness Characteristics
  - Range of disabilities and illnesses (e.g., Down syndrome, autism, ADHD, Cystic Fibrosis, Heart disorders, Cerebral Palsy, Williams Syndrome, Poly Micro Gyria)
- Age of child with disability M=10.48 (SD=3.54)
- Family Structure:
  - All from English speaking backgrounds
  - Single-parent families (n=1)
  - Mean number of children in family = 2.6

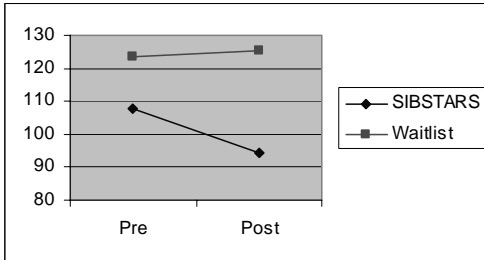
## Preliminary Results: Sibling Adjustment

- Pro-social Behaviour
  - Significant improvement for the intervention group compared to the waitlist control,  $F(1,12) = 7.47, p = .018, \eta^2 = .384$



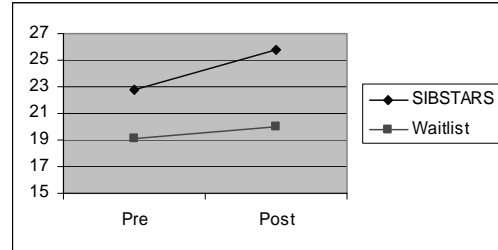
## Sibling Daily Events

- **Sibling Daily Hassles – Intensity**
  - Significant decrease in the perceived intensity of daily stress for intervention group compared to waitlist control  $F(1, 12) = 5.833$ ,  $p=.033$ ,  $\eta^2 = .327$ .



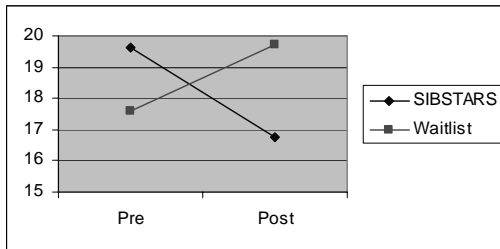
## Sibling Coping

- **Social Support**
  - Significant increase in the use of social support coping for intervention group compared to waitlist control,  $F(1,12) = 5.553$ ,  $p=.036$ ,  $\eta^2 = .316$



## Sibling Coping

- **Distancing**
  - Significant decrease in distancing as a way of coping for intervention group compared to waitlist control,  $F(1,12) = 6.811$ ,  $p=.023$ ,  $\eta^2 = .362$

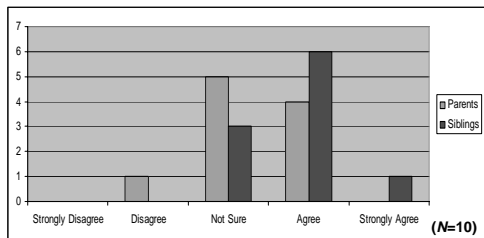


## Parent and Family Functioning

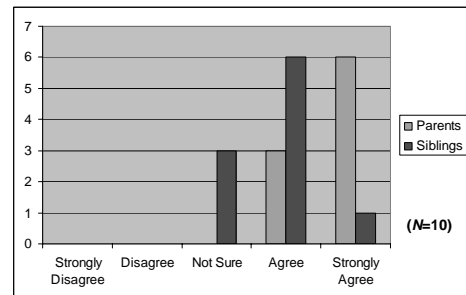
- **No significant effects emerging as of yet.**
- **Parent and family functioning outcomes difficult to change in short-term interventions**

## Participant Satisfaction

Satisfaction ratings pertaining to the usefulness of the life skills and strategies taught



## Would you recommend SIBSTARS to other families?



## Parent Comments

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- 'We received valuable information and also refreshed and renewed our memories on lots of coping skills with problem behaviour and communicating as a family. I would recommend this project to all families with a child with a disability and also to 'normal/ordinary families'.
- I think that telephone format is particularly non-confronting and builds up rapport over the time of the program. Very relaxed.
- It was great to participate in this program. I gained a lot of different ways to deal with my family.
- 'I felt the program benefited the sibling involved. She like the phone conversations and readily worked through the books. There was little new in it for me as a parent but it reminded me to use certain strategies. Most of our problems and stresses are still the same, and rather too complex for a program like this to really impact upon.'

## Sibling Comments

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- I was hoping to meet other siblings and I was disappointed on that. But other than that it was alright (Female, 9 yrs)
- SIBSTARS is great and I can't think of any changes as the program is fantastic and helpful (Female, 16 yrs)
- Have a three way conversation with SIBSTARS, parent(s) and kid(s) at the beginning, middle and end to see how much progress we make. About 2 weeks after finishing SIBSTARS phone and see how far they get (Female, 12 yrs)
- I do not think that anything needed to be changed. I found the program helped me through a lot of problems in life (Female, 11 yrs).

## Conclusions & Future Directions

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- Promising findings despite small sample sizes
- SIBSTARS appears to have the greatest impact on sibling functioning (e.g., Prosocial Behaviour, Daily Hassles – Intensity, Social Support and Distancing Coping)
- Results of pilot study inform continued program development and implementation of SIBSTARS
- Promising alternative form of sibling support - particularly for families who:
  - Require more support than can be offered by sibling support groups
  - Find it difficult to attend sibling support groups or parent information sessions due to a range of factors
  - Live in rural or remote areas

## Contact Details

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