

# 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

(Giallo & Gavidia-Payne, 2003)

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- **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)
- **Non-compliance, aggression, tantrumming, or other refusal behaviour from child with disability or illness**
- **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

(Giallo & Gavidia-Payne, 2003)

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- **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).*
- **When child with disability or illness is hurt or sick**
- **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

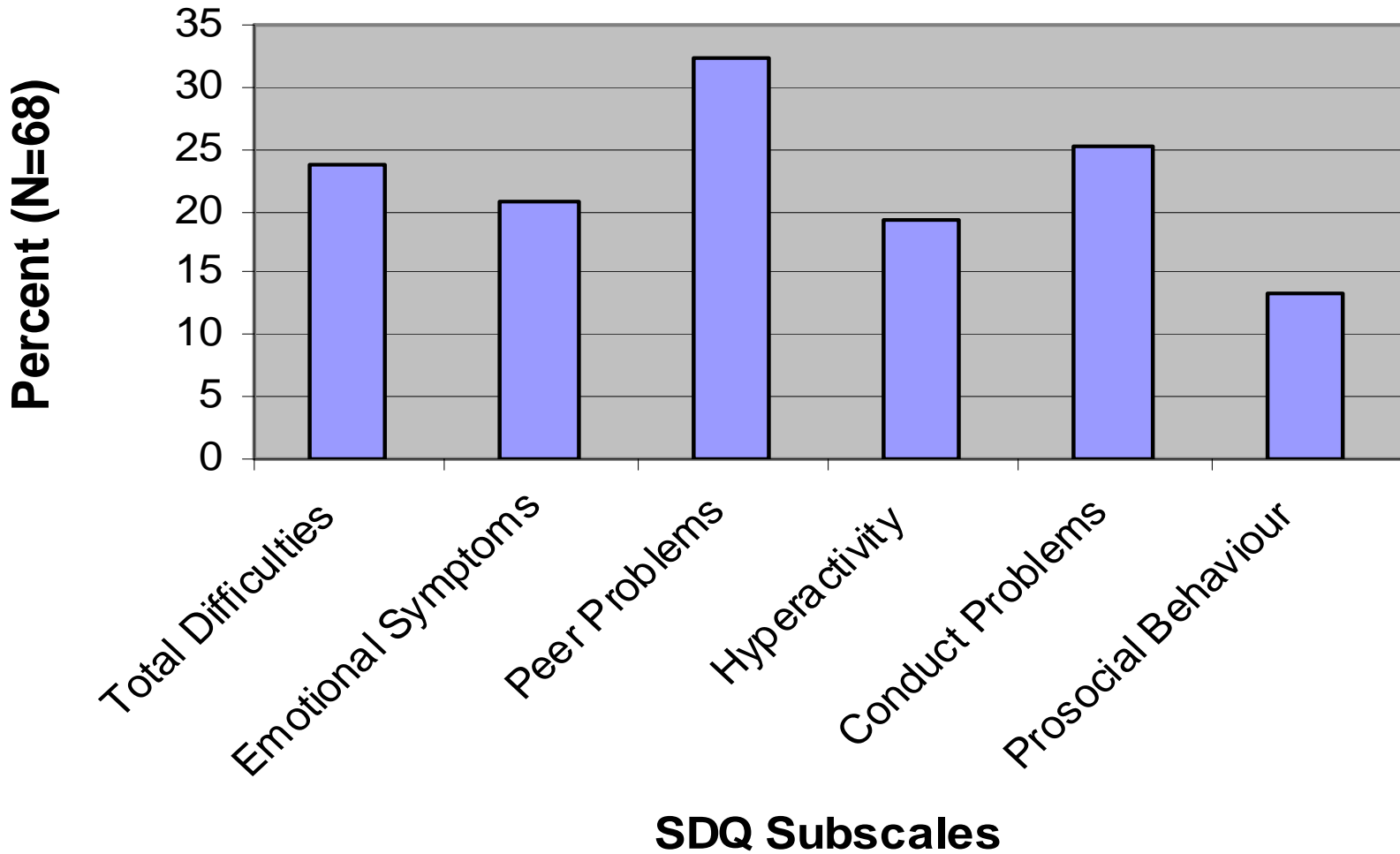
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- **Depression**
- **Anxiety and Worries**
- **Behaviour difficulties**
- **Health complaints**
- **Over-sensitivity to conflict in the family**
- **Poor family relationships**
- **Poor functioning at school**
- **Poor peer relationships**

(Breslau, Weitzman & Messenger, 1981; Breslau & Prabucki, 1987; Cadman, et al., 1988; Cuskelly & Gunn, 1993; Deal & MacLean, 1995; Ferrari, 1984; Faux, 1993; Gamble & McHale, 1989; Haverman & Eiser, 1994; Janus & Goldberg, 1995; Lobato, et al., 1987; McHale & Harris, 1992; McHale & Pawletko, 1992; Newacheck & Taylor, 1992; Roe & Plummer, 1987; Sloper & White, 1996; Spinetta & Deasy Spinetta, 1981).

# % of siblings with difficulties in the at risk and clinical ranges

(Giallo & Gavidia-Payne, 2004)

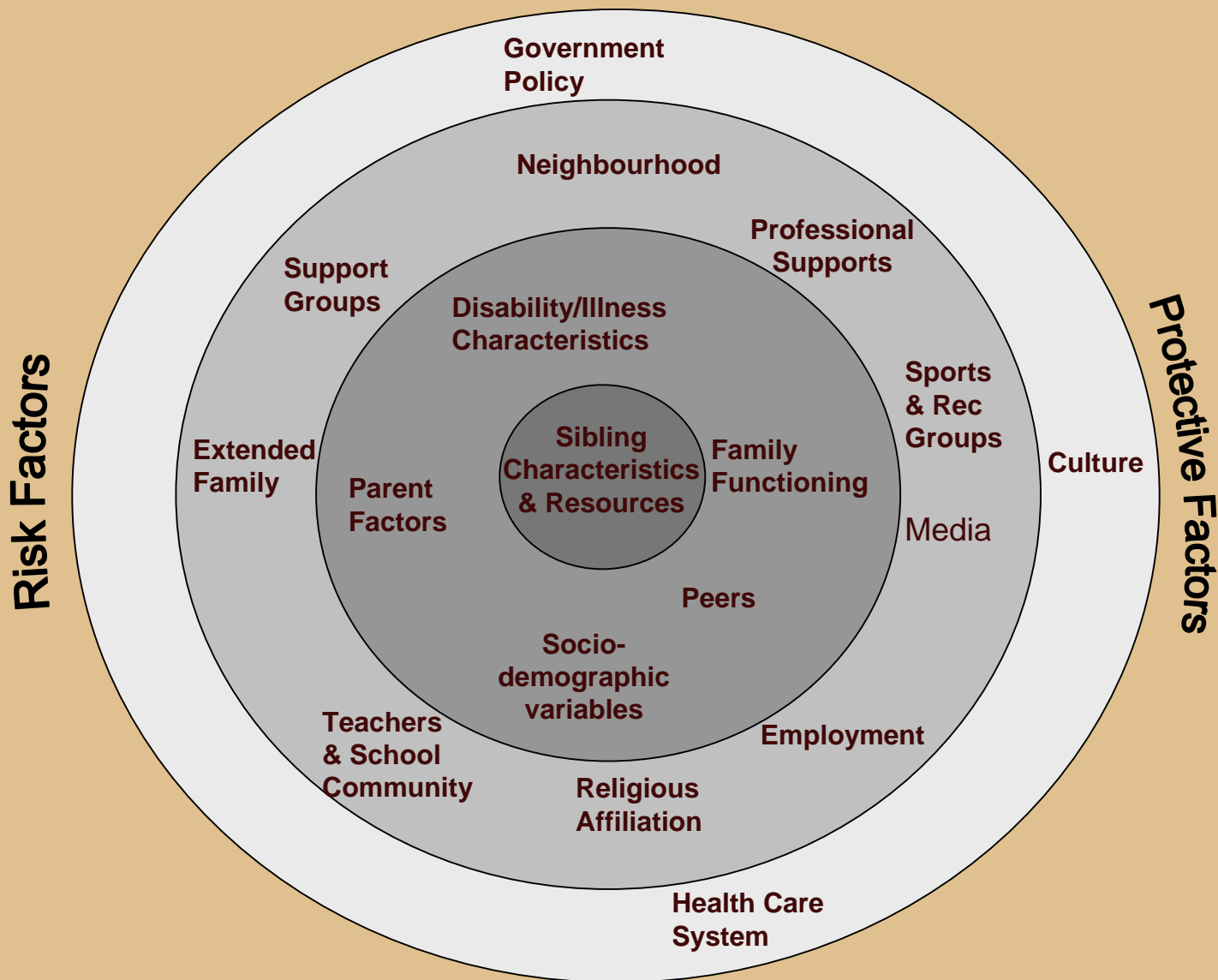


# Positive Outcomes for Siblings

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- **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; Ferrari, 1984; Fireman Kramer, 1984; Horwitz & Kazar, 1990; Havermans & Eiser, 1994; McHale et al., 1986; Stoneman, Brody, Davis & Crapps, 1989)

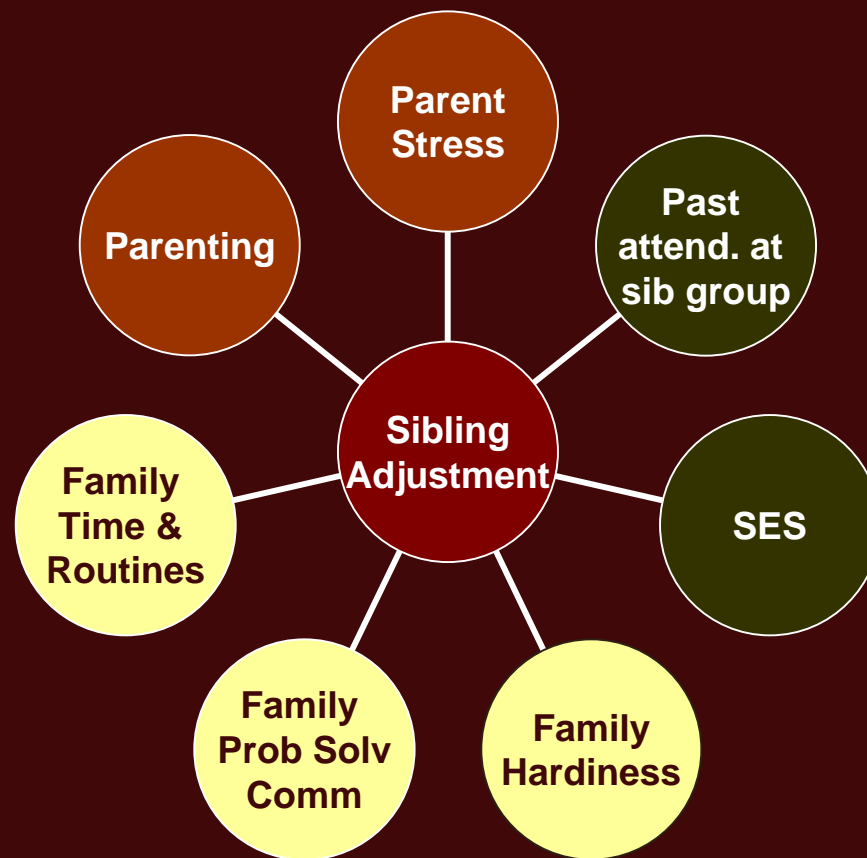


**Factors influencing sibling adjustment from an ecological systems model**

# Predictors of Sibling Adjustment

(Giallo & Gavidia-Payne, 2004)

- Parent & family factors are important determinants of sib adjustment



$R^2 = .47$ , Adjusted  $R^2 = .41$ ,  $F(7, 60) = 7.58$ ,  $p < .001$

# Addressing Parenting Concerns

(Giallo & Gavidia-Payne, 2004)

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- **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

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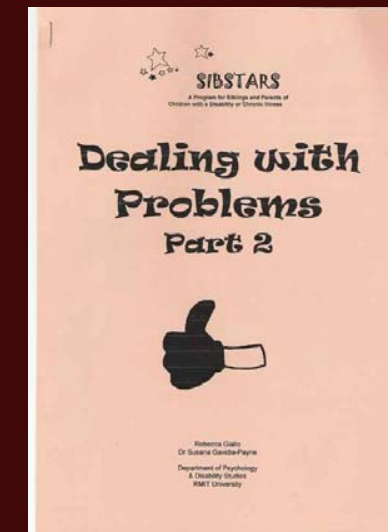
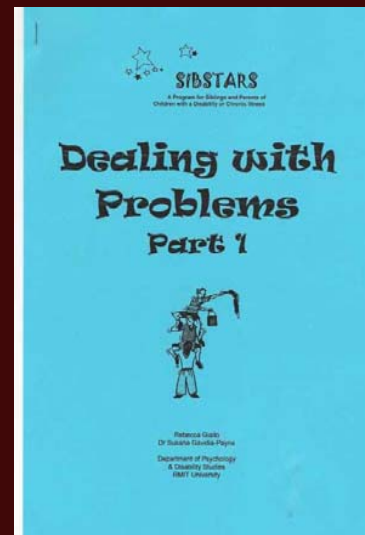
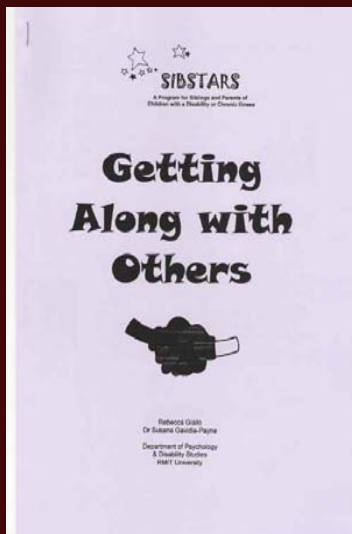
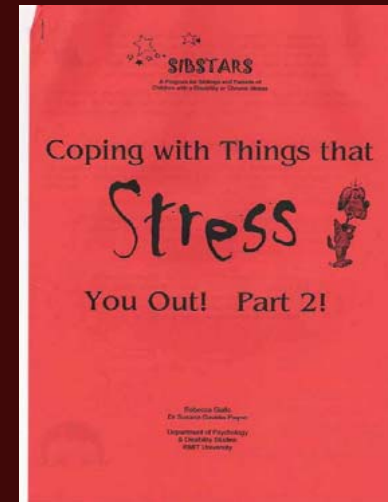
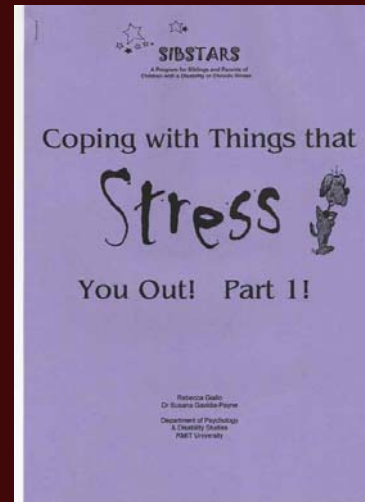
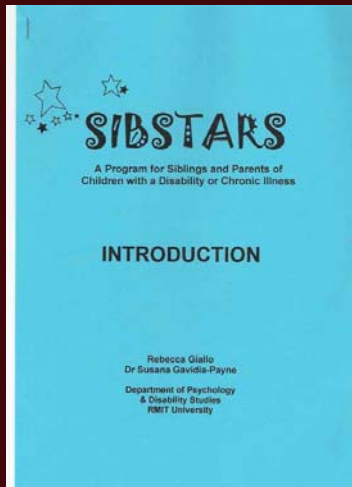
- **To assist both parents and siblings develop and strengthen their coping skills to deal with daily stress encountered in the family environment.**
- **To assist parents to develop and strengthen their coping and parenting skills that will enable them to provide support to siblings and other members 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

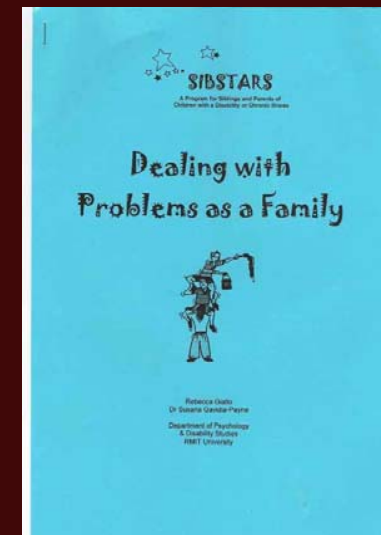
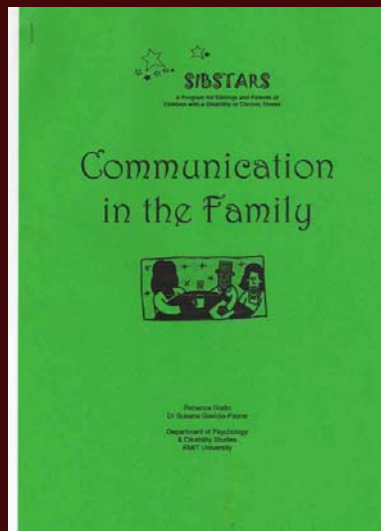
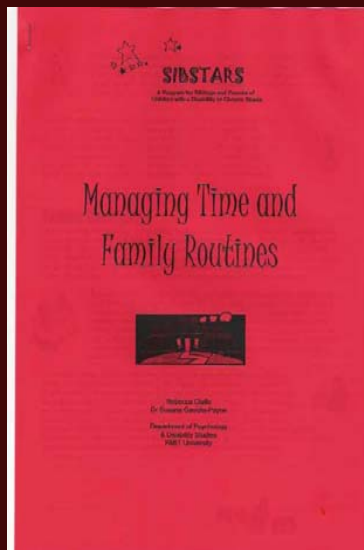
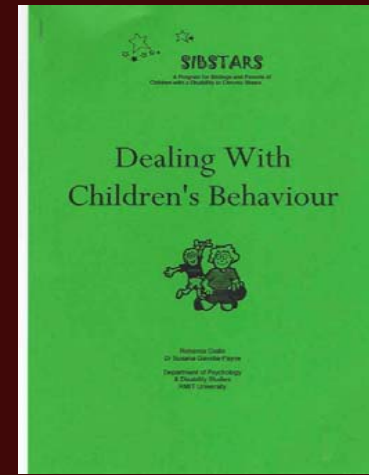
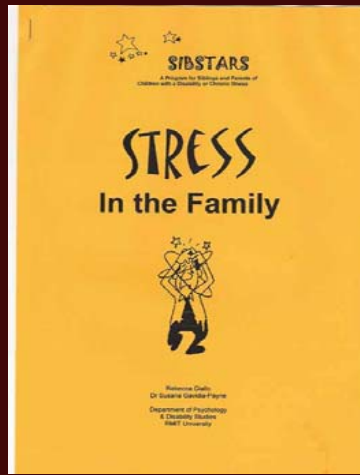
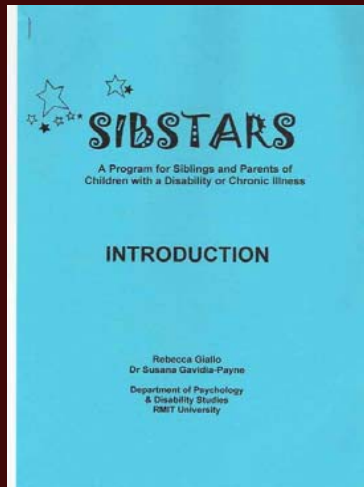
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- **6-7 week program**
- **Pre-program interview & assessment**
- **Written information (5 booklets each for parents & siblings)**
- **Practice activities**
- **Weekly telephone support**
- **Post-program interview & assessment**
- **3 month follow-up**

# Sibling Booklets



# Parent Booklets



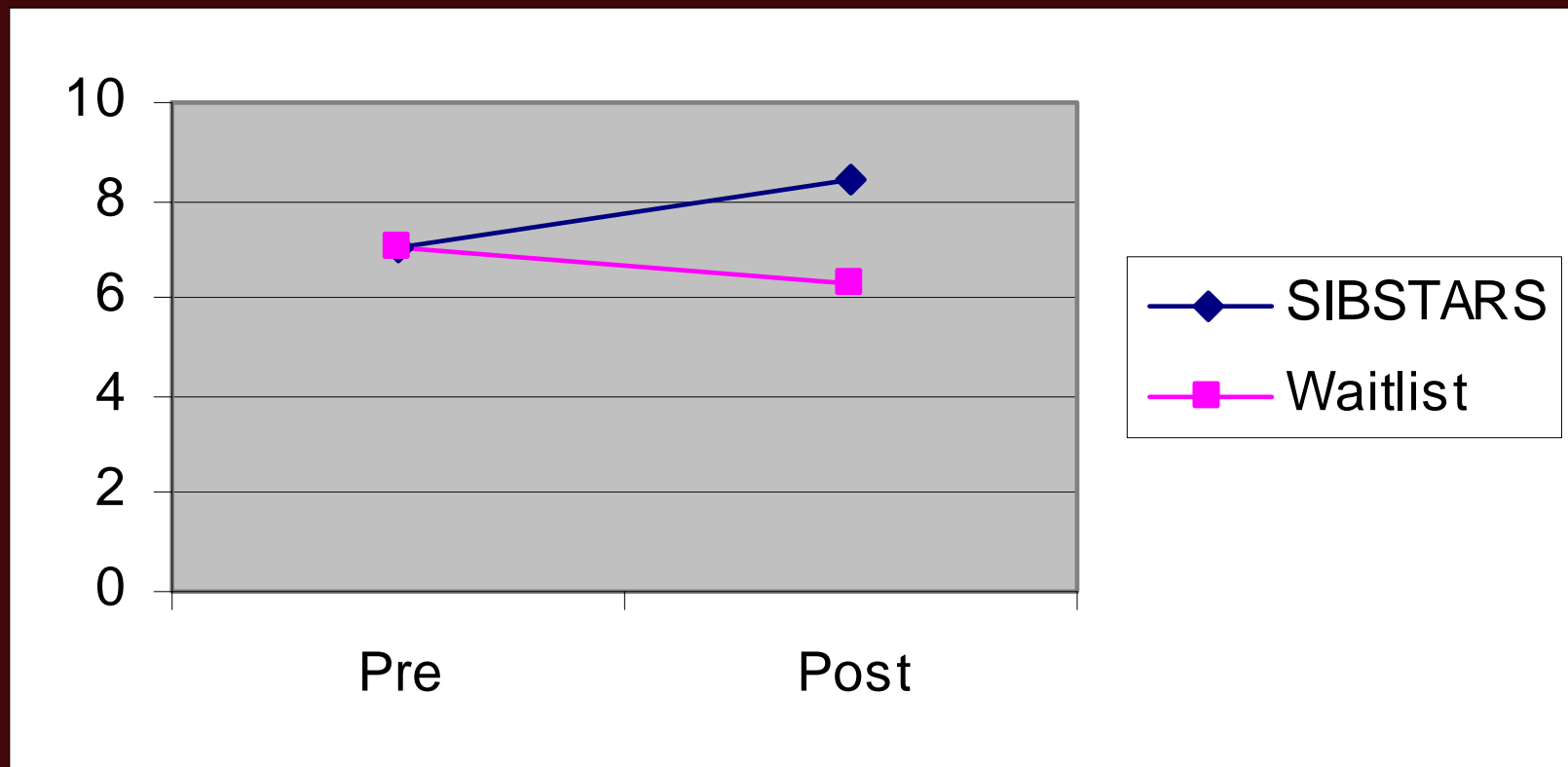
# Method

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- **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

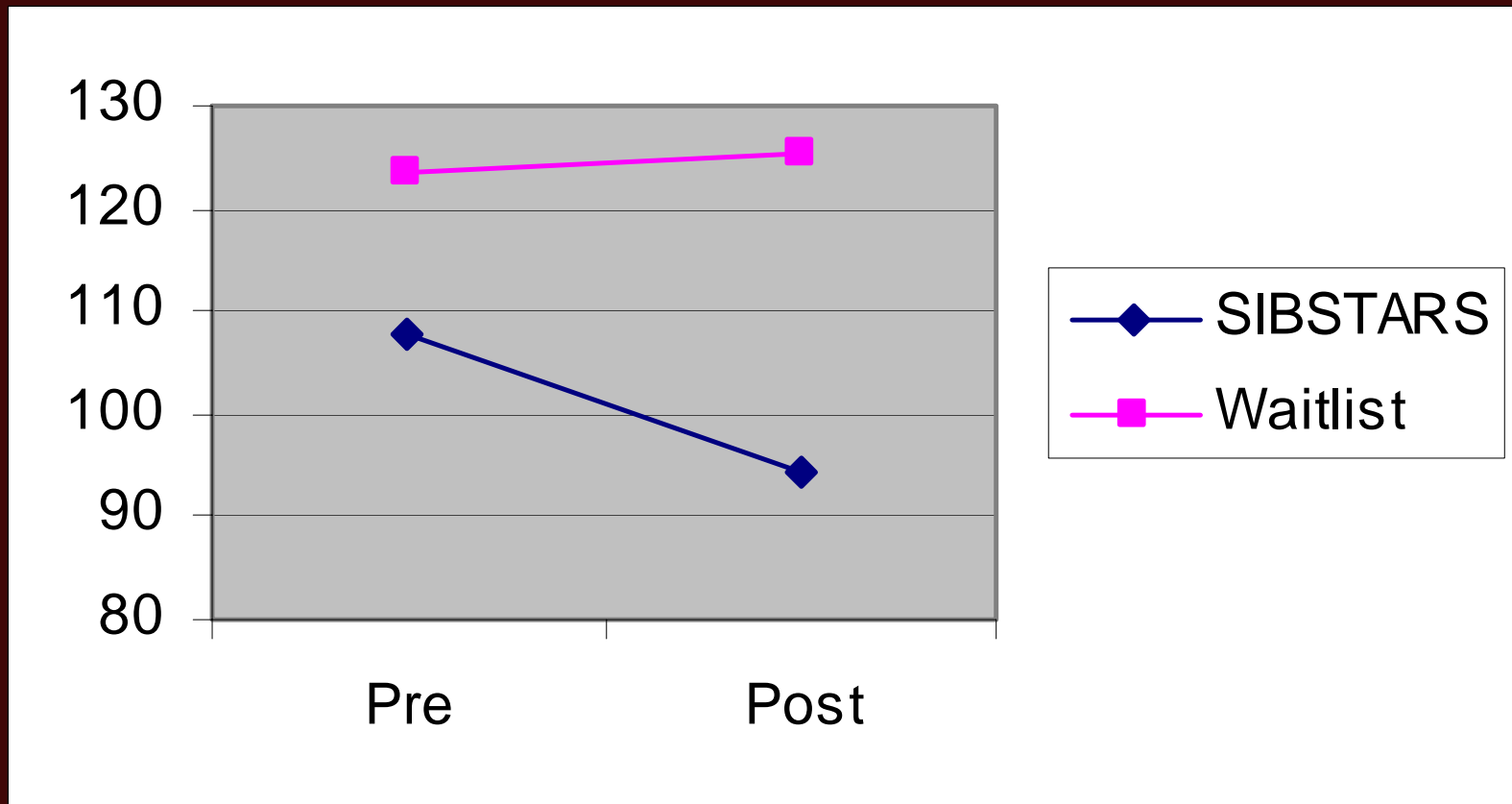
# Preliminary Results: Sibling Adjustment

- 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

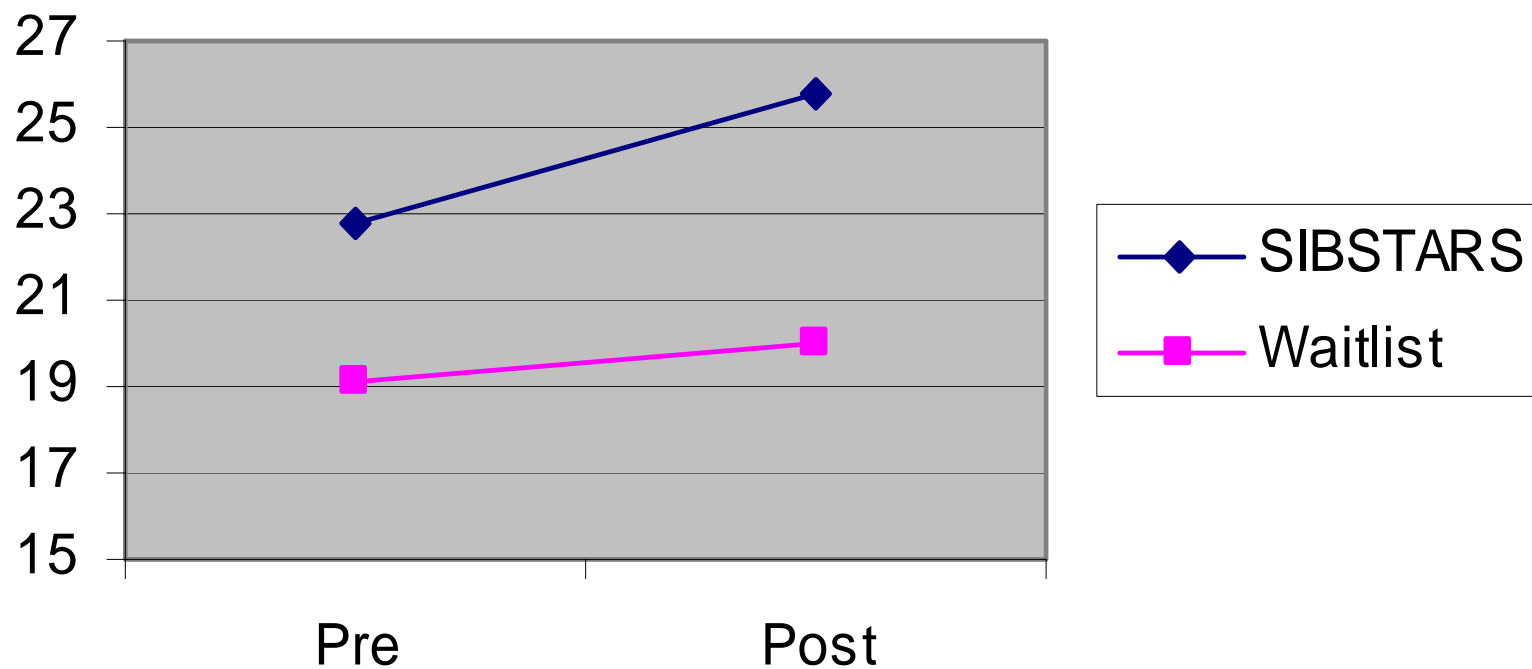
- Sibling Daily Hassles – Intensity
  - Significant decrease in the perceived intensity of daily stress for intervention group compared to waitlist control  $F(1, 12) = 5.833$ ,  $p=.033$ ,  $\eta^2 = .327$ .



# Sibling Coping

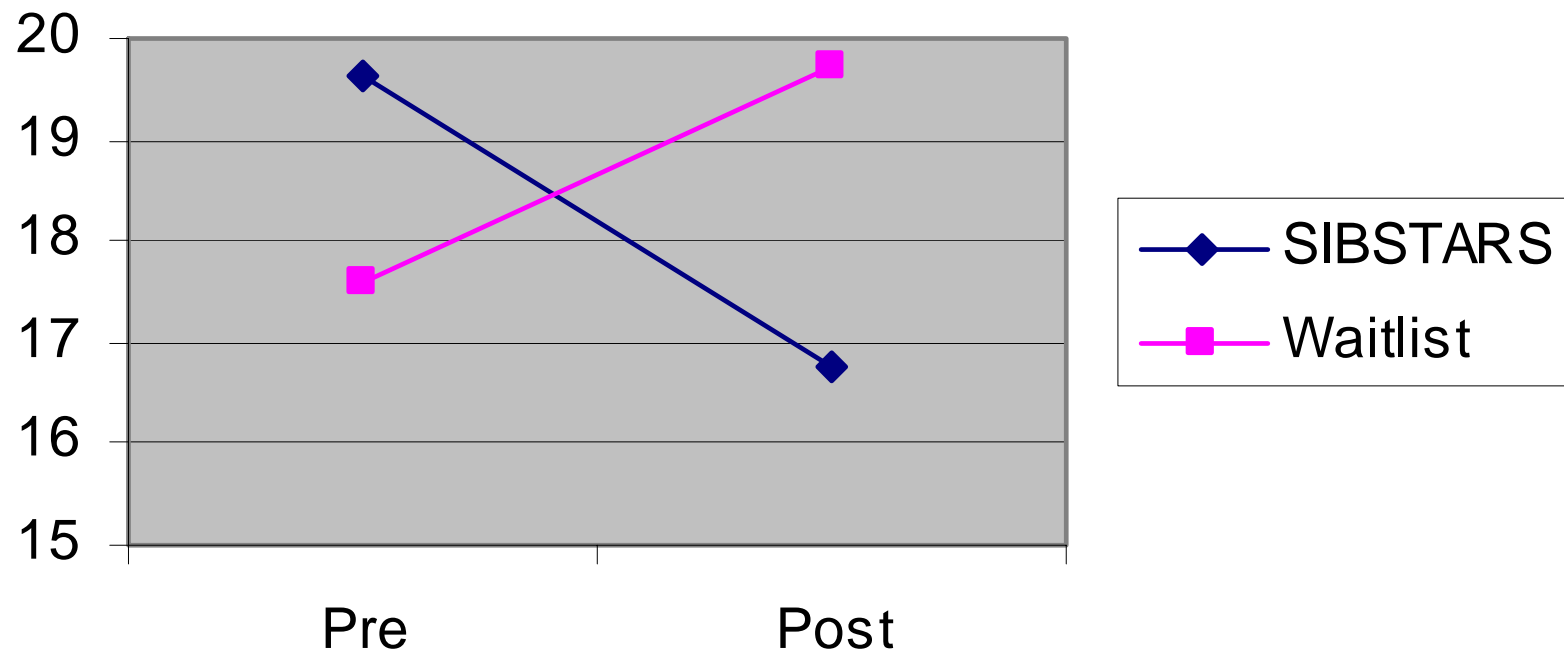
- **Social Support**

- **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,  $F(1,12) = 6.811$ ,  $p=.023$ ,  $\eta^2 = .362$



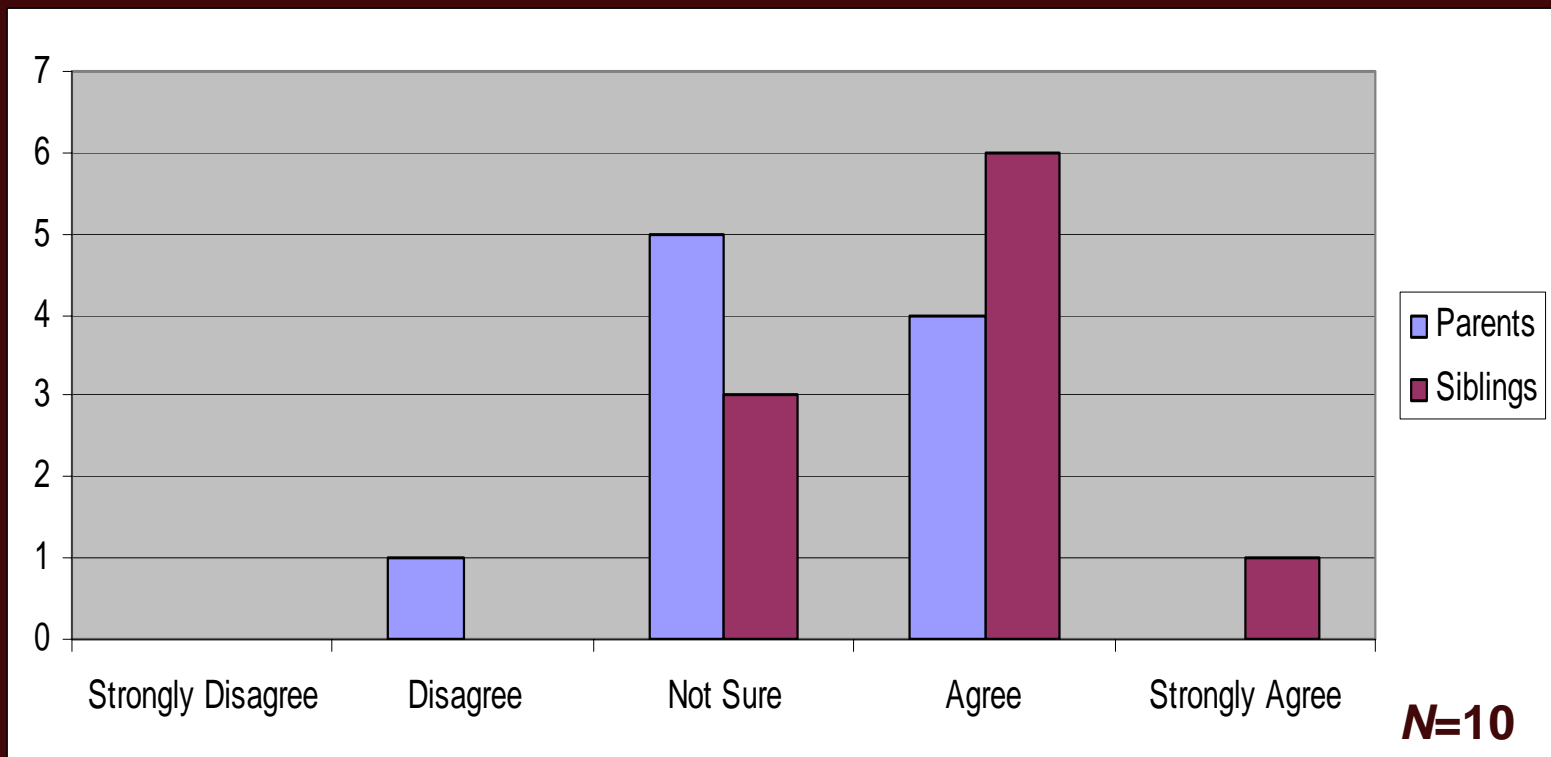
# Parent and Family Functioning

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- **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



# 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'.
- 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 it in 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.'
- I think that telephone format is particularly non-confronting and builds up rapport over the time of the program. Very relaxed.

# Sibling Comments

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- SIBSTARS is great and I can't think of any changes as the program is fantastic and helpful (Female, 16 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).
- 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 was hoping to meet other siblings and I was disappointed on that. But other than that it was alright (Female, 9 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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**For further information about this  
presentation or SIBSTARS,**

**please contact**

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