



Ninth Australasian Conference on Child Abuse and Neglect

- KEEPING FAMILIES WITH A CHILD WITH A DISABILITY SAFELY TOGETHER.
- Joan Bratel
- The Spastic Centre of NSW



# Project team

**Dr Eileen Baldry** (UNSW School of Social Work) - Chief Investigator

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**Other participating agencies:**

Autism Association of NSW

Northcott Society

*We acknowledge the contribution and participation of IFSO family therapist, Jean Kendall, to the early stages of the project.*



# The collaboration

- IFSO (Spastic Centre) and School of Social Work UNSW
- Commitment to evidence based practice
- Collaborative development of grant application to Australian Research Council Strategic Partnership with Industry Research & Training (ARC SPIRT) scheme - successful for mid1999 - mid 2002
- Employment of full-time research officer
- Autism Association and Northcott Society joined project



# Project aims

- 1. To discover whether support program(s) for children with a disability and their families significantly and positively influenced outcomes for the child and family;
- and , if significant changes occurred,
- 2. To discover which program elements, strategies and/or techniques significantly contributed to positive client outcomes.



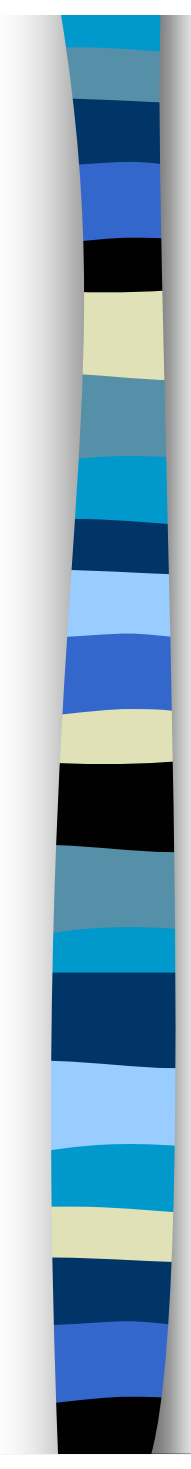
## Why these aims?

- Significant change in past decade (and longer) in working with children with disabilities
- Interest in intervention outcomes with families under stress, where children are at risk
- Increasing use of family centred and strengths focussed work - exploring evidence for this
- Recognition that children with disabilities are more at risk of abuse than other children



# Refining the project

- Project team meetings - planning and development
- Literature search (eg Bailey et al., 1998)
- Development of quantitative and qualitative means to measure change
- Discussion around ethical issues of research with vulnerable families
- Role clarity and boundaries for researchers and therapists - development of trust



# What do we need to measure to show that a family intervention has been successful?

Bailey et.al. suggested a framework for child & family program evaluation based around 8 questions.

Bailey, R. B., McWilliam, R. A., Darkes, L. A., Hebbeler, K, Simeonsson R. J., Spiker, D. & Wagner, M. 1998. **Family Outcomes in Early Intervention: A Framework for Program Evaluation and Efficacy Research.** *Exceptional Children*, 64 (3).



# Bailey's questions

- Did the intervention enhance the family's perceived ability to negotiate systems and services?
- Did the intervention enhance child-parent interaction, help child learn?
- Did the intervention assist building social and community supports?
- Did the intervention make an appropriate difference to the child's life?



## Bailey's questions (cont.)

- Did the intervention make a difference to the family's life?
- Did the intervention enhance the perceived quality of life?
- Did the intervention enhance a positive view of the future?
- Did the intervention result in positive relationship between therapist & parent?



## These questions were developed into factors to be assessed:

- Family's perception of empowerment
- Parent-child relationship
- Perceived support
- Child abuse risk
- Perceived family functioning
- Symptom reduction
- Happiness
- Hope
- Client-therapist alliance



# Measures used for these:

- **Family Empowerment Scale (Koren et al 1992)**
- **Parent-Child Relationship Inventory (Boothroyd 1994)**
- **Child Abuse Potential Inventory (Milner 1986)**
- **McMaster Family Assessment Device - general functioning subscale (Epstein 1983)**
- **Outcome Questionnaire (Lambert et al 1998)**
- **Happiness Measures (Fordyce 1988)**
- **State Hope Scale (Snyder et al, 1996)**
- **Working Alliance Inventory (Horvath & Greenberg 1989)**
  
- **Some: subscales only**



## Put together ...

These measures were combined into a 277-item scale, which took about 90 minutes to administer.

Measures were done pre-intervention, post intervention, 6 months, 12 months after.



# Qualitative data

- **What was gathered**
  - Caregivers comments pre intervention, post intervention; 6 & 12 month follow up
  - Worker post intervention interview
  - Videos of selected sessions
- **How gathered**
  - Open ended questions
  - Workers made diary notes after each session
- **How analysed**
  - N-Vivo thematic analysis



# Participants

- 6 counsellors/therapists
- Families asked by therapists if they were interested to participate - then contacted by UNSW for details and enrollment in the project
- 64 carers from 44 families - drawn from the 3 participating services
  - 45 primary caregivers
  - 19 secondary caregivers



# Characteristics of sample

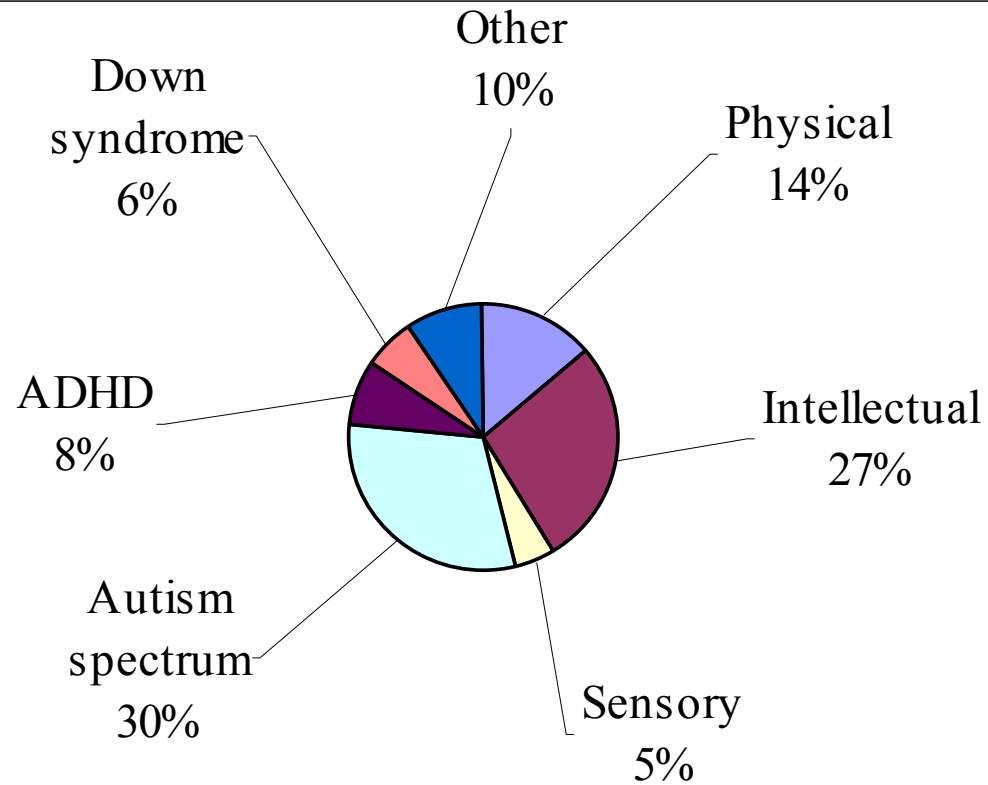
## Age of child with disability

<b>0 - 3 years</b>	<b>11.1%</b>
<b>4 - 7 years</b>	<b>28.6%</b>
<b>8 - 11 years</b>	<b>28.6%</b>
<b>12 - 15 years</b>	<b>22.2%</b>
<b>16 - 18 years</b>	<b>9.5%</b>

## Sex

<b>Male</b>	<b>82.5%</b>
<b>Female</b>	<b>17.5%</b>

# Disability of child





# Family configuration

<b>Single parent</b>	<b>30.2%</b>
<b>Two parent</b>	<b>58.7%</b>
<b>Other</b>	<b>11.1%</b>

# Background

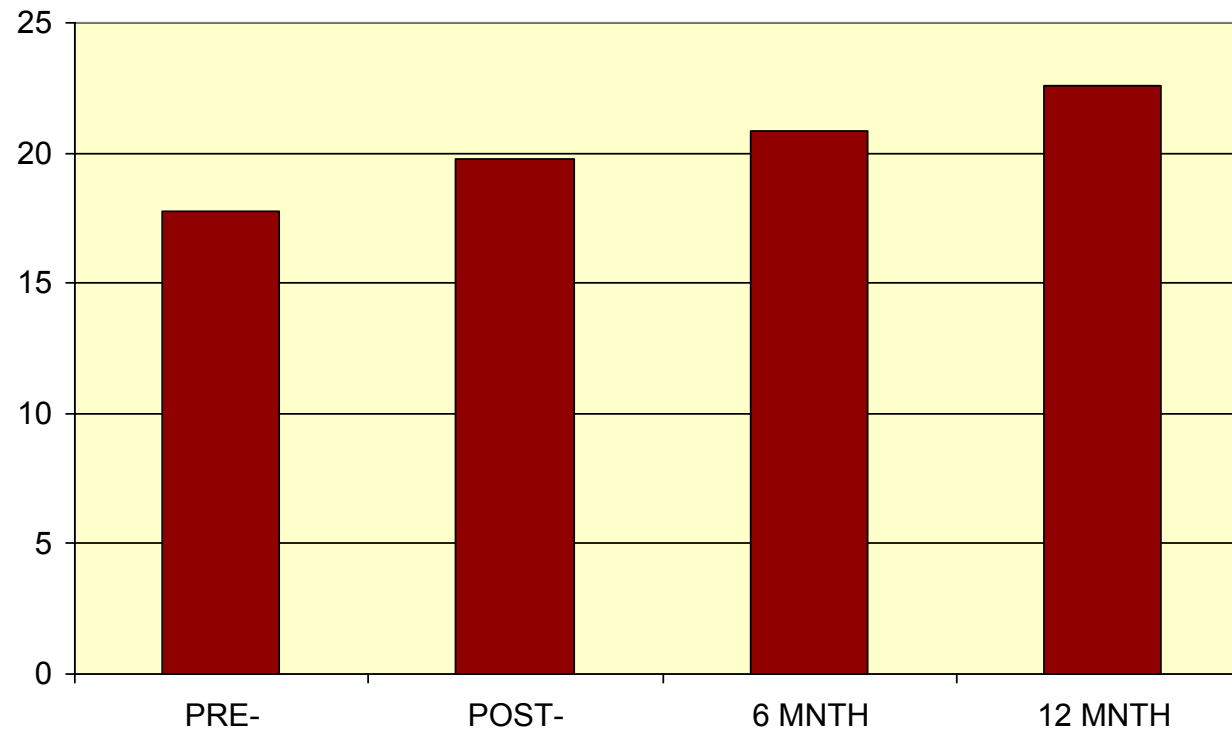
<b>Non-indigenous Aust</b>	<b>82.5%</b>
<b>NESB</b>	<b>17.5%</b>



# Quantitative results

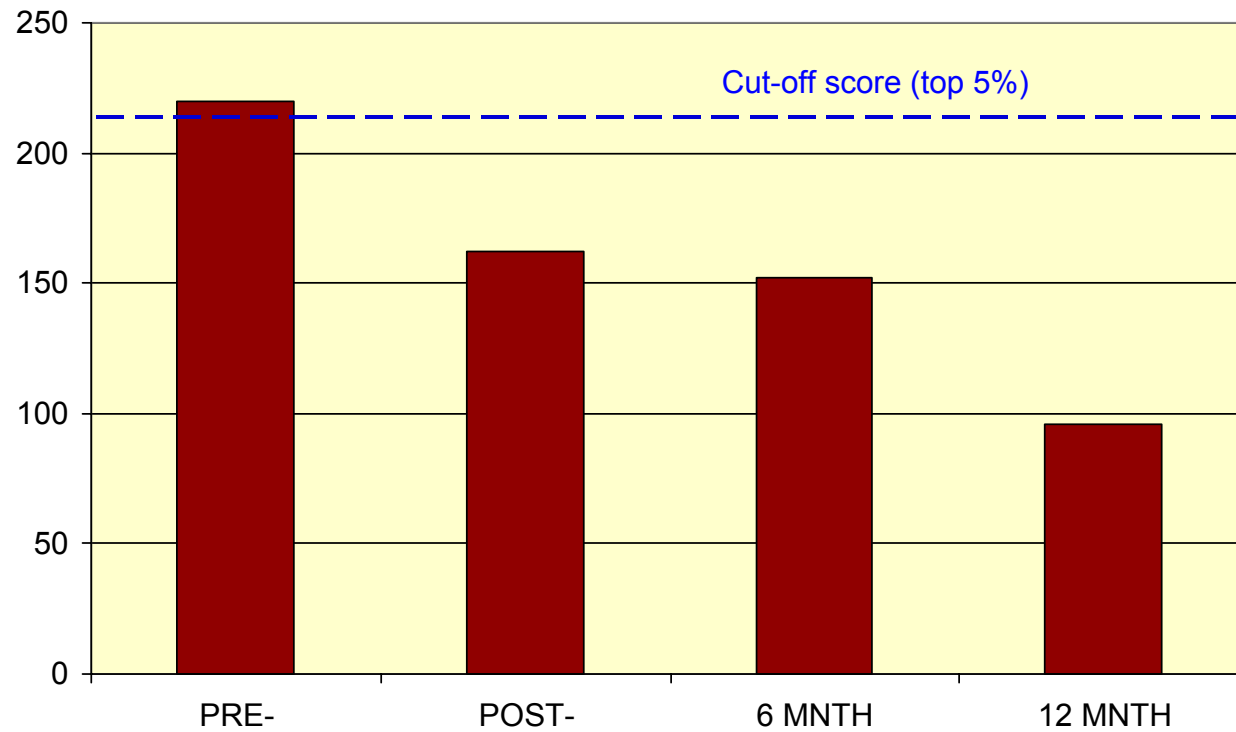
- Results indicate that the families were significantly assisted immediately and over time by the interventions
- In particular, interventions significantly improved primary caregivers scores on 2 variables:
  - perceived support
  - abuse potential

# Mean scores on Perceived Support



(Primary caregivers only)

# Mean scores on child abuse potential

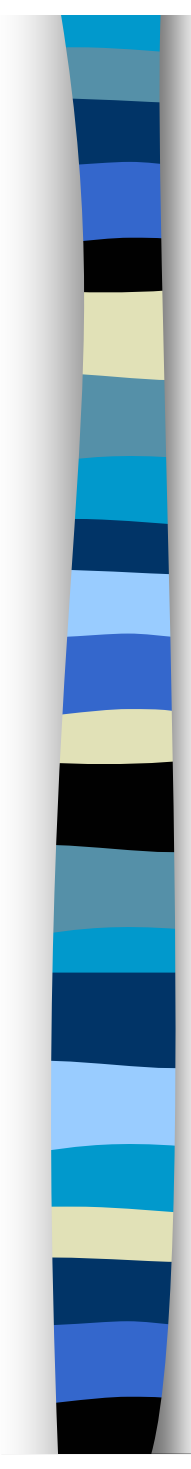


(Primary caregivers only)



# Quantitative results

- Other variables, such as empowerment, happiness, family functioning and hope, also showed improvement, though not at a statistically significant level.



## Which variables were related to other variables (at the end of the intervention)?

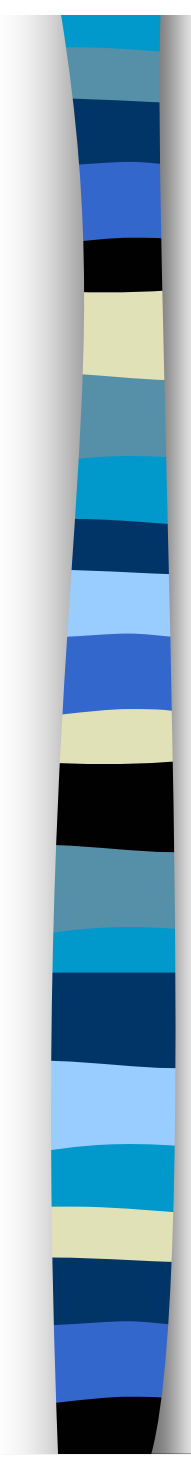
### The most significant relationships included:

- child abuse potential and symptom reduction
- child abuse potential and emotional support
- hope and happiness
- symptom reduction and emotional support



The results suggest that when parents are emotionally supported:

- **their abuse scores decrease**
- **their stress and other symptoms are reduced**
- **that when they are hopeful, their happiness scores increase.**



How much do Emotional Support  
and Symptom Reduction contribute  
to (improvement in) Child Abuse  
Potential?

**At 12 months, 86% of the variance in  
Child Abuse Potential is explained by  
Perceived Emotional Support and  
Symptom Reduction.**



## **THAT IS:**

The analysis indicates that when combined, emotional support and symptom reduction are good predictors of abuse potential – particularly 12 months following intervention.

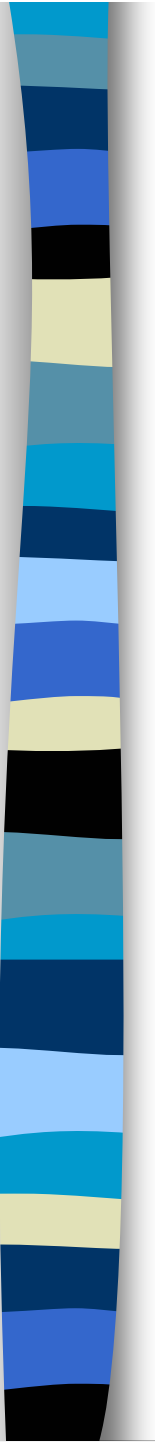
## **WHICH MEANS:**

That if our programs increase parents' sense of support and reduce their psychological symptoms, the risk of child abuse will be significantly decreased.



# Qualitative results

- **Now that we know the crisis interventions, taken as a set:**
  - were successful in helping families improve their general levels of well-being and functioning,
  - were highly successful immediately and over time in reducing potential for child abuse, and
  - improvement in things measured by the support and symptom reduction inventories were highly predictive of that reduction.....
- **We can look at the categories / themes that emerged in the qualitative analysis to help explain WHAT helped produce these results.**



# What helped explain these results?

## ■ ***Common worker strategies***

- Responsive to parents, listening, supportive, encouraging, empowering, strengths focussed

## ■ ***Common program elements***

- Focus on parent, available, home based, flexible, intensive, practical



# Support worker strategies

## ■ Listening

### – parents ‘feeling listened to’

- *Just to talk through some of the stuff*
- *Being here and listening - understanding*
- *It was great to have (the worker) here just to talk about it*
- *Maybe just being here to listen and reflect*
- *Just talk to (the worker) like it was a relief, a calming effect*
- *Having (the worker) to listen takes a lot of weight off*



# Listening

## – non-judgemental

- *Just listen, not too quick to comment, just take it in*
- *(The worker) was calm, not judgemental, didn't tell me the kids were stupid , didn't try to send them to someone else like they were a burden - other counsellors are so judgemental*
- *None of this 'you can't do this or that'*
- *I felt very comfortable talking with (the worker), I mean (the worker) doesn't tell you what to do*
- *Wasn't saying, well do this, like everyone else*



# Listening

- independent (outside family) & confidential
  - *It was good to get it out with someone not involved*
  - *It was good to talk with (the worker) about my daughter - I can't talk with my mother about her*
  - *It was important to have someone who wasn't part of the family to talk to*
  - *You don't know who to trust to talk with but you could trust (the worker)*
  - *Like bounce off someone you're not going to hurt*



# Listening

– taking time to listen

- *Always there if I need to talk*
- *Must have listened to me an hour and a half and showed real interest*
- *Having someone to contact and talk to and unload and explain the problem to and listen and give suggestions back*
- *Never brushed me off, always got back to me*



# Listening

- taking direction from parent
  - *Discuss our ideas, bounce things around*
  - *Having (the worker) to talk to I could sort out my own problems*
  - *Yeah bouncing off ideas. Like a sounding board*
  - *listened to how I wanted things and we looked at ways together how to help*



# Strategies

## ■ Support

### – being there

- *Never really sat down and put my thoughts together - it was just (the worker) being there*
- *Yeah it was the support, I don't have anyone else*

### – respect and care

- *(the worker) is probably the only person I've spoken to about my children and got some rapport and that I can understand*
- *When you feel someone cares for you it helps a lot*



# Support

– positive feedback

- *(the worker) always picked up the positive things and the things we tried went well*
- *Because we were being reinforced we were making the right decision and being supported we now understand what to do in situations*



# Support

- practical matters (getting respite, essential goods)
  - *(the worker) was there when we needed food and bus fares*
  - *Getting interpreters*
  - *Getting mum to medical appointment, taxis, buying essential equipment like a shower commode*
  - *Yeah the respite (the worker) arranged gave me a break - there was no doubt that helped*



# Strategies

## ■ Empowerment

- encouraging, reinforcing led to ‘feeling more in control’ and more confident
  - *I really felt I’d lost a lot of self-control but (the worker) gave me a lot of confidence*
- providing parenting information led to ‘feeling more in control’ and more confident
  - *I didn’t sort of rely on (the worker) to deal with the situation but to help me work out how to go about it so I’d know for next time*



# Empowerment

- information about what to expect from child led to being more realistic about child led to control and confidence
  - *(the worker) helped me rephrase things for (my son) so I felt more able to deal with his behaviour*
- these strategies led to parents' acceptance of children's capacities led to more relaxed parenting
  - *Helped me to look at a situation a different way, that I can't fix everything and just have to learn how to deal with it*
  - *Once you take it all into perspective and you start doing things differently, you see it working*



# Strategies

## ■ Validation

### – encouragement

- *Picking you up and telling you you're good*
- *Very encouraging, helping me make decisions*
- *(the worker) sent me a letter at the end - as long as I live I will keep that letter - (the worker) thought I was a good Mum.*

### – confirming what's working

- *Letting you know when you had a good idea where it was good*

### – working with parents' ideas

- *Remember thinking my idea is right and going with it*



# Strategies

- Positive, strengths focussed
  - *Telling you your good points not always your bad points*
  - *But I feel better and if I feel better then it's going to show with my kids and if the kids are feeling better then there's nothing to worry about*
- Providing ideas / information when requested
  - *Good with ideas but didn't behave like the ideas were the law*
  - *Being able to talk to someone about it and getting ideas*



# Program elements

## ■ Family/parent focussed

- *Would come to our home and talk with both of us together*
- *Really listen to me and my situation*
- *I felt like (the worker) was there personally for us*

## ■ Availability

- *Coming around and working with us at the really important times like 5-8 at night*
- *Other workers never available outside 9-5 which is when all the crises happen*



# Availability

## – Phone

- *It was really great - I could ring up and talk to (the worker) when things were so bad, like when my son was threatening suicide at 9.30pm*
- *So good to know could ring up any time*
- *After hours availability to phone them*
- *I mean if I had something I could ring up and talk to (the worker) whereas (other worker) is always so hard to get hold of*

## – Home visit

- *Having someone to come to my house*
- *That (the worker) came here into the situation*

## – Gave time

- *There when we needed (the worker)*
- *Having the contact anytime*



# Program elements

## ■ Flexibility

- *Worked with us at what we were able to manage*
- *Met at home or at office - whatever suited us best*

## ■ Consistency of worker

- *I couldn't believe I had (the worker) the whole time, not someone else part way. You could trust (the worker)*



# Program elements

## ■ Financial

- ***Paid for specialist visit***
- ***Like for medication, didn't have the money - if (the worker) hadn't been there I would have been stuffed***
- ***Bought washing machine, paid back rent, baby food***



# Program elements

## ■ Ensuring child safety

- *(The worker) explained why it was a problem that I didn't know where my son was - I understand that now*
- *Complimenting parent when succeed with discipline without yelling / losing temper etc*
- *Moving towards positive discipline strategies*
- *Providing positive parenting strategies when asked*



## Other findings:

- Worker strategies more effective if supported by the program elements
- Outcomes were not related to the type of disability of the child
- Secondary caregivers improvements were related to their feelings that the primary caregiver was being supported
- Whole “package’ of support integral to positive outcomes



# Policy Implications

- If Governments want to minimise institutional, substitute care or out of home care, and
- Reduce the abuse potential in family settings then:

**Appropriately resourced intensive support does produce positive outcomes**



# Policy Implications

**In the long run investment in this intensive strengths based style of intervention with families in crises has the potential to be both socially and economically effective.**