



# A Secondary Prevention Model of Family Centred Positive Behaviour Support for Families of Children with Down Syndrome

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## BACKGROUND

Common public misconception: children with Down syndrome (DS) do not have serious behavioural issues, especially compared to children with autism. In fact, 94% of children with DS have behavioural issues that impact daily functioning (Patel et al., 2018)

A widely used and evidence-based approach at the individual tier, **Family-centred Positive Behaviour Support (FCPBS)**, has not yet been examined at a secondary prevention level for any population of individuals.

**Key features of FCPBS:** functional assessment of behaviour, family routines as a unit of analysis, multicomponent PBS plans, contextual fit, collaborative partnership with family members, implementation support, and measurement of social validity (Lucyshyn et al., 2015).

This study employed a group parent training program, an example of a secondary prevention model of FCPBS.

**Research questions:** Did the group parent training program result in statistically significant:

- Decreases in child problem behaviour;
- Increases in child positive engagement;
- Increases in parenting sense of competence;
- Decreases in parenting stress; and
- Increases in family quality of life?

## METHOD

**Participants:** 11 families with children with DS and mild-to-moderate problem behaviour; aged 4-7 years

**Research Design:** Randomized controlled trial (with waitlist control group)

**Data analysis:** Nonparametric analyses (due to small n) of difference scores

### Direct Measurement – Primary measures

- Video recording of child behaviour in a primary problematic routine (identified by parents)
  - Blinding procedures employed with a second data coder
- Primary dependent variables: *child problem behaviour* and *child positive engagement* in targeted routines

### Indirect Measurement - Secondary measures

#### Child behaviour

- Eyberg Child Behavior Inventory; Behaviour Rating Scales for 2 generalization routines

#### Family variables

- Parenting Stress Index; Parenting Sense of Competence Scale; Beach Center Family Quality of Life Scale

## Procedures

**Intervention:** Family Centered Positive Behavior Support Group Parent Training Program

#### Content Elements

- Positive behaviour support strategies (preventative, teaching, and consequence-based); mindfulness techniques; cognitive-behaviour change strategies

#### Process Elements

- Weekly, 2.5 hour small group sessions (14 weeks total)
- An active training model was employed (modelled after PMTO; Forgatch & Domenech Rodriguez, 2016)
- Didactic information; demonstrations; examples and non-examples; role play; home practice exercises, including review and celebrations of success at the start of each session; and one in-home coaching session per family



	Study Phases				
	Phase I		Phase II		Phase III
Experimental Group	O	X	O		O
Waitlist Control Group	O		O	X	O

**Figure 1.** The randomized controlled trial research design represented in chronological order.

Note. O = Observation/Assessment; X = Intervention (Parent Training Program).

## PARENT COMMENTS

“I feel so much better equipped to handle challenging behaviours when they arise.”

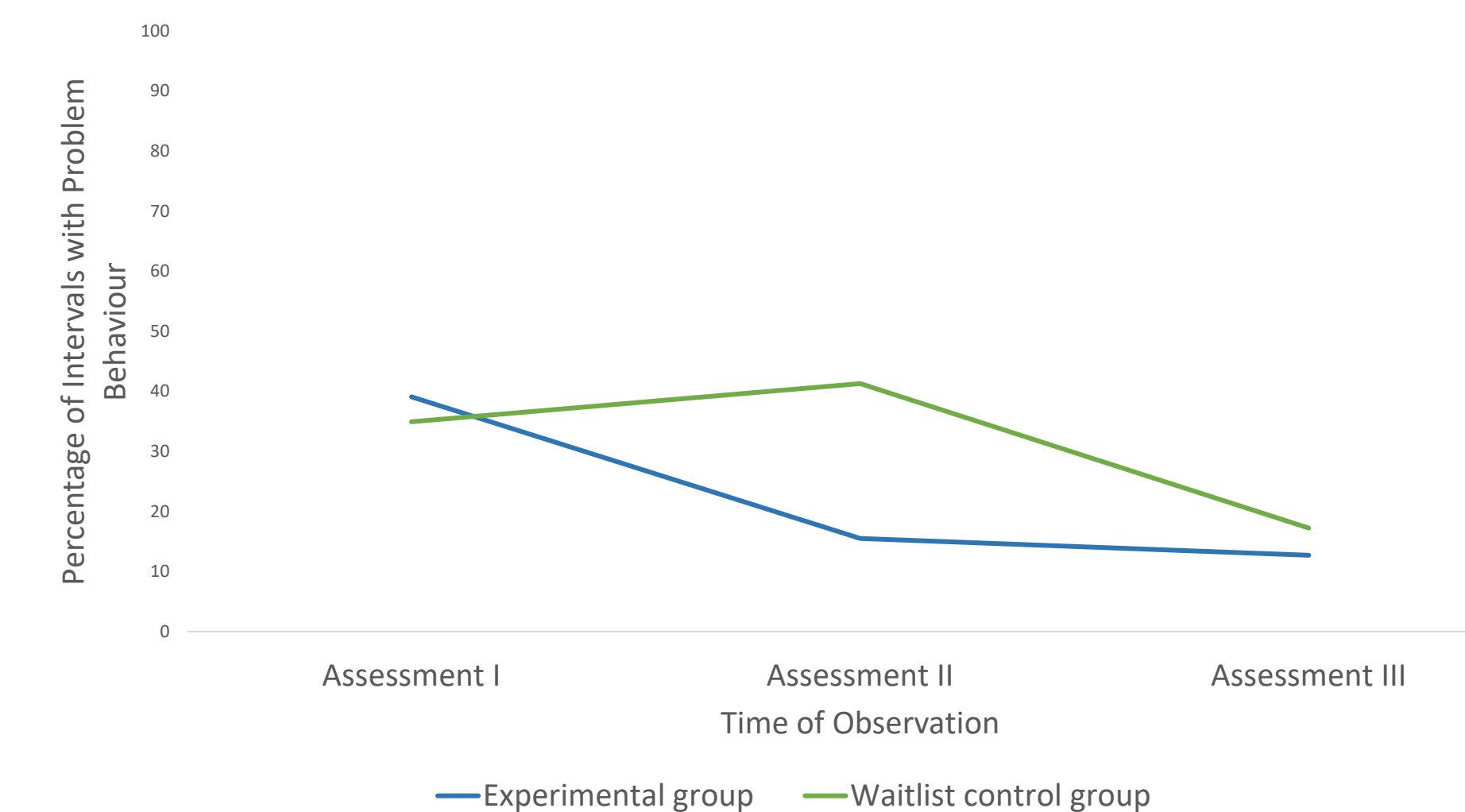
“I loved the program and found it to be so beneficial... it was a big commitment on my part, but the outcome has been so worth it.”

#### Accomplishments parents were proud of:

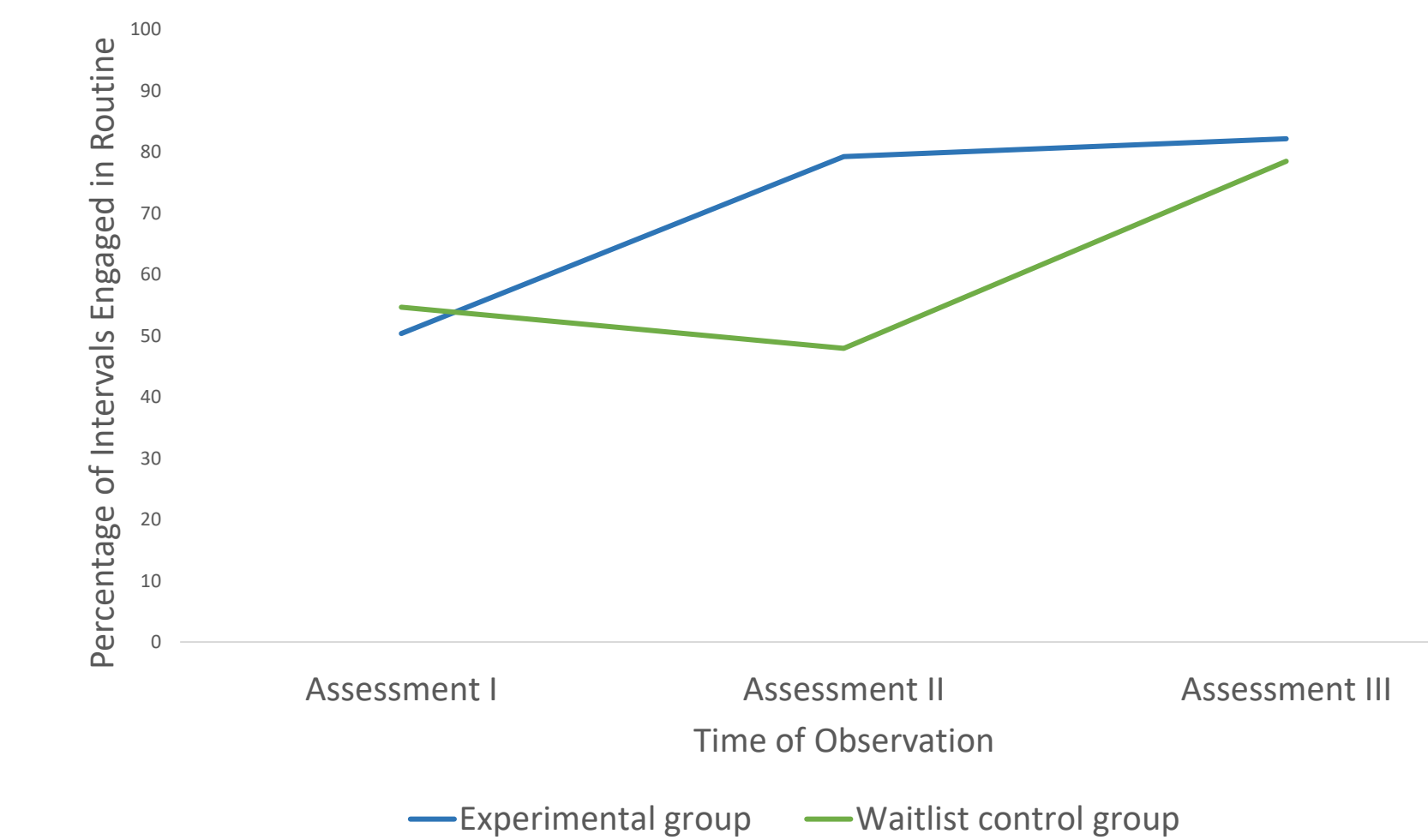
- “Being able to take B to any place without anxiety”
- “We now have confidence and tools to deal with L’s problem behaviour”
- “To see my daughter succeed in daily activities was wonderful”

## RESULTS

Data for the 2 primary outcome variables are shown here



**Figure 2.** Average percentage of intervals of problem behaviour in the primary routine for the two groups across three assessment points.



**Figure 3.** Average percentage of child positive engagement in primary routine for the two groups across three assessment points.

### Child Problem Behaviour Assessment I to II

EG Mdn = -25.48      U = .00      p = .002  
WG Mdn = +5.81      Z = -2.88      η<sup>2</sup> = .75

### Child Positive Engagement Assessment I to II

EG Mdn = +29.07      U = .00      p = .002  
WG Mdn = -3.81      Z = -2.88      η<sup>2</sup> = .75

## DISCUSSION & CONCLUSION

- Family functioning outcomes included decreased stress, improved parenting competence, and improved family quality of life for mothers
- Improved behaviour was found in one additional generalization routine
- High social validity scores: families found the program to be acceptable, feasible, and effective.
- **Limitations included:**
  - Fathers did not improve on family functioning variables
  - Possible inflation of parent report scores due to waitlist control design
- **Next steps:** Amend program to enhance effectiveness for fathers, then examine effectiveness of the FCPBS parent training program in other DS centres

## Takeaway Messages

- This was the **first study** to evaluate FCPBS:
  - With children who have DS (at any intervention tier)
  - At a secondary prevention level
  - Using a randomized controlled trial
- **A secondary prevention model of FCPBS appears to be a promising, cost-effective intervention for families of young children with DS and mild-to-moderate problem behaviour**

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