A Secondary Prevention Model of Family-Centred PBS: The Low-"Down"

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UBC

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Down Syndrome Resource Foundation

Together, Hand in Hand

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Introduction

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Rationale for Study

- Many children with Down syndrome have behavioural health issues
  - Secondary diagnoses (e.g., autism), or
  - Just enough difficulty to negatively impact their ability to learn and to participate in everyday routines
    - Recent study found 94% of children with DS had at least one kind of problem behaviour that was frustrating to parents (Patel et al., 2018)
    - Most common problem behaviours in DS: noncompliance, sitting down and refusing to move, wandering / running away from adults, and aggression
- Currently, no research has examined:
  - A secondary prevention (Tier 2) model of FCPBS
  - FCPBS for individuals with DS

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DS-ASD

- Prevalence: up to **18%** of children with DS will have an additional diagnosis of autism
- Great deal of overlap between DS and autism
  - *Differences in the area of social development are key*
- Funding for therapies, including behavioural therapies, for children with autism in BC is robust
  - In contrast, there is sparse funding available in BC for behavioural therapies for children who have DS

https://www.dsrf.org/information/autism/down-syndrome-and-autism

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Secondary Prevention Model of FCPBS

A 14-week, group-delivered parent training program focused on teaching PBS strategies to families of young children with Down syndrome and mild-to-moderate levels of problem behaviour

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Research Questions

1. Is there a statistically significant improvement in **parent implementation fidelity** of PBS strategies as a result of the group-based, secondary prevention model of FCPBS delivered to families of young children with DS and problem behaviour?
2. Did the group parent training program result in statistically significant (a) decreases in child problem behaviour, (b) increases in child positive engagement, (c) increases in parents' sense of parenting competence, (d) decreases in parenting stress, and (e) increases in family quality of life?

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Research Questions (cont'd)

3. Was implementation of the group parent training program associated with statistically significant **maintenance** of child and family outcomes at 6 months follow up?
4. Was implementation of the group parent training program with the **waitlist control group** associated with statistically significant improvements in (a) parent implementation fidelity, (b) child problem behaviour, (c) child positive engagement; (d) parents' sense of parenting competence, (e) parenting stress, and (f) family quality of life.
5. Did families view the approach as **socially valid** with respect to goals, procedures, and outcomes?

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Integrated Knowledge Translation

Concept paper → Stage 1 study → Randomized control trial

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Method

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Group Parent Training Program

Content
- a set of core, empirically-supported PBS strategies,
- a regular mindfulness practice,
- how to change problematic thought patterns, and
- strategies for caring for the family as a whole

Process
- listening to information with a PowerPoint presentation,
- group discussion,
- role play,
- examples and non-examples,
- videos, and
- demonstrations

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Week	Topic
1	Introductions, functions of behaviour
2	Coercive and constructive processes; child and family strengths
3	Mindfulness; changing problematic thought patterns; praise
4	DS-specific setting events and supports; house rules
5	House rules (cont'd); effective requests
6	Caring for the whole family
7	Positive contingencies with visual supports; offering choices
8	Individual, in-home coaching session
9	Incorporating preferences; safety signals
10	Building successful routines; transitions
11	Play; tangible positive reinforcement
12	Functional communication training; actively ignore and positively redirect
13	Errorless learning (teaching new adaptive skills)
14	Parent presentations; review game; wrap-up

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Sessions 1-3: Foundations

1. Introductions, functions of behaviour
   - Reasons why children engage in problem behaviour: attention, escape, tangible, or automatic reinforcement
   - 4-term contingency: setting events, antecedents, behaviour, consequences
2. Coercive and constructive processes; child and family strengths
   - How unhealthy parent-child interactions develop over time
   - Building from a place of strength
3. Mindfulness; changing problematic thought patterns; praise
   - Taught parents 4 mindfulness practices: sitting, walking, loving-kindness and compassionate abiding
   - "Thinking traps:" Some thoughts you have are unhelpful and sabotage your ability to parent effectively
   - Positive reinforcement of adaptive behaviour via physical or verbal praise

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Sessions 4-7

4. DS-specific setting events and supports; house rules
   - Examples: sleep apnea, medical issues, nutrition
   - A list of values-based rules for all children in the family to follow at home
5. House rules (cont'd); effective requests
   - Acknowledgment system for house rules (tickets & jar)
   - A way of giving children instructions that makes it more likely that they will comply
6. Caring for the whole family
   - Strategies for keeping all family relationships healthy: marriage, siblings, extended family
7. Positive contingencies with visual supports; offering choices
   - Visual supports such as pictures and symbols help enhance predictability for children
   - Giving children a choice of 2 or more options within both preferred and non-preferred activities helps them to be more cooperative

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Session 8: Individual Coaching

- One in-home coaching session for each family in their primary target routine
  - Observed parent carry out the routine; completed a strategy implementation checklist
  - Afterwards:
    - Asked parents to self-evaluate
    - Used checklist to give parents a lot of praise and a little bit of corrective feedback
    - Time for discussion and problem solving

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Sessions 9-11

9. Incorporating preferences; safety signals
   - Building preferred elements in to activities or routines that are hard for children makes it more likely that they will complete them
   - Teaching children to tolerate delays before getting what they want
10. Building successful routines; transitions
   - Parents given a "generalization project:" apply strategies to another problematic routine
   - Why transitions are particularly challenging for children with DS
11. Play; tangible positive reinforcement
   - Improve parent-child interactions, learning, and quality of life for children by engaging in regular play sessions
   - Reinforcement menus

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Sessions 12-14

12. Functional communication training; actively ignore and positively redirect minor problem behaviour
    - For the function of behaviour occurring in a given situation, teach children to use a communicative message that serves the same purpose
    - Redirecting children back to a task or the use the use of language without providing negative or positive attention to them
13. Errorless learning (teaching new adaptive skills)
    - Encouraging children's learning success by providing prompts to them during new or difficult tasks to ensure they respond correctly each time
14. Parent presentations; review game; wrap-up
    - Parents presented on their generalization project routine

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Outline of a Typical Session

- Each 2.5 hour weekly session typically included:
  - Home practice review and celebrations of success
  - Mindfulness practice
  - Cognitive behaviour therapy strategy (e.g., disputing or reframing unhelpful thoughts, affirmations)
  - 1-2 PBS strategies taught via an active training approach
    - Didactic information
    - Examples and non-examples
    - Videos / demonstrations
    - Role play
  - Take-home messages
  - Introduction of new home practice assignment

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Tips for Parent Training using an Active Training Approach

- An active training approach includes:
  - Promoting balance of participation amongst group members
  - Using humour
  - Encouraging and supporting via positive reinforcement
  - Normalizing parent experiences
  - Mirroring / matching parent behaviour
  - Reflecting
  - Interrupting supportively

(Forgatch & Domenech-Rodriguez, 2016)

Homemade baking and good coffee don't hurt, either...

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Participants

- Total of 12 families participated through to the end of Assessment II; 11 participated in the intervention
- Inclusion criteria for children:
  - Diagnosis of DS
  - 4 to 7 years
  - Mild-to-moderate problem behaviour for at least 6 months
- Inclusion criteria for parents:
  - Willing to complete assessments, attend all weekly sessions, and complete weekly home practice assignments
  - Both parents participate (if a two-parent family)
  - Both parents fluent in oral and written English
  - Parents not diagnosed with mental health condition; within normal limits of parental stress

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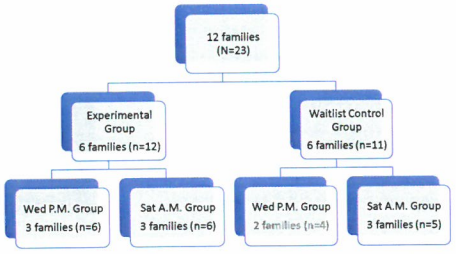
Participants (cont'd)



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Design: Randomized Controlled Trial

	Study Phase				
	Phase I		Phase II		Phase III
Experimental group	O	X	O		O
Waitlist control group	O		O	X	O

O = Assessment point; X = FCPBS group parent training program

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Measurement

Dependent Variables:

1. Direct observation measures
   a) Primary routine – Videorecorded 2x at each assessment point; primary focus of intervention
      i. **Parent implementation fidelity of PBS strategies - % correct usage**
      ii. **Child problem behaviour - % of intervals**
      iii. **Child positive engagement - % of intervals**
2. Indirect observation measures (all parent report)
   a) Generalization measures
   b) Standardized checklist of child behaviour
   c) Sense of parenting competence
   d) Parenting stress
   e) Family quality of life
   f) Social validity

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Results

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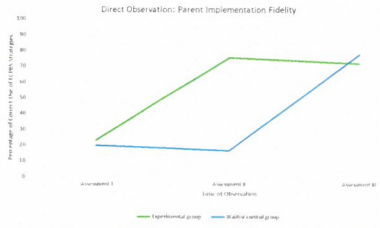
Direct Measures: Parent Implementation Fidelity



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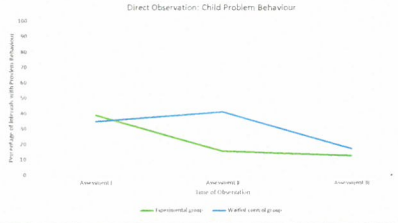
Direct Measures: Child Problem Behaviour



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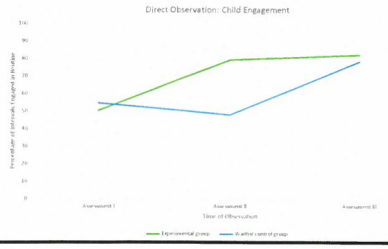
Direct Measures: Child Positive Engagement



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How did the children with DS-ASD fare?

	Problem Behaviour		Positive Engagement	
	Pre	Post	Pre	Post
Family 1	31%	13%	31%	62%
Family 9	32%	8%	57%	88%
Family 10	57%	8%	40%	92%
Group	40%	17%	49%	79%

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Social Validity

- High social validity scores for both mothers and fathers
  - They found the program to be acceptable, feasible, and useful
  - All parents reported that they would recommend the program to others

"I feel so much better equipped to handle challenging behaviours when they arise"

"Learning preventative measures has been very useful"

"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."

"I didn't really click with the mindfulness exercises"

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Other results

- Family functioning outcomes included decreased stress, improved parenting competence, and improved family quality of life for mothers, but not for fathers
- Improved behaviour was also found in one additional generalization routine

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Unique Contributions to Literature

1. FCPBS with families of children with Down syndrome
2. Secondary prevention (Tier 2) model of FCPBS
3. Use of RCT to examine FCPBS intervention

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Clinical Implications

- *A secondary prevention model of FCPBS aimed at families who have young children with Down syndrome appears to be promising*
  - Consider cost of tertiary vs secondary support, particularly for a population of children who do not typically receive behavioural supports

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Limitations & Future Directions

- Difficult to extrapolate results to all families of young children with DS
- Parent training was not as effective for fathers as it was for mothers with respect to family functioning variables

Proposed changes to current program before future research:

- Enhance training on "actively ignore and positively redirect" strategy
- Amendments to improve benefits for fathers

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References

Forgatch, M. S., & Domenech Rodríguez, M. M. (2016). Interrupting coercion: The iterative loops among theory, science, and practice. In T. J. Dishion & J. J. Snyder (Eds.) *The Oxford handbook of coercive relationship dynamics* (pp. 194-214). New York, NY: Oxford University Press.

Patel, L., Wolter-Warmerdam, K., Leifer, N., & Hickey, F. (2018). Behavioral characteristics of individuals with Down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, *11*(3), 221-246.

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