PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: INVESTIGATION INTO BEST PRACTICE INTERVENTION
PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: INVESTIGATION INTO BEST PRACTICE INTERVENTION

Aude Etournaud

A thesis submitted in partial fulfilment of the requirements of the degree of

Doctor of Philosophy

Bond University

March, 2017
CANDIDATE’S DECLARATION

This thesis is submitted to Bond University in fulfilment of the partial requirements for the Doctor of Philosophy degree.

This thesis contains no material which has been accepted for the award of any other degree in any other University and, to the best of the candidate’s knowledge and belief, it contains no material previously published or written by another person except where due reference is made in the text of the project.

Signature

Date: 06th of March 2017
ABSTRACT

Parents of children with Autism Spectrum Disorder (ASD) are reported to experience greater levels of stress, anxiety, and depression than parents of children with other developmental disorders or physical impairments. This group of parents, which presents mental health professionals with unique support needs, is receiving increasing attention due (in part) to the reported worldwide increase in ASD prevalence. Australian figures suggest that approximately 115,400 Australians (0.5%) of the population were reported to have ASD in 2012 (SDAC, 2014). The research demonstrates that formal group support constitutes the most common method for assisting parents of children with ASD to deal with their children’s autism-specific difficulties and their own mental health challenges. However, the literature which evaluates the effects of formal support groups reveals substantial variation in relation to content, delivery methods, and data-collection procedures for monitoring any changes to parent functioning (as a result of parents attending group support). This variation has contributed to poor clarity on what constitutes effective formal group support for parents of children with ASD, and limited translation of evidence-based support group processes to the professional field.

Study 1 sought to investigate the question of which model of formal group support (i.e., broad topic area) might be best suited to meeting the emotional and psychological needs of parents of children with ASD by delivering three six weeks groups, clearly differentiated in content (i.e., Functional Behavioural Assessment Training Group, Skills Training Group, and Combined Group), but kept equivalent in relation to delivery format, timing, and data-collection procedures. Those three groups were delivered to 36 parents of children with ASD, and changes in parent mental health (i.e., anxiety and depression), parent-child relationship quality, and ASD child challenging behaviours were measured across five time periods (i.e.,
Pre-Intervention, Post-Intervention, Follow-Up 1, Follow-Up 2, and Follow-Up 3). The results indicated there were no significant changes in parental mental health across the three support groups. A reduction in the frequency of challenging behaviours was reported across time for all three groups, and participants attending the Skills Training Group reported an increase in the quality of their relationship with their child.

The parent attendance records collected for study 1 indicated a strong trend towards inconsistent participation across all three groups. This finding was substantiated in the literature with researchers suggesting that the poor mental health outcomes reported by parents attending support groups are associated with low attrition and low participation rates. Consequently, study 2 investigated the specific aspects of parents’ lives that might act as barriers to accessing support groups, by conducting semi-structured interviews with 33 parents of children with ASD. Interview findings propose reasonable large variation in the factors which prevent parents from accessing and remaining engaged in support groups. These findings lead to the recommendation that parents undergo individual profiling to understand their particular life circumstances and how these affect participation in support services.
ACKNOWLEDGEMENTS

I wish to extend all my gratitude to the participants, who shared their experiences with me. Their dedication and willingness to help other parents of children with ASD made this research possible.

I am very thankful to my supervisor and mentor, Professor Vicki Bitsika, for her invaluable guidance and support. Her patience, compassion, and her willingness to push me to learn from new experiences have inspired me, and made this research possible.

I would like to thank my other supervisor, Doctor Phillip Fourie. His assistance, wonderful sense of humour and his contributions have improved this project.

Thank you to Professor Christopher Sharpley, his critical feedback and statistical consultation have been truly appreciated.

The support of my parents and my sister, throughout this research, has helped me tremendously. I thank my family and friends for their understanding, constant encouragement, and most of all for their eagerness to celebrate every little achievement throughout this journey.
TABLE OF CONTENTS

ABSTRACT .......................................................................................................................... (iv)

ACKNOWLEDGEMENT ....................................................................................................... (vi)

CHAPTER 1: Introduction .................................................................................................... 1

CHAPTER 2: Description of Autism Spectrum Disorder (ASD) ............................................ 7
  2.1 ASD as a neurodevelopmental disorder ................................................................. 9
  2.1.1. Possible biological underpinnings for ASD ....................................................... 9
  2.1.2. Evolution of diagnostic criteria for ASD in the Statistical Manual of Mental Disorders (DSM) .......................................................................................... 11
  2.2 Current conceptualisation of autism-related conditions ....................................... 14
  2.3 Factors leading to variation in ASD symptom presentation and daily functioning .......................................................................................................................... 18
  2.4 Comorbid Disorders .............................................................................................. 24

CHAPTER 3: Challenges Faced by Parents of Children with ASD Compared to Parents of Typically Developing Children ................................................................. 32
  3.1 Mental health impacts associated with parenting children with ASD .............. 36
  3.2 Physical impacts associated with parenting children with ASD ...................... 39
  3.3 Social/Familial impacts associated with raising children with ASD ............... 43
  3.4 Limitations from previous research findings ....................................................... 53
CHAPTER 4: Psychosocial Factors Associated with Enhanced Stress-Coping Responses in Parents of Children with ASD

4.1 Coping style, social support and personal resilience patterns in parents of children with ASD

4.1.1 Coping style definitions and research findings for parents of children with ASD

4.1.2 Social support definitions and research findings for parents of children with ASD

4.1.3 Personal resilience patterns definitions and research findings for parents of children with ASD

CHAPTER 5: Major Models of Support Developed for Parents of Children with ASD

5.1 Informal group support models for parents of children with ASD

5.2 Formal group support models for parents of children with ASD

5.3 Methodological limitations of research-based informal and formal support group models for parents of children with ASD

CHAPTER 6: Study 1: Comparing Three Models for Delivering Group-Based Support to Parents of Children with ASD

6.1 Study rationale

6.2 Methods

6.2.1 Participants

6.2.1.1 Parent participant features
6.2.1.2 Parent participant support features ............................................................... 95
6.2.1.3 ASD child features ........................................................................................... 97
6.2.2 Procedure .............................................................................................................. 98
6.2.2.1 Recruitment of participants ........................................................................... 98
6.2.3 Setting, research design and assessment .............................................................. 100
6.2.3.1 Setting .............................................................................................................. 100
6.2.3.2 Research design .............................................................................................. 100
6.2.3.3 Description of the three support groups delivered in study 1 ....................... 104
6.2.3.4 Pre-and-Post support group self-report scales used to measure parent and child changes ........................................................................................................... 108
6.2.3.4.1 The Patient Health Questionnaire- 9 (PHQ-9) ......................................... 110
6.2.3.4.2 The Generalised Anxiety Disorder- 7 (GAD-7) ........................................ 112
6.2.3.4.3 The Parent-Child Relationship Inventory (P-CRI) .................................... 113
6.2.3.4.4 The ASD Behaviour Checklist (ASDBC) ............................................... 115
6.2.3.4.5 The Connor-Davidson Resilience Scale (CD-RISC) ............................... 117
6.2.3.4.6 The Parent Profile Questionnaire (PPQ) .................................................. 118
6.3 Participants’ attrition and attendance patterns across the three support groups ... .................................................................................................................................................. 119
6.4 Findings on the three support group effects ......................................................... 121
6.4.1 Data analysis plan .............................................................................................. 121
6.4.2 Pre-and-Post Intervention measures of parent anxiety across the three support groups ................................................................................................................................ 123
6.4.2.1 Functional Behavioural Assessment Training Group ................................... 123
6.4.2.2 Skills Training Group ...................................................................................... 124
6.4.2.3 Combined Group ............................................................................................ 124
6.4.3 Post-Intervention and Follow-Up periods 1, 2 and 3 measures of parent anxiety across the three support groups ......................................................... 124

6.4.3.1 Functional Behavioural Assessment Training Group ...................... 124

6.4.3.2 Skills Training Group ............................................................................. 125

6.4.3.3 Combined Group ..................................................................................... 126

6.4.4 Pre-and-Post Intervention measures of parent depression across the three support groups ................................................................................. 129

6.4.4.1 Functional Behavioural Assessment Training Group ...................... 129

6.4.4.2 Skills Training Group ............................................................................. 130

6.4.4.3 Combined Group ..................................................................................... 130

6.4.5 Post-Intervention and Follow-Up periods 1, 2 and 3 measures of parent depression across the three support groups ......................................................... 131

6.4.5.1 Functional Behavioural Assessment Training Group ...................... 131

6.4.5.2 Skills Training Group ............................................................................. 132

6.4.5.3 Combined Group ..................................................................................... 133

6.4.6 Pre-and-Post Intervention and Follow-Up periods 1, 2 and 3 comparisons of parent-reported frequency of ASD behaviour in children across the three support groups ................................................................................. 135

6.4.7 Pre-and-Post Intervention and Follow-Up periods 1, 2 and 3 comparisons of parent ratings of the quality of the relationship with their children across the three support groups ................................................................................. 137

6.4.8 Parent ratings of support group satisfaction/value in relation to session number and topic across the three support groups ........................................ 138

6.4.8.1 Parent ratings of support group satisfaction ........................................ 138
6.4.8.2 Value ratings in relation to session number and topic attributed by participants attending the Functional Behavioural Assessment Training Group .......................................................... 140

6.4.8.3 Value ratings in relation to session number and topic attributed by participants attending the Skills Training Group .................................. 142

6.4.8.4 Value ratings in relation to session number and topic attributed by participants attending the Combined Group .................................. 144

6.4.9 Summary of findings study 1 ................................................................. 148

6.4.9.1 Summary of parent-reported major difficulties and major concerns for their ASD child ................................................................. 148

6.4.9.2 Summary of parent-reported anxiety findings across the three support groups ................................................................................. 150

6.4.9.3 Summary of parent-reported depression findings across the three support groups ................................................................................. 150

6.4.9.4 Summary of parent-reported frequency of ASD behaviour in children across the three support groups ................................................. 151

6.4.9.5 Summary of parent-reported quality of relationship with their child across the three support groups ....................................................... 151

6.5 Study 1 discussion ................................................................................... 152

6.5.1 Participants’ attendance patterns across the three support groups ....... 153

6.5.2 Group content ...................................................................................... 156

6.5.3 Limitations of previous research addressed in study 1 ....................... 157

6.5.4 Lack of significant changes in anxiety and depression symptoms......... 158
6.5.5 Changes in parent-reported frequency of ASD behaviour in their child.... 160
6.5.6 Changes in parent-reported quality of relationship with their child........ 162

CHAPTER 7: Study 2: Applying a Face-to-Face Semi Structured Interview to Explore the Support Needs of Parents of Children with ASD.......................... 164

7.1 Study rationale ........................................................................................................ 164
7.2 Methods .................................................................................................................... 167
7.2.1 Participants ........................................................................................................... 167
7.2.2 Procedure ............................................................................................................. 168
7.2.2.1 Recruitment of participants ........................................................................... 168
7.2.3 Setting .................................................................................................................. 169
7.2.4 Data-collection methods ..................................................................................... 170
7.2.4.1 Description of the semi-structured interview .................................................. 170
7.2.4.2 Process for administering the semi-structured interview .............................. 179
7.2.4.3 Description of the self-report scales ............................................................... 182
7.2.4.4 Process for completion of the self-report scales ........................................... 183

CHAPTER 8: Thematic Analysis Findings on Parent Support Barriers and Needs........ 184

8.1 Data analysis procedures for the semi-structured interview and the self-report scales ................................................................................................................. 184
8.1.1 Thematic Analysis procedure for the semi-structured interview ...................... 184
8.1.2 Stepwise process for conducting Thematic Analysis of interview data............. 186
8.1.2.1 Outlining the specific analysis process to be performed within the Thematic Analysis framework ................................................................. 186
8.1.2.2 Familiarisation with interview data ........................................... 188
8.1.2.3 Generalisation of initial codes .................................................. 189
8.1.2.4 Location of themes within the interview data set ....................... 191
8.1.2.5 Refinement of initial themes .................................................... 193
8.1.2.6 Definition and naming of themes ............................................ 195
8.1.3 The benefits associated with using Thematic Analysis ................. 197
8.1.4 Reasons why Thematic Analysis is suited to interview data ........... 198
8.2. Findings of the Thematic Analysis on participants’ answers to the open questions of the semi-structured interview .............................................. 201
8.2.1 Major themes identified through the Thematic Analysis ............... 202
8.2.2 Child-focused major themes identified ....................................... 208
8.2.2.1 Theme 1: Aggressive behaviours ........................................... 208
8.2.2.2 Theme 2: ASD symptoms and difficulties ................................. 209
8.2.2.3 Theme 3: Health .................................................................. 211
8.2.2.4 Theme 4: Transitions ........................................................... 212
8.2.3 Environment-focused major themes identified ......................... 213
8.2.3.1 Theme 1: Concerns for child ............................................... 213
8.2.3.2 Theme 2: Most helpful support ................................................................. 215
8.2.3.3 Theme 3: Least helpful support ............................................................... 217
8.2.3.4 Theme 4: Financial .................................................................................. 218
8.2.3.5 Theme 5: School ..................................................................................... 219
8.2.3.6 Theme 6: Work ....................................................................................... 220
8.3 Findings from participants’ answers to the closed-questions from the semi-structured interview ................................................................. 222
8.3.1 Participants’ financial bracket of income .................................................... 222
8.3.2 Participants’ anxiety check ......................................................................... 223
8.3.3 Participants’ depression check .................................................................... 224
8.3.4 Participants’ social support .......................................................................... 225
8.3.4.1 Emotional support .................................................................................... 225
8.3.4.2 Practical support ..................................................................................... 226
8.3.4.3 Financial support .................................................................................... 228
8.3.4.4 Informational support ............................................................................. 231
8.3.5 Participants’ description of child behaviour and functioning ..................... 232
8.3.5.1 Findings on child’s aggressive behaviour ................................................. 232
8.3.5.2. Findings on child’s repetitive behaviour ............................................... 233
8.3.5.3 Findings on child’s sleep behaviour ......................................................... 234
8.3.5.4 Findings on child’s school behaviour ...................................................... 235
8.3.6 Activities participants reported as being most helpful from the programme conducted for study 1 ................................................................. 235

8.5 Participants’ anxiety and depression scores compared between study 1 and study 2 ............................................................................................................. 236

8.5.1 Summary of parent-reported anxiety findings across parents who attended the three support groups ................................................................................. 237

8.5.2 Summary of parent-reported depression findings across parents who attended the three support groups ................................................................................. 238

8.6 Study 2 discussion ....................................................................................... 240

8.6.1 Support seeking/accessing barriers .......................................................... 241

8.6.2 Parents’ participation difficulties in study 2 .............................................. 243

8.6.3 Possible barriers to group access/attendance ............................................ 244

8.6.3.1 Financial burden as a possible barrier to group access/attendance ........... 244

8.6.3.2 Child care as a possible barrier to group access/attendance ..................... 245

8.6.3.3 Work commitment as a possible barrier to group access/attendance ........ 247

8.6.3.4 Parents’ personal needs as a possible barrier to group access/attendance .... 248

8.6.3.5 Family demographics as a possible barrier to group access/attendance .... 250

8.6.4 Parents’ concerns expressed in study 2 .................................................... 251
CHAPTER 9: Recommendations for Effective Delivery of Support for Parents of Children with ASD

9.1 Recommendations on how support might be delivered to parents of children with ASD

9.2 Limitations of studies 1 and 2

9.3 Clinical implications for studies 1 and I

REFERENCES

APPENDICES
# LIST OF TABLES

Table

1. Brief Reasons Given by Participants as to why they did not Access Government-funded Respite Service…………………………………………………………………………………………………….96

2. Participants’ Reasons for not Choosing to Attend the ASDKG…………………………..99

3. Administration of Measures for Participants to Complete at Different Phases of the Support Groups…………………………………………………………………………………………………….104

4. Sex Ratio and Age Range of Participants who Attended the Three Groups………105

5. Topics Addressed in Each Session of the FBATG………………………………………………106

6. Topics Addressed in Each Session of the STG………………………………………………107

7. Topics Addressed in Each Session of the CG………………………………………………108

8. Lists of Scales used in Surveys in Relation to Measurement Point and Week Administered……………………………………………………………………………………………………109

9. Means and Standard Deviations for the Value Attributed by Participants from the CG and by Participants from the FBATG for the Same Three Sessions They Received……………………………………………………………………………………………………145

10. Means and Standard Deviations for the Value Attributed by Participants from the CG and by Participants from the STG for the Same Three Sessions They Received …146
<table>
<thead>
<tr>
<th>Table</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td>13</td>
</tr>
<tr>
<td>14</td>
</tr>
<tr>
<td>15</td>
</tr>
<tr>
<td>16</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure

1 Mean estimates (comprising self-reported anxiety using the total score of the GAD7) calculated separately for the FBATG, the STG and the CG presented across five time periods……………………………………………………………………………...129

2 Mean estimates (comprising self-reported depression using the total score of the PHQ9) calculated separately for the FBATG, the STG and the CG presented across five time periods ……………………………………………………………135

3 Mean estimates of child’s ASD-related behaviour reported by participants from the FBATG, the STG and the CG across five time periods……………………………………136

4 Mean estimates of PCR upon the parents’ evaluations of the quality of their relationship with their child from the FBATG, the STG and the CG across five time periods…………………………………………………………………………138

5 Mean scores attributed by participants (n = 11) to indicate how valuable they found each session of the FBATG to be, using a seven-point Likert scale………………141

6 Mean scores attributed by participants (n = 12) to indicate how valuable they found each session of the STG to be, using a seven-point Likert scale………………143
Figure

7 Mean scores attributed by participants (n = 13) to indicate how valuable they found each session of the CG to be, using a seven-point Likert scale………………..147

8 Participants’ (N = 33) self-report anxiety rating during the semi-structured interview process………………………………………………………………………………224

9 Participants’ (N = 33) self-report depression rating during the semi-structured interview process………………………………………………………………………………225

10 Participants’ (N = 33) rating of the emotional support they received from family members and friends on a 10-point Likert scale, from 1 (not at all) to 10 (all the time)…………………………………………………………………………………………226

11 Participants’ (N = 33) rating of the practical support they received from family members and friends on a 10-point Likert scale, from 1 (not at all) to 10 (all the time)…………………………………………………………………………………………228

12 Participants’ (n = 29) rating of their child’s use of physical aggression and emotional aggression towards other people on a 10-point Likert scale, from 1 (not at all) to 10 (all the time)…………………………………………………………………………………………233

13 Mean estimates of parents’ anxiety self-report from the FBATG, STG and CG across six time periods…………………………………………………………………………………………238
Figure

14 Mean estimates of parents’ depression self-report from the FBATG, STG and CG across six time periods.................................................................239