Family Adaptation and Developmental Disability

Lisa Jane Studman

This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University

September 2014
Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Lisa J. Studman

15 September 2014
# Table of Contents

Declaration.................................................................................................................. ii  
List of Tables............................................................................................................... viii  
List of Figures.............................................................................................................. x  
List of Abbreviated Inventories................................................................................... xi  
Acknowledgements.................................................................................................... xii  
Abstract..................................................................................................................... xiii

Chapter 1. Family Adaptation and Developmental Disability................................. 1  
  Two Families of Children with Developmental Disabilities................................. 1  
  Developmental Disability Defined........................................................................... 3  
  Family Adaptation Defined...................................................................................... 3  
  The Double ABCX Model......................................................................................... 4  
  The Significance of Family Adaptation and Developmental Disability.............. 5  
    Prevalence of developmental disability.............................................................. 5  
    General impacts of developmental disability on families................................. 6  
  Overview of This Enquiry....................................................................................... 8

Chapter 2. Impacts of Developmental Disability on Families................................. 12  
  Family Caregiving Burden...................................................................................... 12  
    Practical burdens.................................................................................................. 12  
    Psychological and health burdens....................................................................... 14  
    Burdens on the family unit.................................................................................. 15  
  Family Caregiving Benefits.................................................................................... 17  
  Family Risk and Protective Variables.................................................................. 19  
    Daily hassles and child/family characteristics.................................................. 19  
    Parents’ relationship, supports, and resources................................................... 21
Parent coping and family functioning................................. 24

Summary.................................................................................................................................................. 28

Chapter 3. The Relationship Between Family Variables and Impact of Developmental Disability on Family Adaptation.................................................. 30

Theoretical Development of the Double ABCX Model of Family Adaptation.................................................................................................................. 30

Early theory-building influences.................................................................................................................. 30

The Double ABCX model explained......................................................................................................... 40

Summary of theoretical development of the Double ABCX model......................................................... 48

Empirical Investigation Into the Relationship Between Family Variable and Impact of Developmental Disability on Family Adaptation.................. 49

Examples of studies that relate sub-sets of family variables................................................................. 49

Examples of studies that attempt to assemble family variables into predictive models.............................. 55

Original psychometric evaluations of the Double ABCX model........................................... 62

Subsequent psychometric evaluations of the Double ABCX model.................................................... 67

Summary of empirical inquiries.................................................................................................................. 78

Family Support Programs and Family Adaptation to Disability............................................................... 78

Does the Parents Plus Program facilitate positive family adaptation?..................................................... 83

Does Signposts Building Better Behaviour facilitate positive family adaptation?........................................ 84

Does Stepping Stones Triple P improve family adaptation?........................................................................ 86

Summary of Theoretical, Empirical, and Applied Inquiries................................................................. 91

Chapter 4. Scope and Specifications of the Current Inquiry........................................................................ 93

Aims and Rationale.................................................................................................................................. 93

Specific Research Questions.................................................................................................................... 97

Goals and Hypotheses............................................................................................................................. 98
Study One........................................................................................................ 98
Study Two........................................................................................................ 99
Summary of Scope and Specifications of the Current Inquiry.................... 111

Chapter 5. Study 1: Differential Effect Sizes of a Parent Support Program on
Targeted and Non-targeted Family Variables............................................... 112
Method........................................................................................................... 113
Participants.................................................................................................. 113
Measures..................................................................................................... 115
Procedure.................................................................................................... 119
Research design.......................................................................................... 121
Statistical analysis....................................................................................... 121
Results......................................................................................................... 124
Attrition analysis....................................................................................... 124
Group equivalence...................................................................................... 124
Descriptive statistics................................................................................... 127
Assumption testing..................................................................................... 129
Testing hypothesis 1.................................................................................. 129
Testing hypothesis 2.................................................................................. 133
Testing hypothesis 3.................................................................................. 135
Discussion................................................................................................... 137
Limitations.................................................................................................. 141
Summary..................................................................................................... 142

Chapter 6. Study 2: Evaluation of the Double ABCX Model of Family
Adaptation to Disability Using Structural Equation Modelling................... 144
Method......................................................................................................... 147
Participants.................................................................................................. 147
Measures........................................................................................................ 151
Procedure........................................................................................................ 156
Data analysis.................................................................................................. 159
Assumption testing....................................................................................... 160
Replacing missing values............................................................................ 163
Determining adequate sample size............................................................. 163
Results............................................................................................................ 165
Descriptive statistics.................................................................................... 165
Stage 1: Dimensionality of measures......................................................... 167
Stage 2: The measurement model............................................................... 169
Stage 3: Testing structural models............................................................... 172
Summary and comparison of models tested................................................. 182
Discussion..................................................................................................... 184
The additive model....................................................................................... 184
The single mediator model.......................................................................... 185
The two mediator model.............................................................................. 186
Moderator model........................................................................................ 187
Comparisons with previous studies............................................................. 188
Strengths and limitations............................................................................ 191
Conclusion..................................................................................................... 193
Chapter 7. Discussion, Summary, and Conclusion..................................... 195
Key Findings and Research Comparisons.................................................. 196
Effects of behavioural family intervention on family adaptation.............. 198
Empirical support for the Double ABCX model of family adaptation...... 198
Key Contributions and Implications of this Research for the Field of
Family Adaptation and Developmental Disability................................. 199
Theoretical and empirical considerations............................................. 200
Applications to family support programs............................................. 207
Limitations and Recommendations for Future Evaluation..................... 211
Does behavioural family intervention effect family adaptation?............ 211
Can mediating or moderating influences in the Double ABCX model be determined?.............................................................. 212
Does family support, targeting family adaptation to disability, improve family and child outcomes?.................................................... 214
Summary and Conclusion........................................................................ 214
References................................................................................................. 216
Appendix A. Study 1 — Parent Information and Consent Form................. 260
Appendix B. Study 1 — Assessment Booklet............................................. 263
Appendix C. Study 2 — Pilot Test and Outcomes...................................... 277
Appendix D. Study 2 — Promotional Flyer................................................ 280
Appendix E. Study 2 — Introductory Letter and Participant Information Sheet. 281
Appendix F. Study 2 — Reminder Parent Letter........................................ 284
Appendix G. Study 2 — Measurement Model and Hypothesis Testing Syntax.. 285
List of Tables

Table 1  Rationale for Measures Used to Construct the Measurement Model... 102
Table 2  Summary of the Content of Standard Stepping Stones Triple P........ 122
Table 3  Research Design and Group Labels at Each Data Collection Time Point................................................................. 123
Table 4  Baseline Demographic Data Comparing Intervention and Control Conditions.................................................................................. 126
Table 5  Descriptive Data (adjusted Means, SDs, and Ns) Comparing Treatment and Control Conditions at all Measurement Points on Each Outcome................................................................. 128
Table 6  Statistical Group Comparison of Baseline Means......................... 129
Table 7  Results of the Omnibus Maximum Likelihood Mixed Effects Linear Regressions for Each Outcome................................................................. 131
Table 8  Least Significance Difference (LSD) Tests of the Simple Main Effects of Time for the Group x Time Interactions With Pairwise Contrasts of Pre-test and Post-test for All Variables......................... 134
Table 9  Results of the Omnibus Maximum Likelihood Mixed Effects Linear Regressions Comparing Intervention to Treated Control Groups on Each Outcome.................................................................................. 136
Table 10 Sample Biographical Information for Children............................. 148
Table 11 Sample Biographical Information for Families............................. 149
Table 12 Family Income Range......................................................... 150
Table 13 Test of Multivariate Normality Across Items for Each Measure (N = 404).................................................................................. 161
Table 14 Test of Multivariate Normality Across Subscales (N = 404)........... 161
Table 15 Tolerance Values Across Items for Each Measure (N = 404)........ 162
Table 16 Upper Limits on the Percentage of Item Missing Values for Each Measure (N = 404).................................................................................. 163
Table 17 Sample Sizes Required for a CFA of Each Questionnaire .......... 164
Table 18 Sample Size Required for Testing the Structural Models.............. 165
Table 19  Sample Size, Means and Standard Deviations for Each Variable..... 166
Table 20  Goodness-of-Fit Indicators for CFAs of Each Measure (N=404)..... 168
Table 21  Goodness-of-fit Indicators for the Original and Modified Measurement Models (N = 404).................................................. 170
Table 22  Correlational Matrix of Latent Variables.......................................... 172
Table 23  Goodness-of-fit Indicators for the Additive Model (N = 404)............. 173
Table 24  Goodness-of-fit Indicators for the Single-Mediator Model (N = 404)..... 175
Table 25  Goodness-of-fit Indicators for the Two-Mediator Model (N = 404)..... 176
Table 26  Goodness-of-fit Indicators for the Moderator Models (N = 404)........ 179
Table 27  Summary Outcomes and Comparisons of Model Testing....................... 183
Table 28  Example Family Caregiving Burdens, Measures Used to Identify Them, and Examples of Support Services that Directly Target Them..... 209
List of Figures

Figure 1. Bronfenbrenner’s ecological model of human development.......................... 33

Figure 2. The Double ABCX model of family adaptation........................................... 42

Figure 3. Theoretical models derived from the Double ABCX conceptualisation of family adaptation to be tested................................. 107

Figure 4. CONSORT diagram of participants progress through the phases of the randomised control trial indicating attrition rates at each stage........... 123

Figure 5. Mean outcome scores at pre-test and post-test for each group............. 130

Figure 6. Graphs of DBC and PS effects at the four points in time....................... 133

Figure 7. Number of surveyed household in each decile ranked socio-economic level......................................................................................................................... 149

Figure 8. The measurement model................................................................................. 169

Figure 9. The additive Double ABCX model showing Family Resources & Supports (bB), Family Stress & Demands (aA), and Family Perceptions (cC) as additive predictors of Family Adaptation (xX).... 170

Figure 10. The single-mediator Double ABCX model showing Family Perceptions (cC) as a partial and a full mediator for pathways between (i) Resources & Supports (bB) and Family Adaptation (xX), and (ii) Family Stress and Demands (aA) and Family Adaptation(xX).... 172

Figure 11. The two-mediator Double ABCX model showing Family Resources & Supports (bB) and Family Perceptions (cC) as (a) partial, and (b) full mediators of the relationship between family Stress & Demands (aA) and Family Adaptation (xX)............................................................. 175

Figure 12. The full factorial and reduced moderation models showing Family Resources & Supports (bB) and Family Perceptions (cC) as moderators of the relationship between Family Stress and Demands (aA) and Family Adaptation (xX) with and without controlling for interactions.................................................................................................................. 178

Figure 13. The relationship between Family Stress & Demands (aA) and Family Adaptation (xX) for median-split groups of ‘high’ and ‘low’ Family Resources & Supports (bB)..................................................................................... 180
### List of Abbreviated Inventories

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAS</td>
<td>Abbreviated Dyadic Adjustment Scale</td>
</tr>
<tr>
<td>DASS (-21)</td>
<td>Depression Anxiety and Stress Scale (-21)</td>
</tr>
<tr>
<td>DBC</td>
<td>Developmental Behaviour Checklist</td>
</tr>
<tr>
<td>FACES-II (-IV)</td>
<td>Family Adaptability &amp; Cohesion Evaluation Scales II (IV)</td>
</tr>
<tr>
<td>FAD (FAD-GF)</td>
<td>Family Assessment Device (General Functioning Subscale)</td>
</tr>
<tr>
<td>FBQ</td>
<td>The Family Background Questionnaire</td>
</tr>
<tr>
<td>FCOPE</td>
<td>Family Crisis Oriented Personal Evaluation Scales</td>
</tr>
<tr>
<td>FHI</td>
<td>Family Hardiness Index</td>
</tr>
<tr>
<td>FRS</td>
<td>Family Resources Scale</td>
</tr>
<tr>
<td>FSS</td>
<td>Family Support Scale</td>
</tr>
<tr>
<td>GHQ (-12)</td>
<td>General Health Questionnaire (-12)</td>
</tr>
<tr>
<td>LDI</td>
<td>Life Distress Inventory</td>
</tr>
<tr>
<td>KIPP</td>
<td>Kansas Inventory of Parental Perceptions</td>
</tr>
<tr>
<td>PCS</td>
<td>Positive Contributions Scale</td>
</tr>
<tr>
<td>PHS</td>
<td>Parenting Hassles Scale</td>
</tr>
<tr>
<td>PSoC</td>
<td>Parenting Sense of Competence Scale</td>
</tr>
<tr>
<td>PS</td>
<td>Parenting Scale</td>
</tr>
<tr>
<td>QRS</td>
<td>Questionnaire on Resources and Stress</td>
</tr>
<tr>
<td>QRS-F</td>
<td>Questionnaire on Resources and Stress (Friedrich’s short-form)</td>
</tr>
<tr>
<td>SRRS</td>
<td>Social Readjustment Rating Scale</td>
</tr>
</tbody>
</table>

1Inventories referenced four or more times in this manuscript are abbreviated.
Acknowledgments

I am grateful to all the families that participated in this research. The new National Disability Insurance in Australia will hopefully help to lighten your load.

I thank the Disability Services Commission of Western Australia for supporting this research during my employment. Special thanks to Mairead McCoy and Lee Shew Lee, who advocated strongly for the initial development and trial of Stepping Stones Triple P (SSTP), and its integration into services for families. Thank you also to technical staff that supported my access to the database for Study 2.

Curtin University and Healthway Funding have provided facilities and support to undertake this project. Thank you to Dr. Robert Kane for valuable guidance in research methods and statistical procedures, and for ongoing encouragement. Thanks to Associate Professor Clare Roberts whose supervision, positivity, and encouragement has been instrumental in achieving this project. Thank you also to Dr. Trevor Mazzucchelli for friendship and collegial support in our SSTP work together.

Thank you also to Professor David Hay and Professor Matt Sanders for early discussions about family adaptation and developmental disability. And thanks to Dr. Des McWilliam and Triple P International for supporting me to complete this manuscript.

Finally, I thank my recently passed Dad for inspiring my pursuit of knowledge and education; Mum for showing me a quiet, effective resilience and persistence; and Blaiz, my son, for your love. Thank you also to Dr. David Bonser for many years of great discussions, fun, and life together. Now we live the dream!
Abstract

How families of children with developmental disabilities adapt to increased and prolonged family caregiving burden is related to health and well-being outcomes of children and families (Reichman, Corman, & Noonan, 2008; Wallander, Decker, & Koot, 2006). Family adaptation is influenced by a range of family variables relating to (a) the extent of daily hassles and child/family circumstances, (b) the quality of parents’ relationships and their perceived supports and resources, and (c) the psychological make-up of parents, and quality of family functioning.

Study 1 examined the effects of a behavioural family intervention, (Stepping Stones Triple P (SSTP) (Sanders, Mazzucchelli, & Studman, 2004) on targeted variables (dysfunctional parenting styles and child behaviour problems) compared to non-targeted family variables (family resources and stress, family adaptation, parent sense of competence, parental dyadic adjustment, and parental mental health). Significant, large intervention effects were found for the targeted variables; small to moderate, but non-significant effects, were found for the non-targeted variables. All effects were in directions that indicated positive improvements. These results provided a rationale for further inquiry into how family variables, not targeted in SSTP, may interact to determine positive family adaptation to disability.

In the second study, structural equation modelling was used with a sample of 404 Western Australian families of children (aged 2 - 12 years) with developmental disabilities in an attempt to model family adaptation according to the Double ABCX model (McCubbin & Patterson, 1983). Four versions of the Double ABCX model were tested. Firstly, an additive model proposed that latent variables of Family Stress & Demands, Family Resources & Supports, and Family Perceptions act as correlated exogenous variables that combine additively to predict Family Adaptation. Secondly,
a single-mediator model proposed that the relationship between latent variables of Family Stress & Demands and Family Adaptation, and the relationship between Family Resources & Supports and Family Adaptation, are mediated by Family Perceptions. Thirdly, a two-mediator model proposed that the relationship between latent variables of Family Stress & Demands and Family Adaptation is mediated by both Family Resources & Supports and Family Perceptions. Finally, a moderator model proposed that latent variables of Family Resources & Supports and Family Perceptions moderate the relationship between Family Stress & Demands and Family Adaptation. Fit statistics, in conjunction with theoretical plausibility and scientific parsimony, supported the additive version of the Double ABCX model. Theoretical, empirical, and applied implications of the research are discussed.
Chapter 1

Family Adaptation and Developmental Disability

Two Families of Children with Developmental Disabilities

The Ross family consists of both parents and their two children. Nathan is 6 years old and has Down syndrome. Sam is 4 years old and developing typically. Both are physically healthy but have developed behavioural difficulties. Nathan, who has a mild intellectual disability, demands attention and has tantrums when he cannot have what he wants. He has not learnt to settle and sleep in his own bed and other children at school are at risk of being hurt by him when he is angry. Mrs Ross has a history of childhood trauma and harsh punishment. She suffers from mild depression and is overburdened by dealing with educational and behavioural programs for Nathan at school and home. She alienates herself from the school community and professional services. She has no contact with extended family and just one friend that she turns to for emotional support. She is angry that Nathan has Down syndrome and when she talks about it, she blames herself for his genetic condition, his behavioural problems, her own lack of coping, and the dissatisfaction arising in her marital relationship. Mrs Ross resents not being employed outside of the home and believes that her husband is lucky to get away from the burden every day by going to work.

The Black family consists of both parents, 7 year old Sarah, and Ben who is 5 years of age. Sarah has a genetic condition and is severely intellectually disabled. She is non-verbal but uses some key-word signing to indicate needs and preferences. She attends an educationally-supported school with a full time education-assistant.

---

2 Pseudonyms have been used for all family and individual names
Mrs Black studies part time and gave up work to raise the children in their early years. She participates on the Parent Board and contributes to the school community. Mr Black works full time and participates at home in the evening by feeding Sarah and settling her down to sleep with stories and music. The family have a supportive extended family that helps when they can. Mr and Mrs Black live in a small neighbourhood and when asked how they cope, their response is, “We feel lucky to have Sarah because she gives our family so much strength, and it has made us strong”.

Here are two families that have responded differently to the experience of raising a child with a developmental disability. Although Nathan has a mild disability, the family are burdened by their lack of resources, coping ability, partner support, and unclear boundaries around family roles. They are also burdened by Nathan’s disruptive behaviour and have not been able to implement positive behaviour support programs successfully. The family functions poorly and has not adapted well to the challenges of raising a child with a disability. On the other hand, the Black family have a child with complex care needs and they function well as a unit, or family system; they have practical and emotional resources, a positive outlook, and a meaningful way to understand their own roles in family life.

What is it about this contrasting experience that ultimately contributes to how families adapt over time? What aspects of the Ross’s family life should be targeted for intervention from a family support program? What can we learn from families that adapt well to family caregiving to inform the process of adaptation for families that do not cope well?
Developmental Disability Defined

The term *developmental disability* refers to a diverse group of severe chronic conditions caused by sensory, physical, or neurological impairments, or acquired brain injury (or any combination thereof). These conditions are permanent, with childhood onset, and cause reduced capacity in at least one area of functioning (i.e., communication, learning, mobility, independent living, decision-making, and self care). People with a developmental disability require ongoing lifelong support. Examples of conditions that can give rise to developmental disabilities include: intellectual disability; cerebral palsy; genetic conditions such as trisomy 21 (Down syndrome) and fragile X syndrome; pervasive developmental disorders such as autism and Asperger syndrome; spina bifida; cystic fibrosis; muscular dystrophy; and epilepsy (Western Australian Disability Services Act, 1993).

Family Adaptation Defined

The term *family adaptation* refers to how a family responds over time to managing their experience as a family. It is a process that involves stimulus regulation, and environmental control and balancing, to achieve a level of functioning (McCubbin & Patterson, 1983a; 1983b). This process is said to preserve the family unit and enhance the system in a way that will determine the growth and development of family members. In the context of this thesis, the concept theoretically applies to how members of a family change to accommodate both short- and long-term stressors and demands that may be related to having a child with a developmental disability. It is the culmination of these responses that manifest as an overall sense of coherence and communication, and which is influenced by support and life-orientation or coping style. Therefore, it incorporates personal and relational aspects of all members of a family and the interactional effects of all components of that family. Measures that tap
aspects of it include those that pertain to individual characteristics, child behaviour, stress and demands, coping styles, family orientation to coping, parental relationship, personal adjustment quality, and general physical and psychological health of members (McCubbin & McCubbin, 2001). Poor adaptation may be characterised by deterioration in family integrity, loss of individual or family development, or a decrease in family independence and autonomy. Healthy or positive adaptation can be characterised by strong family integrity, individual and family enhancement of development, family independence and a high sense of control over environmental influences (Walsh, 2003a).

**The Double ABCX Model Defined**

The Double ABCX model of family adaptation, proposed by McCubbin and Patterson (1982; 1983b) conceptualises how family variables interact to predict how family caregiving burden impacts on family adaptation. Although it has been applied and empirically tested with various samples of families at risk of enduring burden (e.g., defence force families and socially disadvantaged families), it is applied primarily in theory and research, to families of children with developmental disabilities (McCubbin & McCubbin, 2001). The model proposes that family adaptation (Factor xX) is influenced by three other variables. Factor (aA) is the nature of past and present caregiving burden, or ongoing sources of stress and demands, such as child-care tasks or financial burden. Factor (bB) is any prior or acquired family resources, such as social support or improved coping. Factor (cC) is made up of pre- and post-crisis family perceptions or meanings, such as optimism or making positive appraisals of the situation. The model was initially an extension of Rueben Hill’s (1949) mediating ABCX model where he described the impact of stress and demands (Factor A) on family adaptation (Factor X) as being determined by the extent of
resources (Factor B) and a family’s definition of the problem (Factor C). The nature of the interactions between factors in the model is unclear. There have been research attempts to establish the model empirically, describing both mediating and moderating interactions (e.g., Bristol, 1987; Lavee, McCubbin, & Patterson, 1985; Pozo, Sarria, & Brioso, 2014; Stuart & McGrew, 2009). However, the interactional mechanisms of the model remain inconclusive.

The Significance of Family Adaptation and Developmental Disability

Prevalence of developmental disability. In Australia, the prevalence rate of developmental disability for children, between 0 and 14 years, is reported to be 7.2% (this includes children with both core-activity limitations and schooling restrictions) (Australian Bureau of Statistics [ABS], 2012). A comparison of Australian census data from 1981 to 2004 has shown that the rates of disability, in 0 - 14 year olds, increased from 5.2% to 7.6%. This trend is thought to be related to increases in diagnosis and awareness of developmental disabilities (such as autism, attention deficit/hyperactivity disorder) and the increased survival rate of low birth-weight infants in that period of time (Australian Institute of Health and Welfare, 2004). The current reduced rate (ABS, 2012) suggests that although children may experience a variety of long-term conditions, the disabling impact of many less severe conditions has reduced over time. Data collected by the ABS in 2009 (ABS, 2012) suggested the most common conditions to be reported were mental (intellectual) or behavioural disorders, which affected 63% of children with disabilities. This represented an increase from 53% in 2003. Of this 63% of children with disabilities, 1 in 8 (13%) were reported to have autism or related (ABS, 2012).

The prevalence rate of developmental disability is thought to increase with age and be higher among boys (prevalence rate of 8.8%) compared to girls (prevalence
rate of 5.0%) (ABS, 2012). Psychological and behavioural disorders amongst children with a disability are also reported to be higher amongst boys (69%) than girls (52%).

A Western Australian population survey revealed parent-reported diagnosed child developmental problems in 5.6 – 7.6% of children between 0 and 15 years of age. At the time of survey, 6.9% were girls and 8.1% were boys (Tomlin & Joyce, 2013). In the same report, a relatively stable but fluctuating prevalence trend of 6.9% from 2002 to 2012 was noted. Rates of permanent childhood disability that put a burden on the family were reported to be 4.5% for 0 – 4 year olds; 9.2% for 5 – 9 year olds; and 12.5% for 10 – 15 year olds. More families felt burdened by the demands as children with developmental disabilities increased in age.

In the United States, the mean prevalence rate of childhood disability from 1997-2008 has been reported to be 13.87% (including learning disabilities; attention deficit hyperactivity disorder, developmental delay, and autism) or approximately 1 in 6 children. The trend is said to have increased by 17.1% over the 12 years, with boys reported to have had twice the prevalence rate compared to girls (Boyle, et al., 2011).

**General impacts of developmental disability on families.** Developmental disability impacts on the child with the condition as well as their family. Among an Australian sample of children with intellectual disabilities, it has been estimated that 40% experience severe emotional or behavioural disorders. It is estimated that this is 2-3 times the rate within the general population (Einfeld & Tonge, 1996; Emerson, 2003) and that these problems persist over time, reducing to 31% over a period of 14 years (Einfeld, et al., 2006). The Australian Carers Health and Well-being Study reported on the nature and impact of caring for family members with a disability, and specified that childhood disability was significantly related to lower levels of family
problem-solving and decision making skill. It also reported higher levels of conflict, decreased marital satisfaction, less family cohesion, and poorer adaptability in families with a child who has a disability (Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008). Comparing large samples of carers of family members with a disability \((n = 4,107)\) and the general population \((N = 30,000)\), 19% of carers reported being in the extremely severe range on the *Depression Anxiety and Stress Scale* (DASS; Lovibond & Lovibond, 1995a); 18% in the severe range; and 19% in the moderate range (Cummings, Hughes, Tomyn, Woemer, & Lai, 2007). In a survey of family carers of children with autism \((n = 134)\), significant lower levels of family adaptability and cohesion were reported, compared to normative data (Higgins, Bailey & Pearce, 2005). Mean scores fell outside the healthy family functioning range on *Family Adaptability & Cohesion Evaluation Scales – II* (FACES-II; Olsen, Bell & Portner, 1982). Families of children with developmental disabilities, compared to other general families, are at risk of experiencing heightened levels of stress as they attempt to cope with the added practical and emotional demands associated with raising a child with a disability (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008).

How a family adapts to increased levels of stress and demands has consequences on a number of levels. Firstly, poor family adaptation is related to poor developmental outcomes, emotional/behavioural problems (Wallander, et al., 2006), and negative impact on health and well-being of children who have a disability (Reichman, et al., 2008). Developmental problems are associated with higher numbers of out-of-home placements, longer stays in foster care, and a decreased chance of returning to parental care. Predictors of family breakdown or out-of-home placement have been reported to include mental health status, challenging behaviour, and the stress that caregiving puts on families (Rosenberg & Robinson, 2004).
Secondly, poor family adaptation is related to aspects of family functioning including poor parenting, marital stress, and negative effects on siblings. On a broader level, it has exuberant financial consequences on communities and public services (Allen, Lowe & Brophy, 2007; Hudson, Jauernig, Wilken, & Radler, 1995). The 2012-13 Annual Report from the Disability Services Commission of Western Australia depicts expenditure of $88.02 million spent on providing family and carer support in that year. Some 4,938 families received support and this represented a 6.2% increase from the previous year (Disability Services Commission, 2013).

**Overview of This Inquiry**

This inquiry begins with an overview of documented impacts of young children (up to 12 years) with developmental disabilities on families. Family caregiving burden is described in terms of practical burden, psychological and health burdens, and burdens on the family unit as a whole. Family caregiving benefits identified in the literature are also outlined. Chapter 2 also brings together a body of literature relating to family risk and protective variables. These include those related to (a) daily hassles and child/family circumstances, (b) parents’ relationship, supports and resources, and (c) parent coping and family functioning.

Chapter 3 provides a detailed account of theoretical, empirical and applied aspects of the relationship between family variables and the impact of caregiving burden in families of children with developmental disabilities. Firstly, early theoretical frameworks of family functioning and family adaptation are described in terms of how they have influenced the development of the Double ABCX model of family adaptation. This model is then described in detail as it applies to families of children with disabilities. Secondly, empirical investigations into the nature of interactions between family variables and how they impact on family adaptation is
discussed in terms of (a) studies that relate sub-sets of family variables, (b) studies that attempt to assemble family variables into predictive models, and then (c) original and subsequent psychometric evaluations of the Double ABCX model. This review of empirical inquiry demonstrates how a clear, concise and replicable, predictive model of family adaptation has only partially been achieved due to recurrent, methodological limitations. It argues a strong need for consolidation of an empirically supported model of family adaptation. Thirdly, application of theory and research is discussed in Chapter 3, in terms of family support programs and family adaptation. Principles that have drawn from theory and research to guide development of support programs are outline. Then evaluation trials of three key programs, Parents Plus (Coughlin, Sharry, Fitzpatrick, Guerin, & Drumm, 2009), Signposts Building Better Behaviour (Hudson, et al., 2003), and Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004) are summarised in terms of how effectively they target family adaptation. This section argues that although family support programs yield replicable positive effects on a sub-set of family variables, their impact on the broader context of family adaptation is essentially not yet investigated.

Chapter 4 presents the rationale, aims and specific research questions for the current project. The scope and specifications of two investigations are outlined. The first inquiry related to how SSTP impacts on family adaptation compared to how it affects targeted family variables of child behaviour and parenting style. The second inquiry uses structural equation modelling to evaluate the Double ABCX model of family adaptation and describe the predictive nature of interactions between factors. Specific hypotheses for each study are outlined and the rationale for inventories used to construct the measurement model is presented. This section also explicitly presents
four models that are tested: an additive model; a single-mediator model; a two-mediator model; and a moderating model.

Chapter 5 depicts the first study, *Differential Effects Sizes of a Parent Support Program on Targeted and Non-targeted Family Variables*. It describes a minor independent study from within the original broad evaluation of SSTP, using a randomised, controlled design (Roberts, Mazzucchelli, Studman, & Sanders, 2006). Study 1 quantified the relative effect sizes of SSTP on targeted variables (parenting style and child behaviour) and non-targeted variables related to family adaptation (resources and stress, family adaptation, parental sense of competence, dyadic adjustment, and parental adjustment). Chapter 5 discusses evidence for SSTP yielding positive and significant, large effects on parenting style and child behaviour (as reported in the broader evaluation) and non-significant, small to moderate effects on other family variables related to family adaptation (reported here as part of this project).

Chapter 6 depicts the second study in this thesis, *Evaluation of the Double ABCX Model of Family Adaptation to Disability Using Structural Equation Modelling*. It consolidates the conceptualisation of key terms in the Double ABCX model by developing a reliable measurement model consisting of a wide range of observed variables that theoretically pertain to the four latent variables in the model. These are: Factor (aA) – *Family Demands & Stress (aA)*, child/family-related caregiver burden and general life stressors that build-up over time; Factor (bB) – *Family Resources & Supports (bB)*, indications of general family resources, formal and informal practical supports, and internal family emotional resources or hardiness; Factor (cC) – *Family Perceptions (cC)*, positive perceptions that parents make about having a child with a disability, and general family approach to problem solving over
time; and Factor (xX) – *Family Adaptation (xX)*, indications of general physical and psychological health of parents and family adaptation in relation to dimensions of the McMaster model of family functioning (Epstein, Ryan, Bishop, Miller, & Keitner, 2003). This chapter describes the methodology, analysis, and results of structural tests of four competing, theoretically-derived models. Models are compared on fit-statistics, an Akaike Information Criterion (AIC; Akaike, 1974), conceptual plausibility, and parsimony. Results are discussed and highlight the evidence for an additive model with direct pathways from Factors (aA) and (bB) to Factor (xX). No conclusive predictions from Factor (cC) were found.

Finally, the concluding chapter in this thesis outlines key findings of both studies and relates their findings to past research. Key contributions of this research to the field of family adaptation and developmental disability are discussed, firstly in terms of theoretical and empirical considerations. Secondly, key contributions are discussed in terms of recommendations for application of findings into the development of family support programs to facilitate family adaptation for families of children with disabilities. Before the final summary and conclusion, a number of limitations and recommendations for future evaluation of (a) behavioural family interventions for parents of children with disabilities, (b) the Double ABCX model, and (c) applied family support programs that target family adaptation, are reported.
Chapter 2

Impacts of Developmental Disability on Families

Having a child with a disability can impact on families in positive and negative ways. *Family caregiver burden* refers to parents’ stress, the practical activities, and emotional demands they may experience. *Family caregiver benefit* refers to the positive experiences that contribute to a sense of achievement, meaning, and quality of life (Green, 2007). In this section, both the potential negative and positive impacts of having a child with a disability on a family are outlined.

**Family Caregiving Burden**

Family caregiving burden can be described with three points of reference: a parent’s response to the practical aspects and burdens of being a parent of a child with a disability; the psychological and health aspects of that experience; and the burden of care on family relationships and the family unit as a whole.

**Practical burdens.** The practical aspects of parenting a child who has a disability can contribute to an experience of burden because they are often over and above that for parents of children developing typically. They can include both the burden of daily hassles and financial strain.

Parents of children who have a disability are often required to do more for their child on a daily basis. Sometimes these tasks are referred to as *daily hassles* (Coplan, Bowker & Cooper, 2003; Crnic & Greenberg, 1990; Gavidia-Payne & Stoneman, 2006; Plant & Sanders 2007a). Parents may need to provide extra time and assistance with activities of daily living such as self care (e.g., bathing, grooming, toileting, and eating meals), social interactions (e.g., communicating, playing, and enjoying being with others), learning (e.g., implementing home-education or therapy programs, doing homework, and providing increased incidental teaching throughout
the day), and behavioural/emotional development (e.g., teaching self-regulation, managing difficult behaviour at home and in public, and nurturing warm positive relationships). In addition to daily tasks, parents usually spend time and energy seeking educational/therapy services; consulting with health professionals; advocating for the inclusion of their child in least restrictive environments such as mainstream schools; implementing complicated medicinal regimes; providing transport; keeping paperwork up-to-date; following through with treatments and interventions at home; dealing with their child’s willingness to comply with treatment regimes; minimizing pain for their child; having ongoing concern about prognosis; and dealing with challenging behaviour (Plant & Sanders, 2007a). This of course, is on top of other general duties that parents provide for their family and other children.

The financial burden associated with raising a child who has a developmental disability can also be significant. Costs can come from therapeutic equipment to support learning and development (e.g., toys, computer programs, modified cutlery, and self-care items); social development (e.g., special educational play groups, after school programs, and respite); mobility (e.g., support braces, wheelchairs, and modified car safety equipment); and health and nutrition (e.g., pre-prepared dietary foods and purees, naso-gastric tube-feeding equipment, and incontinence pads). On top of such everyday expenses, there can be costs associated with accessing medical, education, and psychological support for their child and family. Specialists may include speech pathologists, occupational and physio-therapists, teachers and tutors, medical officers and paediatricians, and psychologists and family counsellors.

Some 23% of respondents to the Mecap Report in the United Kingdom (Mencap National Centre, 1997) claimed that they, or their partner, had to give up work to care for their child with a disability. Many talked about the stresses and
demands experienced from having a child with a disability and the consequent effects on working status and salary. Further, a review of economic costs of autism spectrum disorder in Australia estimated costs between $4.5 billion and $7.2 billion annually. This was related mostly to costs of general and mental healthcare, social services, education, employment, informal care, and the impact of caregiving burden. The most significant impact on families reported included the costs associated with reduced income due to reduced employment and the costs of informal care (Synergies Economic Consulting, 2007).

**Psychological and health burdens.** These can include the experience of grief, stress, health problems, and burdens on siblings. When a child who has a developmental disability arrives, parents can experience a strong emotional reaction that may change or persist and may contribute to a sense of caregiving burden. The birth of a child with a disability can be a critical and even traumatic life experience for a parent. It can evoke the complexity of a crisis reaction in families and potential psychosomatic and psychological problems (Bruce & Schultz, 2001). Recurrent grief associated with the perceived loss of the ‘expected child’ can be experienced at different times or stages of the child’s life. Bruce, Schultz, Smyrnios, & Schultz (1994) argue that the extent of discrepancy between a parent’s perceptions of the child they have and the child they wished for, or ‘ideal child’, is persistent over time. That is, the experience of loss and the need to grieve remains as children develop or may recur at different stages of family life. Parents can feel stressed and exhausted, emotionally drained, angry or resentful. Dyson (1993; 1996) reports that parental pessimism about the child’s future increases over time when their child has a disability. Some parents also experience excessive self-blame and guilt (Nixon 1993; Seligman, 1993). This can interfere with development of attachments with children,
effective parenting, marital relationships, and self-care abilities (Nixon & Singer, 1993).

Parents of children with developmental disabilities are also more likely than others to experience high levels of stress, anxiety, and depression (Baker, et al., 2003; Gerstein, Crnic, Blacher & Baker, 2009; Gupta, 2007; Hastings & Beck, 2004; Oelofson, & Richardson, 2006). Meta-analysis comparing scores on depression inventories between mothers of children with and without a disability has shown a significantly elevated risk for the former group (Singer, 2006). Parents of children with disabilities are also reported to be at increased risk of physical health problems such as back-pain, migraine headaches, stomach/intestine ulcers, asthma, arthritis and pain (Brehaut et al., 2004; Murphy, Christian, Caplin, & Young, 2007).

In addition, impacts on siblings include higher levels than a normative sample on parent reported behaviour problems, less prosocial behaviour (Hastings, 2003) and more emotional problems compared with siblings of children without a disability (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009).

**Burdens on the family unit.** Family caregiving burden can also relate to the potential impact on marital relationships, family functioning and social networks.

With respect to impact on marital quality alone, the jury has been out for a number of years since some researchers report negatively skewed comparisons to parents of children without disabilities (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) while others have reported substantial evidence that the quality of marital relationships for these families is not at risk of decline (Gavidia-Payne & Stoneman, 2006). Rather, marital quality is related to how individuals support each other and share the family burden of care. A meta-analytical review examining levels of divorce and marital satisfaction in parents with and without children with disabilities
concluded that the parents of children with disabilities are only 3 – 6% more likely to divorce than others (Risdal & Singer, 2004). Higgins, et al., (2005) report on primary caregivers of children with autism spectrum disorder in Victoria, Australia, concluding that lower levels of marital satisfaction, family cohesion and family adaptability can be perceived as part of the family caregiving burden. From a comparison of parents of children with autism \((n = 25)\) and parents of typically developing children \((n = 20)\), the former reported lower levels of total social support and relationship satisfaction \((p < .05)\) compared to the latter but no significant differences between reports of perceived spousal support, respect for their partners, or commitment to their relationships (Brobst, Clopton, & Hendrick, 2009).

Patterson and McCubbin (1983) have reported extensively that family relationships and the family unit can become strained leading to such symptomatology as: parental over-protectiveness that jeopardises the child’s development or independence; coalitions between members of family to the exclusion of others; scape-goating and blaming of the child or of the parent believed to be genetically responsible; overt or covert rejection of the child which affects physical and emotional development; worry or resentment about extended parenting/care-taking responsibilities past the normal age range when parents are expected to be providing for their children; sibling competition for parent time and attention; sibling comparisons and discrepancies regarding uneven physical emotional, social and intellectual development; and an overall increase in intra-family tension and conflict. There can also be modifications in family activities and goals, reduced flexibility in leisure time and restricted options for vacations. Parents can also have less opportunity to pursue careers and may spend time and energy worrying about having more children when disability is genetically linked. The increase and nature of the
demands (both physical and emotional) that need to be met by the family may result in significant changes to routines, roles and expectations of family members (Rutter, Taylor, & Hersov, 1994), putting strain on the family unit. Siblings of children with disabilities have been reported to show significantly higher than normal levels of emotional symptoms and peer problems (Giallo & Gavidia-Payne, 2006).

Reported impacts of disability on family social opportunities and networks are related to stress associated with: reactions and expectations of others; family embarrassment; limited mobility or access for people with disabilities; unavailable child care; and fear of accidents or exposure to infections. These restraints can lead to limited opportunities for families to integrate with their general community and develop natural social networks and experiences (Llewellyn & Gustavsson, 2010; Woolfson, 2004).

**Family Caregiving Benefits**

There is also strong evidence that families can benefit psychologically, as individuals and as a family unit, from the experience of overcoming challenges related to caring for a member with a developmental disability.

Such personal characteristics as coping ability, hope attachment, optimism and faith, courage, an altruistic view of humanity, and joy in daily tasks, are some of the reports that have emerged over the last three decades (Burden & Thomas, 1986; Corman, 2009). Dyson (1999) compared a matched cross-sectional sample of siblings of children with developmental disabilities on self concept, behavioural adjustment, and self competence to children of non-disabled siblings and reported that the two groups did not differ significantly over time. She argued that how siblings adjust is related to the quality of family relationships, organisation and family emphasis on personal growth. Benefits for siblings that have been reported include aspects of
personality characteristics such as increased tolerance and awareness of difference; a caring, compassionate nature; increased maturity compared to peers; and an enhanced appreciation of their own health and abilities (Dyke, Mulroy, & Leonard, 2009).

Behr and Murphy (1993) examined how the experience of raising a child with a disability can act as a catalyst for a parent to restructure their life along more meaningful lines. Their research involved an examination of parent perceptions of positive contributions. Factor analysis of responses from a scale they developed revealed nine dimensions of parent reported positive benefits of parenting a child with a disability. These included: learning through experience with special problems in life; happiness and fulfilment; personal strength and family closeness; understanding life’s purpose; personal growth and maturity; awareness of future issues; expanded social networks; career or job group; and pride and cooperation. Further psychometric evaluation of the instrument, the Positive Contributions Scale (PCS) indicated a further four factors including: a sense of accomplishment in having done one’s best for the child; sharing love with the child; becoming a better person (more compassionate, less selfish, more tolerant); increased spirituality; and making the most of each day, living life at a slower pace (Hastings & Taunt, 2002).

Family units can be strengthened through the experience of developing positive belief systems, values, and a compassionate worldview. As a family unit, a more positive outlook and worldview can be developed when families have a strong sense of coherence and control, and a way of examining their priorities, parenting and family roles, and their disability-related values (King et al., 2006).
**Family Risk and Protective Variables**

Family variables considered risk factors for poor family adaptation or an increased experience of burden, and those that relate to positive family adaptation or protection from the risk, are different for each family. Caregiver burden is experienced in a context that determines the experience for parents. That context includes (a) the extent of daily hassles and child/family characteristics (such as child disability, age, gender, behaviour problems, and socioeconomic status), (b) the quality of parents’ relationships and perceived social supports and resources, and (c) the psychological make-up of parents and quality of family functioning.

**Daily hassles and child/family characteristics.** A number of studies have reported that the extent and type of disability that a child has can be a significant predictor of family stress and adaptation. The more debilitating the impairment, the more caregiver burden (Beckman, 1983; Crnic, Friedrich, & Greenberg, 1983; Davis & Gavidia-Payne, 2009; Haveman, van Berkum, Reijnders, & Heller, 1997; Plant & Sanders, 2007a; Wang, et al., 2004). Other investigators suggest that the burden of care and management problems decrease with the severity of the disability and this is related to less psychological distress (Sloper, Knussen, Turner, & Cunningham, 1991). Different type and extent of disability can be related to different types of specific needs and the likelihood that a child develops behaviour problems.

Behaviour problems are considered to be a particular burden for parents of children with developmental disabilities and are a risk factor for poor adaptation. (Emerson et al., 2001; Herring et al., 2006; Plant & Sanders, 2007a). When a child has these problems, parenting can be more difficult and this can add to family stress. In a study comparing parents of children who had disabilities with and without behavioural disturbances it was reported that the presence of maladaptive behaviours
and poor health of children with disabilities is associated with higher levels of family stress (Heller, Hsieh, & Rowit, 1997).

The child’s age is another important variable that can be a risk factor for burden. Minnes (1988) reported that levels of perceived stress are negatively correlated with the child’s age. Parent stress can increase at times of transition from one developmental stage to another. For example, parent stress during early childhood can be high at first and then decrease as families develop resources to cope. When the child moves onto middle childhood years and begins formal school, family stress can increase again until new resources are found to assist parents to cope with the new challenges (Bruce & Schultz, 2001).

Family characteristics including socioeconomic status, has been cited many times as a risk factor for increased caregiver burden. Fergusen and Watt (1980) showed that socioeconomic status was associated with distress levels in families of children who had disabilities. They compared mothers of school-aged children with and without disabilities on levels of anxiety. The authors reported that socioeconomic status was a higher predictor of anxiety than whether the child had a disability. This finding has been replicated over the years (Crnic, et al., 1983; Dyson, 1993; Emerson, 2003; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008).

Emerson (2003) looked at family variables associated with family stress of 9726 mother-child dyads in the United Kingdom, with and without a child with a disability. He concluded that families supporting a child with a disability were significantly economically disadvantaged compared to parents of typically developing children. He also reported that levels of mental health problems were mostly related to the child’s difficulties; the social impact; child gender (boys being a higher risk); the child experiencing more than one potential stressful life event; being in receipt of
welfare benefits; and ‘unhealthy family functioning’ as measured by the *Family Assessment Device* (FAD; Epstein, Baldwin, & Bishop, 1983). Interestingly, this analysis suggested that once these factors were accounted for, the presence of child intellectual disability appeared to be moderately protective against maternal mental health problems. That is, once risk factors were statistically controlled, mothers of children with intellectual disability were less likely to screen positively for mental health problems.

Another variable reported to influence family stress is the number of siblings in a family and how those siblings cope with the added practical and emotional demands. The less well a sibling copes with the demands, the increased risk of parent stress and poor family functioning (Crnic, et al., 1983; Crnic & Leconte, 1986; Dyson, 1999; Giallo & Gavidia-Payne, 2006).

**Parent’s relationship, supports, and resources.** Higher levels of support, less conflict, and free expression of personal feelings have been reported to promote adaptation and healthy coping (Dyson, 1993). Marital quality and pregnancy stress can correlate highly with acceptance of a child who has a disability (Bradley, Rock, Whiteside, Caldwell, & Brisby, 1991). The Mencap Report on families of children with disabilities in the United Kingdom (Mencap National Centre, 1997) was a benchmark survey of 400,000 parents of children with disabilities. It posited that having a child with a learning disability can put a severe strain on parents’ relationships. Approximately one third of parents (29%) reported that their marital relationship had not been affected whilst about the same number argued that the quality of their relationship had been enhanced through the experience. However, 20% of families did experience more marital arguments since finding out about their child’s disability and another 16% reported marital breakdown. Through the
qualitative interviewing that researchers completed, marital arguments and breakdown was explained as a consequence of excessive stress and lack of external support such as parent support programs or counselling. Quality of parents’ relationships is a risk/protective factor for poor family outcomes.

Family resources, practical and emotional, that exist or are acquired can also be a protective variable, enabling families to cope more positively. Within the family such resources can include: open communication style; effective problem-solving strategies; shared roles and responsibilities; cohesion and love; spiritual or belief systems; and financial and material resources. Extra-familial resources can include assistance from extended family members or social and professional networks, such as: day care; respite; health professional input; counselling; behavioural programming; social connection with other parents of children with disabilities; church activities; and early childhood educational programs (Dunst, Trivette & Deal, 1988; 1994). Resources and support are family strengths that promote emotional, physical, informational, instrumental, and material aid, and that assist to maintain health, well-being and positive adaptation to life events.

Sources of family support can be seen as either informal or formal (Dunst, Trivette, & Deal, 1988; 1994). Informal sources may come from kin, friends, neighbours, ministers, etc., while formal sources arise from hospitals, early intervention services, health departments, etc. Results from the early work of Dunst and colleagues has shown that adequacy of different types and forms of support could promote parent and family well-being, decrease time demands on parents by their child with a disability, promote positive caregiver interactive styles and enhance positive parental perception of child functioning.
More recently, Canary (2008) reviewed one hundred and three peer-reviewed empirical articles constituting an amalgam of quantitative and qualitative research on support for families of children with disabilities. She unveiled nine focus areas of resources and support that were claimed to positively influence family outcomes. In terms of socioeconomic factors, she claimed that it is evidenced that low-income families are more likely to report low levels of informational support about disability issues, limited access to professional support services, and inconsistent use of available supports. Whereas positive outcomes were shown to be associated with intervention programs such that a child’s peer and social acceptance could be improved, family well-being could be increased, and sibling relationships improved. Reportedly, there can also be an increased positive perception of support, and parents’ knowledge of disabilities can be improved when a family chooses to participate in a program.

Canary (2008) also highlighted research that suggested that grandparents can provide an important source of support, and other research, where they do not. It seems that maternal grandmothers provide more instrumental and emotional support than other grandparents (Trute, 2003). Canary (2008) suggested that social support benefits siblings positively and professional support benefits parents, especially when professionals work outside of narrow job descriptions and deal with families on a personal basis. Another well-recognised source of support reported was religion. She provided evidence that parents often report gaining strength and meaning from faith that helps them relate to their child and deal with challenges. And finally, Canary (2008) purported that difficulty accessing services or a lack of coordination in service planning and delivery can be burdensome for families.
Parent coping and family functioning. The third contextual element that can have a risk/protective influence on families is a parent’s and/or a family’s psychological characteristics. Resiliency or protective variables include parents’ gender, self-efficacy, appraisal and coping style, beliefs, sense of coherence and personality. How parents make meaning, affirm strengths, become more compassionate, find spirituality, and develop belief systems can all be influences on family outcome (Bayat, 2007).

Parent gender. Mothers tend to report periodic crises or recurrent grief associated with child disability while fathers tend to report steady gradual adjustment that is time-bound (Bruce, et al., 1994; Petchel-Damrosch & Perry, 1989). Some studies have reported that mothers express higher levels of distress and depressive symptoms, more pessimism regarding the future, more concerns with child development and behaviour problems, more problems related to demands on time and more poor health (Bruce, et al., 1994; Frey, Greenberg, & Fewell, 1989; Scott, Atkinson, Minton, & Bowman, 1997). Parent gender also influences what is perceived to be supportive. That is, fathers report higher stress levels as a function of stressful family environments, whereas mothers are more affected by personal support networks, or lack of them (Scott, et al., 1997). The use of family problem-solving and coping behaviours has been reported to play a more important role for fathers than mothers, and to be mediated by social support and marital satisfaction (Katz, 2002).

Sense of efficacy. Parent sense of efficacy has been related to coping in their role and in general maternal warmth, sensitivity, and consistent parenting (Sanders & Wooley, 2005). Others have extended this idea to argue that self mastery is a more global dispositional trait and is the perception that one has control over life events. It has been found to be related to higher levels of active coping and problem-solving. In
an analysis of 225 United States families, Paczkowski and Baker (2007) found no significant difference between levels of self-reported self mastery in parents of children with developmental delays compared with those of typically developing children. They did find however, that self-mastery was related to parenting and child behaviour problems, therefore having an indirect protective influence on family stress and adaptation.

**Appraisal and coping style.** How parents appraise caregiver burden influences their experience of it. Stress theory (Lazarus, 1993; Lazarus & Folkman, 1984) has long demonstrated the importance of cognitive appraisal or perceptions when determining how a person reacts to a potentially stressful event. Making a judgement about how equipped they are to deal with a potential stressor increases their coping ability. Summers, Behr and Turnbull’s (1989) early work on family perceptions applied this idea to families. They drew on Taylor’s cognitive adaptation theory (Taylor, 1983) to argue that adjustment to threatening events is influenced by three dimensions of cognitive adaptation. The first of these is considered to be the causal attributions that a parent makes about their child’s disability. That is, finding meaning and cause, is associated with better psychological and physical health whether that cause is medical, genetic, environmental, or based on spiritual beliefs.

The second dimension is a sense of mastery or gaining control as a way to manage the threat of a potential stress and prevent it from occurring again. This is considered to be enhanced when parents take *informational control* by learning as much as possible about the event or situation and *behavioural control* when they take direct action to change or improve the situation. The third dimension is enhancing self-esteem by selectively attending to the positive aspects or benefits of a situation or by making
downward social comparisons to view oneself positively and thereby enhance self-esteem.

This work was extended by Behr, Murphy, and Summers (1992) when they focused on developing a measure to assess families on these dimensions of cognitive adaptation. The Kansas Inventory of Parental Perceptions (KIPP) was used with over 1200 parents of children with a disability and factor analyses supported a hypothesis that major dimensions of cognitive adaptation comprised numerous underlying dimensions. They reported four perceptions related to cognitive adaptation of parents with children with disabilities. Firstly, there was a perception of positive contribution as represented by the 9 factors of the PCS (part of the KIPP). Secondly, there was a perception of social comparison represented by 4 factors (similar comparisons; downward comparisons; upward/favourable comparisons, and upward/unfavourable comparisons). The third dimension was labelled, attributing a cause, and was described as a perception comprised of fate or chance; special purpose; physiological cause; professional blame; and self-blame. The fourth perception, mastery or control, consisted of factors related to personal and professional control. When they looked at how parents scored on some of these dimensions and compared those scores to how well parents coped generally in their role, they found weak to moderate relationships between perceptions and parent psychological outcomes. Clearly, parental perceptions alone could not account for all variability in family caregiving burden but appears to be one important risk/protective factor.

Hastings, Allen, McDermott and Still (2002) adapted the early measure of positive contributions (the PCS), and surveyed 41 parents of children with autism, to explore the association between parental perceptions and positive versus negative coping outcomes. They found support for the idea that positive perceptions were
associated with coping strategies that focus on positively reframing stressful events. They argue that the experience of burden is related more to psychological variables than demographic and child ones. Specifically, parents who used reframing coping strategies had more positive perceptions of their experience.

**Family beliefs.** A family’s belief system comprises worldviews, values and priorities that emerge as a shared construction of reality amongst family members and can influence adaptation to adverse situations or events (McCubbin & McCubbin, 1993; 1996; Walsh, 1998; 2003a). Hastings and Johnson (2001) reported that in their sample, beliefs about the efficacy of interventions had a direct relation to a parent’s pessimism or optimism toward the symptomatology of their children who had autism. Belief systems are used to cognitively organise family processes and approaches and increase options for problem resolution, healing and growth. They help family members make meaning from crisis, facilitate hope, optimism and can be related to spiritual pursuits (Walsh, 2003a; 2003b). Indeed parents have reported directly in qualitative interviews that their changes in belief systems led to different ways of viewing their child, their role as parents, and their family (King et al., 2006).

**Sense of coherence.** Antonovsky (1998a) described this concept as “a way of seeing the world which facilitates successful coping with the innumerable, complex stressors confronting us in the course of living”, (p. 22). It is a global orientation that is the extent to which a person has a pervasive, enduring sense of confidence that makes experiences structured and predictable; makes available internal and external resources to meet demands; and promotes the view that daily demands and hassles are challenges worthy of investment and engagement (Antonovsky, 1993; 1998a; Antonovsky & Sourani, 1988). Parents of children with disabilities have reported, in comparison to those with typically developing children, that they had significantly
lower levels of a sense of coherence, higher levels of parenting stress and poorer health (Oelofsen & Richardson, 2006). Related to a sense of coherence is the style of coping strategies that parents adopt. ‘Approaching’ and taking an active problem solving approach rather than ‘avoiding’ problems can have benefits (Atkinson et al., 1995; Lloyd & Hastings, 2008). A problem-solving coping style rather than an emotional coping style has been associated with better family outcomes (Katz, 2002).

**Personality.** Neuroticism, as a personality quality, has been said to be a strong predictor of depression for birth and adoptive parents of children with disabilities (Glidden & Schoolcraft, 2003). Glidden and other colleagues further suggest that there may be a dispositional or trait-related notion of coping (Glidden, Billings, & Jobe, 2006). They found that neuroticism as measured by the *NEO Five-Factor Inventory* (Costa & McCrae, 1992) in their sample of 97 parents of children with disabilities was strongly related to an ‘escape-avoidance’ coping strategy which was associated with lower levels of subjective well-being.

**Summary**

In summary, family caregiving burden related to having a child with a disability includes practical demands (i.e., daily hassles around added caregiving tasks, and financial strain from additional costs and loss of employment), psychological and health burdens (i.e., recurrent grief related to diagnosis, parent emotional stress, healthy-related concerns, and affects on siblings), and burdens on the family unit (i.e., some aspects of relationship quality and social support that can be affected, family functioning such that instability within roles and routines can emerge, and families can become socially isolated). In contrast, a number of family caregiving benefits have also been identified in the literature. These are incorporated into a body of literature that considers the positive contributions that parents identify
that are related to having a child with a disability. Examples include: personal and family attributes (e.g., coping ability, optimism, personal worldview, positive sibling adjustment, belief systems, and compassion).

Since families respond to caregiver burdens and benefits differently, a number of risk and protective variables have been identified that can influence child and family outcomes. These include child/family characteristics (e.g., child age, type, and extent of disability, behaviour problems, family economic status, and sibling adjustment); parent relationship, supports and resources (i.e., a supportive marital relationship, and increased practical and emotional resources improves outcome); and parent coping and family functioning (i.e., higher levels of self-efficacy, sense of coherence, positive attributional style, and active problem-solving coping style are related to better child and family outcomes). How these family variables interact is important since they may buffer families against caregiver burden and negative family outcomes. Many of the risk and protective factors identified in the literature are deduced from simple correlational examination. It is important to consider what theory, research, and applied practice can provide in terms of understanding how these variables interact to reliably predict family adaptation.
Chapter 3

The Relationship Between Family Risk Variables and Impact of Developmental Disability on Family Adaptation

This chapter firstly introduces theoretical approaches to understanding how family risk variables influence the impact, of developmental disability, on family adaptation. It begins with a description of early theoretical influences on the development of the Double ABCX model. It then describes the model in detail. Secondly, in this chapter, empirical approaches to understanding the relationship between family risk variables and family adaptation is provided and considers three broad bands of research. And thirdly, this chapter considers applied approaches to facilitating family adaptation by reviewing family support programs. It focuses on the clinical effects of three specific programs and whether they have been shown to facilitate family adaptation in families of children with developmental disabilities.

Theoretical Development of the Double ABCX Model of Family Adaptation

Early theory-building influences. Understanding how family variables interact to determine family adaptation begins with understanding how personal variables interact to determine the effect of stress on individual coping. It also involves the theoretical influence of models of ecology, family systems theory, and models of normative family functioning and change across the lifespan.

Stress-coping theory related to individuals. Psychological stress is referred to as, “...a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources” (Lazarus & Folkman, 1986, pp. 63). Negative effects of prolonged strain or crisis appear as physical, psychological or physiological problems in individuals (Lazarus & Folkman, 1984). The nature and extent of the experience of stress for an
individual, is influenced by the way that an individual processes and experiences stress and environmental demands. Lazarus and Folkman (1984) suggested that stress results from a perceived imbalance between demands and resources, or when demands exceed a person’s perception of their ability to cope. A person’s resources and ability to cope was said to mediate the relationship between stressors (environmental demands) and stress (physiological and psychological responses to stressors). Key concepts in this definition of stress are cognitive appraisals and coping.

The concept of appraisal explained individual differences in responses to stressors. Cognitive appraisal was said to be determined by personal and situational factors such as motivational dispositions, goals, values and expectancies. The concept of coping was seen to be the cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts (Folkman & Lazarus, 1980). Coping actions could then be distinguished by their focus on different elements of a stressful encounter. The theory argues that a person can attempt to change actual things that are perceived as stressors in their environment (problem-focused coping) or they can attempt to reduce internal negative emotional states by changing their appraisal of the demanding situation (emotional-focused coping).

Quine and Pahl (1991) applied theory of stress and coping to families who were adapting to having a child with a disability. They took a stratified randomised sample of 166 parents of children with disabilities up to sixteen years old and conducted structured interviews at two points in time, 3 years apart. Family variables examined included child functioning and behaviour; family environment and relationships; social supports and coping; impact of the child on family; acceptance of the child; health; and satisfaction with services. They tested Lazurus and Folkman’s
model of stress using stepwise multiple regression analysis finding that maternal health, behaviour problems, coping, social class, acceptance, and finances, explained the greatest proportion of variance in maternal stress (the outcome variable). In a second regression analysis, entering variables in a hierarchical order, they found that child variables explained 12% variance and coping resources explained 43%. They concluded support for a mediator model indicating that the effect of child characteristics on maternal stress was mediated by factors related to coping resources and strategies.

**Ecological theory.** General systems theory was first described by Gregory Bateson, a Cambridge anthropologist. He integrated cybernetic theory and psychology to explain how a change in part of an interacting system generates change in other aspects of the system, through feedback that triggers system change. Feedback could comprise behaviour patterns, communications, and contexts which could maintain clinical problems (Bateson, 1972, cited in Carr, 2012). The theory ascertains that a system has capacity to use feedback about past performance to improve outcomes for the system in the future. Individuals, groups, or families could be explained as systems in homeostasis. When applied to families it poses the question of how a family system uses feedback to remain stable or to adapt to new circumstances (Carr, 2012). A balance is thought to exist among all parts of the system. So whenever one part of the system strives for unrestrained growth or change, the entire system will lose its healthy balance, and seek to adapt and resume healthy balanced functioning (Nichols & Schwartz, 2001).

Applied to child and human development, a dominant systemic approach has been Bronfenbrenner’s ecological systems theory (Bronfenbrenner, 1979; 2005). It identifies five subsystems that influence how a person develops and how they
experience life (see Figure 1). The *microsystem* is said to include the settings in which the person interacts, such as with family, peers, school, and neighbourhood.

![Bronfenbrenner's ecological model of human development](http://en.wikipedia.org/wiki/File:Bronfenbrenner%27s_Ecological_Theory_of_Development.jpg)

*Figure 1. Bronfenbrenner’s ecological model of human development. Reproduced from [http://en.wikipedia.org/wiki/File:Bronfenbrenner%27s_Ecological_Theory_of_Development.jpg](http://en.wikipedia.org/wiki/File:Bronfenbrenner%27s_Ecological_Theory_of_Development.jpg). Permission is granted to copy, distribute and/or modify this document under the terms of the GNU Free Documentation License.*

The *mesosystem* is said to be the relationships between microsystems. For example, how parents interact with teachers will influence the stability of the family microsystem. The *exosystem* is said to include the links between a social setting, which the individual does not have a role, and their immediate context. For example, a parent’s experience at work may influence a child’s experience of home. The
*macrosystem* is described as the culture in which a person lives, including elements of community, socioeconomic status, ethnicity, and religion. Lastly, the *chronosystem* is said to be the pattern of events and transitions throughout a person’s life course and historical circumstances.

This model has been applied to families of children with disabilities to conceptualise how factors that influence coping and adaptation interact. Rentinck, Ketelaar, Jongmans, and Gorter (2007) completed a literature search of factors related to the process of adaptation when a family has a child with cerebral palsy and used Bronfenbrenner’s model to conceptualise a framework. Olsson and Hwang (2002) also applied this model to explore the ‘macrostructure’ in Sweden, identifying societal differences in family characteristics when there is a child with intellectual disability and/or autism compared to other countries.

The ecological perspective maintains a focus on both the environment and the individual person’s coping capacities. This resulting transactional view results in the understanding of a family as a social system, or living system, which is typified by fundamental aspects including boundaries between members, adaptation to change, a steady state of equilibrium, energy, communication, and organisation (Lesser & Pope, 2007). Transactional processes reflect the quality of interactions that continually move in both directions between family members and can reveal complex patterns of influence and quality of family life. Interactional observation, with analysis of reciprocal causality, is considered a method that reveals the operation of some key family processes. Ecological aspects of family life, including income, neighbourhood, cultural goals and values, beliefs about raising a child with a disability, and family life, are thought to be mediated through child activity settings and routines where children interact with family members (Lucyshyn, et al., 2004). Moment-by-moment,
aversive, micro-social interactions, whereby dysfunctional interactions are reciprocally reinforced by the respective response of both parent and child, were first described by Patterson’s coercion theory (Patterson, 1982). Based on this, Lucyshyn et al. (2009) have broadened the unit of analysis in family research by developing an observational method to code family routines and activity-based interactions. Multiple baseline designs across time can then provide longitudinal data. Observations made throughout daily routines such as ‘free-time’, ‘dinner-time’, and ‘homework-time’ have been found to correlate with parent reports on measures of parental stress, social support, and parent locus of control.

**Models of normative family functioning.** Systems and ecological theory, applied to family psychology, has influenced family therapy paradigms. Theoretical perspectives on how families cope with stress, and function as systems, emerged. Models of family coping, functioning and adaptation became more relevant to family theorists than models of individual coping. Two specific models are outlined below that relate theoretically and empirically to families of children who are developing typically and have influenced the development of the Double ABCX model (McCubbin & Patterson, 1983a; 1983b)

**The Circumplex model.** The Circumplex model (Olson, Sprenkle, & Russell, 1979; Olson, 2000; Olson & Gorall, 2003) was developed in relation to marital and family systems as a clinical assessment and treatment planning tool, and to measure outcome effectiveness. It describes families in terms of 3 dimensions, or family variables. *Family cohesion* is “the emotional bonding that family members have toward one another” (Olson & Gorall, 2003, pp. 516). This can be measured or conceptualized by using terms such a emotional bonding; boundaries; coalitions; time; space; friends; decision-making; and interests. The focus of cohesion is how family
members balance their needs for separateness and togetherness. *Family flexibility* is “the amount of change in a family’s leadership, role relationships, and relationship rules… (it) concerns how systems balance stability with change” (Olson & Gorall, 2003, pp. 519). This includes concepts such as: leadership (control, discipline); negotiation styles; role relationships; and relationship rules. Families need stability as well as the ability to change to meet new demands or circumstances. *Communication* within a family system is the third dimension of the model. It facilitates movement on dimensions of cohesion and flexibility. A family’s communication is measured by focusing on how they listen and speak to each other; whether they make self-disclosures comfortably; their clarity; continuity tracking (staying on topic); respect and positive regard toward each other; empathy in listening; and attentiveness.

According to Olson (2000), a family system under stress may respond by changing to another way of functioning by modifying their levels of flexibility and cohesiveness. They argue that *balanced* family systems are likely to change functioning style in an attempt to adapt while *unbalanced* systems (those with extreme low or high levels of flexibility and cohesion) are more likely to remain in their extreme pattern and this can eventually cause more stress.

Over 25 years of development and refinement, there have been over seven hundred studies published that investigate the use of the Circumplex model and four hundred and fifty empirical studies using the associated assessment device the *Family Adaptability and Cohesion Evaluation Scales- IV* (FACES-IV; Olson, 2008; Olson, Gorall, & Tiesel, 2002). It has been claimed that with 75 published reviews and commentaries on the application of the model for research and clinical practice, there is overwhelming support for its dimensions being related to health and developmental outcomes for families (Kouneski, 2001). The model has been evaluated using
structural equation modelling techniques by Thomas and Ozechowski (2001) who reported clear support for the curvilinearity of cohesion and adaptability and the relation between these two variables and family functioning. Strong correlations between cohesion and adaptability suggested a moderating effect, rather than a mediating effect as hypothesized. The FACES-IV was developed to tap the curvilinear nature of each dimension from the model and various psychometric investigations have revealed moderate to high reliabilities (Franklin, Streeter, & Springer, 2001; Olson, 2011; Rivero, Martinez-Pampliega, & Olson, 2010). The measure is highly positively correlated to other measures of family functioning including the FAD which is used in the current investigation as an outcome measure of family adaptation.

The McMaster’s model. The McMaster’s model (Epstein, et al., 2003) is another well established and applied model that has been influential in theory-building towards the Double ABCX model. It offers a conceptualisation of ‘healthy’ family functioning. Based on systems theory, Epstein et al. described crucial assumptions, such that: all parts of the family are interrelated; one part cannot be understood in isolation from the rest of the system; understanding each of the parts does not lead to understanding the system; structure and organisation impact on the behaviour of members; and transactional patterns of the family system shape the behaviour of the family members.

The model is built on the idea that families have three areas of tasks to fulfil and six dimensions of being a family, that contribute to how that family meet and address each task area. The basic task area comprises things like providing food, shelter, money, and transport. The developmental task area includes handling crises or general developmental issues concerning each individual’s life stage. The
hazardous task area involves how a family handles non-normative crises such as illness, accident, loss of income, and so forth. Dimensions described by Epstein et al. (2003) include (a) problem solving, which is defined as a family’s ability to resolve problems to a level that maintains effective family functioning, (b) communication, or the quality and effectiveness of exchanging verbal information within the family, (c) role functioning, which is the repetitive pattern of behaviour through which families complete functions, including provision of resources; nurturance and support; adult sexual gratification; personal development; and maintenance/management of the family system (i.e., decision-making, boundary and membership functions, behaviour controls, household finance functions, and health-related functions including caregiving), (d) affective responsiveness, or a family’s ability to respond to each other with an appropriate quality and quantity of a full range of feelings, (e) affective involvement, or how family members show an interest in each other’s activities and the interests of individual members, and (f) behaviour control, which is the way a family handles physically dangerous situations; situations requiring psychobiological needs and drives to be expressed; and interpersonal or socialisation situations within and outside the family. Epstein et al. (2003) theorise that how these aspects of family life are handled can be rigid, flexible, laissez-faire, or chaotic. A flexible style of behaviour control is considered to be optimal and most effective. Chaotic styles are considered to be least healthy.

Over the last 40 years, the authors of this model have researched its components and how the health of individuals relates to family functioning. Early research concluded that the most crucial element to family functioning was the parents/couple relationship. If couples were emotionally close, met each other’s needs, and encouraged positive self-images, then they were likely to be good parents
and have healthy families (Epstein et al., 2003). One of their foundational studies involved 1,869 families and reported on the validity of the General Functioning subscale of the FAD (FAD-GF) (Byles, Byrne, Boyle, & Offord, 1988). The FAD was developed to assess family functioning along the dimensions of the McMaster model. The construct validity of the GF subscale as a measure of family functioning is supported and is found to be the best predictor of a child psychiatric diagnosis.

Indeed, the FAD, and particularly the FAD-GF subscale, has been used for multitudinous research with a wide range of presenting samples such as families with children with asthma, cancer, cerebral palsy, and spinal cord injuries (Alderfer et al., 2008). It has also been used specifically as an outcome variable in research with families of children with developmental disabilities with regard to program evaluation (Quinn, Carr, Carroll, & O’Sullivan, 2007; Sherer, et al., 2007), assessing impact of caregiver burden (Ammerman, et al., 1998; Chen & Clark, 2007; Hanks, Rapport, & Vangel, 2007; Luescher, Dede, Gitten, Fennel, & Maria, 1998; Lustig, 2002; Wiegner & Donders, 2000), and identifying families at risk (Akister & Stevenson-Hinde, 1991; Josie et al., 2008; Lemelin, Lafontune, Fortier, Simard, & Robaey, 2009).

Both the McMaster and Circumplex models focus on family cohesion, communication and problem solving style as a way to conceptualise healthy to pathological family functioning. They were developed from family systems and family therapy literature, essentially providing a measure and understanding of how a family functions at any one point in time during a family’s life-course of normative events and changes. These models conceptualise the outcome of a family’s effort to adapt to normative transitions. Family functioning is seen to be the outcome, or consequence of how a family cope with their attempts to manage normative demands and stress.
**The Double ABCX model explained.** Family stress research has focused on the impact of acute and non-normative events that place increased demands on a family and trigger a response that can be either adaptive or maladaptive (Olson, Lavee & McCubbin, 1988). While models of family functioning help to conceptualise family cohesion and how a family adapts to change throughout their lifespan, the family stress literature is concerned with what causes a family to make changes and what contributes to how they change or adapt over time. The Double ABCX model of family adaptation draws on family stress literature and models of normative family functioning, applied to families under non-normative pressure, particularly those with children who have disabilities. Initially, Hill (1949) described the ABCX model to examine family variables related to family adaptation. The Double ABCX model was an extension of this model to incorporate both *existing* and *acquired or resultant* family variables that emerge from family circumstances and experiences over time (McCubbin & Patterson, 1982). These and further derivative models from the same group of authors are described in detail below.

**Hill’s ABCX model.** Rueben Hill first wrote of the ABCX model of family stress and adaptation (1949; 1958) and focused on family changes in response to non-normative events such as war separation, and reunion. His early ABCX model assumed a causal link between external demands and increased levels of strain or stress. He sought to conceptualise (a) the conditions of a family that make them vulnerable to heightened ambiguity or tension when they are faced with increased demands or problems, and (b) how the interactional patterns between family members change in response to that ambiguity or tension (Mederer & Hill, 1983). The model focused on the resulting occurrence of a *crisis*, as an outcome variable. Hill described this model as: “A (the stressor event) - interacting with B (the family’s crisis meeting
resources) - interacting with C (the definition the family makes of the event) - produce X (the crisis)", (1958, pp. 141). In this way the extent of crisis experience was determined by interactions between the extent of the stressor or event, a family’s resources, and a family’s perceptions of the event. Hill’s model argued that a direct relationship between the stressor event and the resulting crisis does not exist but is mediated by family resources (Factor B) and the family’s definitions of the stressor or perceptions (Factor C). He argued that at family transition points, when they enter a new stage of development (e.g., getting married, first parenthood, school-aged children, adolescence, launching, or empty nest) a family needs to restructure and reorganize in order to meet the individual needs of its members. In this time, a period of disorganization occurs as they de-structure and then rebuild or restructure. This process is then followed by a new level of re-equilibration, or stabilisation, where the family has either a better or worse level of adjustment, or functioning, than before.

The distinction between Factors A and X is often confounded in research since stressors can be identified in terms of their effects and then these effects can be taken to be evidence of stressors. To clarify this, Scott and Howard (1970) proposed that Factor A variables (stressors) are conceptualized according to their locus of initiation. It was asserted that they are produced by (a) the internal physical environment of the family, (b) the external physical environment of the family, (c) the psychological environment of family members, and (d) the social culture. Factor A variables, then, are the demands and stress that pile-up or accumulate over time (Mederer & Hill, 1983).

**McCubbin and Patterson’s Double ABCX model.** The Double ABCX model (McCubbin & Patterson, 1982; 1983b) focuses, not on the crisis as the outcome variable, but on family adaptation over time. This is considered to be the family’s
responses to ongoing crises that follow a pile-up of demands, and a shift in family resources that become available to cope, throughout non-normative events such as raising a child with a developmental disability. McCubbin and Patterson (1982) proposed that in prolonged stress situations, stressors pile-up over time and this makes it more likely that family stability will be disturbed by the stressor event. They argue that the ABCX model is strengthened by adding ‘post-crisis variables’ such as added family caregiving burdens, acquired resources, and attempts to develop cognitive coping skills. They have suggested that the model could be used to describe and predict a family’s efforts over time to recover from a crisis situation. They draw on Piagetian concepts of cognitive schema development to describe how families *assimilate* new experiences or demands for which they already have the resources to cope. This process entails families simply doing more of what they already know how to do in times of stress, without any need for structural or family organisational change. Over time if demands continue and there is a pile-up of simultaneous life-events and chronic stressors, families enter a crisis, or a period of instability, and they may need to *accommodate* to new demands. That is, family roles, structure, goals, perceptions, and beliefs change, in order for adaptation to occur. This adaptation can be either to a higher or lesser degree than the family’s initial level of adaptation or stability. To this extent then, family adaptation can be positive and adaptive, or negative and maladaptive. How individual families respond to the need to assimilate or accommodate is influenced by their level of responsiveness to change, the *rigid* versus *chaotic* attributes, as described on the adaptability dimension of the Circumplex model.

Figure 2 is a diagrammatic representation from McCubbin and Patterson’s (1982) early work depicting the Double ABCX model. It attempts firstly to portray
an initial family crisis response, to increased stress or demands, which is influenced by stressors; existing resources; and family perceptions. This essentially, is the component of the model predicted by Hill’s ABCX model. The figure then depicts a longer term family adaptation process or outcome that is influenced by a pile-up of stressors; existing and new resources; and family perceptions of their situation.


In early depictions of the Double ABCX model, a moderating rather than mediating relationship between variables is suggested. This is in contrast to written descriptions of proposed mediating variables in Hill’s work. Also in this early depiction, the direction of arrows between the post-crisis variables and the box labelled ‘coping’ suggest a moderating interaction. The ‘coping’ box appears to be a culmination of Factors (aA), (bB), and (cC), yet is not determined as a variable itself, in any predictive equation. McCubbin and Patterson (1983) describe this diagrammatic icon as a conceptualisation of stress that is produced in the family
which arises from an actual or perceived demand-capability imbalance. The interactional effects of family variables depicted in this model have been a source of confusion around the model’s interpretation for over 30 years now, as has been the poorly defined and operationalised ‘coping’ variable. The more defined variables in this model are described in McCubbin and Patterson’s original work (1982) and are relevant to the current evaluation of the model.

**Definition of Factor (aA): Family Stress & Demands.** This factor comprises events or situations that present as a stressor, demand, or caregiving burden for a family. McCubbin and Patterson (1982) identify three types of stressors that contribute to a pile-up. These include the initial stressor event; family life changes or events which occur irrespective of the initial stressor; and sources of stress that are a consequence of the family’s efforts to cope over time. For a family with a child with a disability, Factor (aA) may include daily hassles and family caregiving burden as well as other sources of family stress such as financial strain, housing, employment, social, educational, or personal strain that exists regardless of having a child with a disability.

**Definition of Factor (bB): Family Resources & Supports.** This factor is made up of the resources that a family has for meeting the demands of a stressor or hardship. McCubbin and Patterson (1982) identify two general types. There are resources that are already available to the family before any crisis or increase in demands. These serve to minimize the impact of the stressor. Then there are coping resources that are strengthened or acquired as a response to the crisis. They argue that these resources can be *personal, family, or social* in nature and can include self-reliance; self-esteem; family integration; and social support. For a family with a child with a disability, this factor would include general family resources such as: food; money; housing; medical care; relaxation time, and time to socialise. Secondarily,
this factor would include: practical and emotional support with managing family caregiving burden; and a family’s acquired resistance to crises, or hardiness.

Definition of Factor (cC): Family Perceptions. This factor describes the way a family defines their circumstance or situation. It comprises their perception of the stressor (Factor aA) and their perception of how they can cope with the crisis. McCubbin and Patterson (1982) state that this can include the meanings and attributions that families make about their situation. This can involve religious beliefs, ability to cognitively redefine or reframe a situation, and how positively a family can develop a meaningful narrative to describe their situation. Examples of relevant family perceptions for a family of a child with a disability can be their general coping style and problem-solving style, as well as cognitive coping attributes they have developed in response to managing their caregiving burden. It can include whether parents take a problem-focused or emotion-focused approach to problem solving, and the extent to which they experience their relationship with their child as a burden or a benefit.

Definition of Factor (xX): Family Adaptation. This is how a family responds over time to managing their experience. McCubbin and Patterson (1983b) state that it is a process that involves stimulus regulation, environmental control, and balancing to achieve a level of functioning. This process is said to preserve the family unit and enhance the system in a way that will determine the growth and development of family members. Poor adaptation (referred to as maladaptation in the Figure 2) may be characterised by a deterioration in family integrity, loss of individual or family development, or a decrease in family independence and autonomy. Healthy adaptation (referred to a bonadaptation in Figure 2) can be characterised by strong family
integrity, individual and family enhancement of development, family independence, and a high sense of control over environmental influences.

**Double ABCX derivative models.** McCubbin and McCubbin (2001) state that inductive theory building has predominantly been the source of concepts and propositions that have contributed to the advancement of both stress and resiliency approaches to family research. They have further developed the conceptual Double ABCX model, reworking it firstly into the *Family Adjustment and Adaptation Response* (FAAR) model (McCubbin & Patterson, 1983b; McCubbin & McCubbin, 2001). FAAR focuses on pre- and post-crisis family variables and describes how a family continues to adapt through multiple events or situations with a predictable pattern. This argument depicts an ongoing process that a family experiences which involves stages of *Resistance* (being unwilling to make changes to cope with an increase in stress or demands), *Restructuring* (making changes in roles and routines and organising the family differently), and *Consolidation* (making changes to accommodate the increased stress that restructuring can cause). This process is thought to occur in two distinct phases. The *Adjustment Phase* is characterised by families coping with stress by resisting change. The theory suggests they can do this by using an avoidance-style problem solving strategy, by removing the stressor and ridding itself of demands, or by assimilating the demands into already-existing family structures. That is, they can do more of what they already do without making structural or organisation changes to roles and routines. The *Adaptation Phase* is prompted by further increases in caregiving demands and stressors which cause a crisis for the family. This phase theoretically involves a family’s attempts to restructure roles, routines, goals, and patterns of interaction so that demands can be met. Further focus on the concepts and propositions of the FAAR is beyond the scope
of this review. Its complex, inductive creativity stretches far beyond the basic premises of Hill’s ABCX Model and the Double ABCX model from which it originated.

Another conceptual advancement of the original model, the Typology Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983b; McCubbin, Thompson, & McCubbin, 2001), described types of families based on a set of basic family attributes that characterise how the family system appraises situations and behaves. They are said to be predictable patterns of family life reinforced by rules and norms, and guided by family values and goals. These characteristics can be used to classify a family and make predictions about their likely response to stress and demands and their likely adaptation outcomes. The theory describes four basic family typologies, each comprising of an orthogonal matrix of two family contrasts. For example a Regenerative Family Typology comprises concepts of family coherence and family hardiness and builds on the idea that types of families have a certain amount of regenerative power when faced with hardship. Along these two continuums, a family can be categorised as (a) vulnerable (low coherence and low hardiness), (b) secure (low coherence and high hardiness, (c) durable (high coherence and low hardiness, or (d) regenerative (high coherence and high hardiness). Other typologies include a Versatile Family Typology (involving attributes of bonding and flexibility); Rhythmic Family Typology (involving attributes of time/routines and how a family values time/routines); and Traditionalistic Family Typology (involving family traditions and family celebrations).

The Resiliency Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 2001) is another conceptual derivative of the original model from the same authors and focuses on family types, processes, patterns, system properties,
appraisal strategies, meanings, coping styles, supports and transactions with the community. This theoretical direction incorporates family coping and problem solving and four domains of family functioning: interpersonal relationships; development, well-being and spirituality; community relationships and nature; and structure and function. It also introduces discrete levels of family appraisal of their situation. These include: schema; coherence; paradigms; situational appraisal; and stressor appraisal.

Another derivative of the Double ABCX model of family adaptation has come from the work done on the concept of Family Quality of Life (Schalock, et al., 2002; Schalock, 2004). This body of literature focuses on research into family variables that contribute to healthy family functioning; family centred early intervention service models; and individual quality of life (Smith-Bird & Turnbull, 2005). A dedicated effort to establish reliable measures of family quality of life has been the initial focus (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Family quality of life themes have already been incorporated into the development of early intervention service delivery models (Smith-Bird & Turnbull, 2005) including positive behaviour support programs (Carr et al., 1999). It has gathered much momentum in the area of service delivery models for family support programs and has taken an alternative direction to theory and research into family adaptation. The family quality of life literature identifies key elements for service and policy development rather than establishing predictive models of family risk and protective variables.

**Summary of theoretical development of the Double ABCX model.** Theory of family stress, family functioning, and family adaptation to disability has developed along strong and empirically supported lines from throughout its genesis from Lazarus and Folkman’s (1984) stress-coping model for individuals, Bronfenbrenner’s
ecological theory (1979), systemic family functioning ideologies, and models of family functioning such as the McMasters and the Circumplex models. Models of normative family functioning and associated psychometrically-sound measures have been verified empirically and clinically.

Hill’s (1949) ABCX model and the Double ABCX model (McCubbin & Patterson, 1982) theoretically account for non-normative functioning related to families of children with disabilities where members are required to adapt to the ongoing demands and stress of caregiving. Derivative models have emerged in theory and practice in advance of clear empirical support for the Double ABCX model, or clear understanding on the mediating or moderating effects of latent variables (Factors aA, bB, and cC) on family adaptation (Factor xX).

**Empirical Investigations Into the Relationship Between Family Variables and Impact of Developmental Disability on Family Adaptation**

There have been many attempts to integrate ideas about the interrelationship between risk and protective factors and how family variables function to influence and predict how having a child with a disability impacts on families. This section provides chronological examples of studies that attempt to do this by relating sub-sets of family variables. It describes some of the methodological limitations associated with such an approach. It also outlines examples of studies that employ improved research designs and attempt to assemble family variables statistically into predictive models. Then early and subsequent attempts to empirically validate the Double ABCX model are outlined. The advantage of model testing in this manner is that all relevant family variables can be accounted.

**Examples of studies that relate sub-sets of family variables.** There is a body of research literature into the impact of developmental disability that focuses on
interactions between sub-sets of family variables that are only loosely theoretically related. There have been many attempts to reveal predictive relationships between them. There are also serious limitations in common methodology used.

For example, Judge (1998) focused on the Lazarus and Folkman model of stress and coping, and referred to the Double ABCX model, but interpreted the outcome variable to be ‘family strengths’ rather than functioning or adaptation. The study aimed to determine the coping strategies that predicted family strengths when there is a child who has a disability. A sample of 69 participants completed the Family Hardiness Index (FHI; McCubbin, McCubbin, & Thompson, 1991) as the dependent variable in a multiple regression analysis that focused on the predictive values of demographics and family coping. Results showed that parents’ use of problem-focused coping strategies, emphasized efforts to seek social support, actively solve problems, and maintain a positive outlook accounted for most variance in family hardiness or strength. Although the composition of family hardiness as a construct is important, this study misses the importance of certain caregiver burdens (i.e., extent of caregiving demands) and their potential influence on how family strength/hardiness and coping strategies emerge. It misinterprets the Double ABCX model and conceptualises family strength/hardiness as an outcome variable independent of a child’s level of need and demand (Factor aA in the model).

Family hardiness, as a variable that predicts parent stress related to child disability has also been a focus for Weiss (2002). Again referring to the Double ABCX model, but not operationalising it or using a latent variable structure, this study assessed the roles of hardiness and social support, on the dependent variable of parent depression, anxiety, and burnout. Regression analyses were conducted separately for the three outcome variables. It was reported that hardiness predicted depression and
anxiety. Also perceived social support from a partner was predictive of less somatic complaints and higher sense of accomplishment in parenting. Hardiness and social support were reported to be related but causality remained undetermined. The main limitation in this study is again the lack of accounting for other potential family variables that may interact to determine family outcome. There was no measure relating to the degree of caregiving burden experienced. Also, data was assessed using both families with and without children with disabilities.

Another example, Hastings, et al. (2002) used some very well established measures such as the *Family Support Scale* (FSS; Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988), the *Family Crisis Oriented Personal Evaluation Scales* (FCOPE; McCubbin, Olsen, & Larsen, 1991) and the KIPP to focus on significant predictive variables for positive perception scores. They also devised a scale to assess care-demand of a child with a disability by having parents rate their level of difficulty in 15 domains of practical caregiving. This measure was reported to have a high internal consistency but no other available psychometric data. A small sample size (*n* = 41) and low survey response-rate (33%) provided data for regression analyses with predictors (care-demand, social support, and coping) entered simultaneously into models of positive perceptions. All predictors were found to be statistically significant in relation to variance associated with positive perception scores. In addition, the researchers reported that the level of positive impact of a child with a disability (happiness and fulfilment) and effects on the family (strength and closeness) were positively predicted by the use of reframing coping strategies. The sub-set of family variables examined here is broad and focuses on predictors of positive perception. Without a theoretical model to use as a framework to conceptualise broad family and child outcomes, the concept of family adaptation is
missed here again. The assumption made is that positive parent perceptions is an outcome to target. Other limitations of this study were the small sample size, and the possibility that results were related to measurement overlap (i.e., high positive correlations between measures of positivity, such as ‘reframing’ and ‘positive perceptions of child’).

Another example of past research that has focused on relations between isolated variables and their effect on parental stress has been from Baker, et al. (2003). They used a large sample to perform hierarchical multiple regression analyses and reported that both child behaviour problems and negative family impact was highly stable over time. Also, changes in problem behaviour over one year were associated with increases in levels of parent stress and vice-versa. They suggested that the two variables have a mutually escalating transactional effect on each other. Although this is an important finding in relation to developing family behavioural interventions, it did not explore mediating or moderating effects of family variables such as resources, support, or family perceptions.

Again, inquiring into parent stress as an outcome variable, Hastings (2003) investigated the different experiences of it between mothers and fathers who have a child with a disability. They explored the primary correlates of maternal and paternal stress, in relation to child behaviour problems and partner mental health. They found mother’s stress was significantly more affected by child behaviour problems than fathers. They also found maternal stress was significantly associated with paternal levels of depression and anxiety. There were no significant partial correlations between levels of fathers’ stress and child behaviour problems or mothers’ mental health. Aside from attempting to look at interactions between such few family variables, the sample used in this study was small (n = 18, married couples) and
lacked statistical power. Also the sample consisted of mostly families of children who did not live with their families on a daily basis. These issues limit the generalisability of results.

Inquiring into a wider range of variables, Higgins, et al. (2005) took a sample of parents \((n = 52)\), and used standardised measures, to investigate interactions between family functioning, marital quality, self-esteem, and coping strategies. They reported lower mean scores on a measure of family functioning (FACES-II) than norms of a comparison US sample, but failed to report significance of the difference. They also reported undetermined high levels of stress with some families (25%) describing a negative effect of having a child with a disability on family life.

Hierarchical multiple regression analysis was performed to inquire about the predictive nature of specific coping strategies on happiness, cohesion, adaptability, and self-esteem. Family satisfaction and availability of services was held constant and results were not significant. This analysis did not account for other potential family variables that may have additive predictive value, such as challenging behaviour or family, social, and practical resources. They suggested a selection bias may have influenced results since recruitment involved accessing families who were in receipt of support services.

In a similar way, without a recognised theoretical framework, Gallagher, Phillips, Oliver and Carroll (2008) reported on the effect of social support, child behaviour problems, sleep quality, and caregiver burden on a measure of depression and anxiety. They found the strongest predictor was caregiver burden, which was measured using the Caregiver Burden Index (Zarit, Reever, & Bach-Peterson, 1980). This measure was originally developed for relatives caring for elderly, disabled relatives. The nature of caregiving burden for children is fundamentally different
from that of the elderly. The use of this measure is a limitation in this study along with its investigation into only a sub-set of family variables. The small sample used \((n = 29)\) for linear and logistic regression analysis provided insufficient power for results to be generalisable.

In another example, Lopez, et al. (2008) described relations between family stressors including parental stress, types of coping, child behaviour, and family income, without strong theoretical foundation. They used standardised measures of variables and conducted appropriate analyses (MANOVA and multiple regression analysis) but failed to find significant differences between two groups of families – those of typically developing or developmental delayed children. However, the generalisability of the results is questionable since sample sizes were small \((n = 29\) and 17 respectively). Also, only two potential variables related to parent stress, were entered into the analysis (financial situation and problem behaviour). Potential interactions, between these variables and others not included, were unaccounted.

A final example of an attempt to integrate variables using only sub-sets of family variables has been reported by Lightsey and Sweeney (2008). This study involved developing a conceptual model of family satisfaction. It was predicted that self-efficacy, emotion-oriented coping style, family cohesion, and meaning in life would account for variance above perceived stress and demographic variables. They used psychometrically validated measures of variables and hierarchical regression to test for mediating interactions with a sample of 90 parents of children with disability. They found that perceived stress, emotional coping and family cohesion accounted for most variance (31\%) in family satisfaction and that meaning mediated the relationship between stress and family satisfaction. This provided support for some family variables interacting to predict an outcome but again ignored other important ones,
such as social support. In addition, having family satisfaction as an outcome was not linked to a theoretical model of family adaptation, or stress and coping.

In summary, there have been recurrent research limitations in this area of inquiry that continue to present challenges for further research. These include: using large enough sample sizes to report adequate power statistics; using measures that are well-established within the field; operationalising the concept of family adaptation; using statistical designs that are complex enough to provide support for the predictive nature of family variables on family adaptation; interpreting results accurately and objectively; and the lack of a sound theoretical framework from which family variables can be conceptualised as latent constructs in a meaningful and theoretically validated way.

**Examples of studies that attempt to assemble family variables into predictive models.** A number of more sophisticated inquiries have attempted to account for the complexity of the relationship between the impact of disability and family adaptation. These have made valuable contributions to the state of knowledge and have led to a rationale for comprehensive deductive model evaluation based on sound empirical formulation of latent variables.

For instance, Hastings (2002) devised a simple conceptual model based on various aspects of family life that have been considered to impact on parenting stress and family functioning. He presented an argument that child behaviour problems influenced parental stress which in turn influenced parenting behaviours which then influenced child behaviour problems in a circular manner. He raised the issue of causal directionality and highlighted the lack of research into the directional relationship between child behaviour and parent stress. His argument contended that studies have shown that child behaviour problems predict parental stress when salient
family variables such as socio-economic status, family size, and social support are controlled. He also purported that more refined statistical analysis had been suggesting that parenting, coping strategies, and other variables could mediate the impact of child behaviour problems, on stress. He described a mediator variable as one that carries the effect of another variable. That is, parent stress mediates the relationship between child behaviour problems on parenting behaviour. He argued further that moderating variables could also have a role whereby they change the relationship between two other variables. For example, the impact of child behaviour on parenting could be changed when a variable of parent stress is added. Hastings (2002) cited research supporting the idea that parental appraisals, parental beliefs about intervention efficacy, and parental self-efficacy influence the impact of child behaviour and disability characteristics on parent coping. He reported that parental self-efficacy mediated the impact of their child’s behaviour on mother’s anxiety and depression but moderated this relationship for fathers. Hasting’s research provides a good analysis of some of the variables that have been shown to contribute to family adaptation but does not integrate all family variables into a meaningful model of family adaptation. Parent stress was the outcome focus.

Drawing on one component of the Double ABCX model (i.e., parental perceptions), Oelofsen and Richardson (2006) also attempted to construct a meaningful model of family variables and family functioning. They explored parental perceptions in the context of a sense of coherence construct (Antonovsky, 1998a), comparing families of children with developmental disabilities \( n = 59 \) and those with typically developing children \( n = 45 \). They used well-established measures such as the Orientation to Life Questionnaire (Antonovsky, 1987), the Parenting Stress Index (Abidin, 1995), the Health Perceptions Questionnaire (Ware, 1976), and
the FSS to measure family social support. Scores on parenting stress measures were significantly higher for families of children with disabilities; scores on health and sense of coherence were significantly lower than for parents of typically developing children. These data were more extreme for mothers compared to fathers. They found that social support did not emerge as a significant differentiating variable in any of their analyses. They argued that their findings strengthened the case for stress interventions as part of child development or early intervention services. This may be the case; however, without a holistic approach to developing a model of family adaptation, that establishes the interactional links between all variables that affect family outcome, designing family support targets is premature.

Thirdly, Stoneman and Gavidia-Payne (2006) focused on daily hassles “...the irritating and annoying demands of everyday life...’ (pp. 2) and how these relate to marital adjustment and coping styles in an attempt to create a model of family adaptation. Using good measures of marital adjustment (the Dyadic Adjustment Scale; Spanier, 1976), stressors/hassles (the Hassles and Uplifts Scale; Delongis, Folkman, & Lazarus, 1988), and coping (Coping Orientations to Problems Experienced; Carver, Scheier, & Weintraub, 1989), they reported on hierarchical multiple regressions of scores from 67 couples of children with developmental disabilities. Variables were added to regression models to predict marital adjustment. Marital adjustment for mothers was predicted by lower maternally-reported hassles/stressors and when fathers used more problem-focused coping strategies as opposed to emotion-focused coping. For fathers, reports of higher marital adjustment were predicted by fewer hassles/stressors and when they themselves used more problem-focused coping styles. Their partners’ coping styles did not account for significant variance, as did for mothers. Fathers’ own coping styles accounted for
variance in their perceptions of the marital relationship over and above the variance accounted for from their experience of their hassles/stressors. This paper presents good news in how we understand the interplay between a number of variables. However, given the plethora of other factors known to impact on families, there is a need for further research like this to explore marital adjustment as one of many family variables related to overall impact of disability, or family adaptation.

A fourth significant inquiry into family variables that interact to influence the process of family adaptation has been reported by Rentinck, et al. (2007). They identified a broad range of family factors related to the process of adaptation by reviewing 22 studies ($n = 22 – 160$) that had used psychometrically valid measures. Drawing on Bronfenbrenner’s (1979) bio-ecological model of human development, they attempted to describe interactions between family variables that could account for multilevel systems of family functioning. Their conceptual modelling suggested replicable themes including child-related factors (e.g., type and extent of disability or dependence, presence of behaviour problems), parent-related factors (e.g., stressful life events, mental health issues, self-mastery and esteem, and marital functioning), contextual support (e.g., social and professional support), and factors related to different stages of family life (e.g., time of diagnosis and transition into school). Although no statistical modelling was conducted, this review highlighted the need for longitudinal research and pointed to the difficulty in comparing research outcomes due to the lack of consensus about important terminology such as family adaptation, family functioning, family stress, family well-being, and social support. Papers that use these terms interchangeably and/or define outcomes of impact of disability, using measures of these different constructs, are essentially incomparable.
A fifth significant research agenda in modelling family adaptation has focused on the mediating/moderating relationship between family resources and social support, and the impact of disability on family coping and empowerment (e.g., Dunst, 2007; Dunst, Trivette, & Cross, 1986; Dunst, Trivette, & Deal, 1988; 1994). Dunst’s research group has been prolific in their inquiry, the development of psychometrically valid measures of family supports and resources, and providing the procedural guidelines for many child development-, early intervention- and community- services for families of children with disabilities (Dunst, et al., 1994). The concept of social support and resources includes family variables that range from concrete financial resources, housing, clothing, and education, to time to be together, people that provide emotional support, information about disabilities, specialised medical services, and rehabilitation or early intervention programs. It also includes such things as personal coping styles and family hardiness or resilience. Dunst, et al., (1986) argued that there was already a sizeable body of literature supporting social resources as a powerful meditational influence on personal and familial well-being. They took measures of family resources (income, social status, and socio-economic status scores); child variables (age, IQ, and diagnosis); and social support (measured with the FSS). Using scores on the Questionnaire on Resources and Stress (QRS; Holroyd, 1974) as the dependent variable, they entered hierarchical multiple regression analyses using structurally related groups of measures. They reported that after accounting for all other variables, the unique contribution of social support determining scores on the QRS was statistically significant. They also concluded that social support had a mediating influence on child behaviour and development. This indirect effect of having a high level of social support was related to parental perceptions of their children’s physical limitations, social acceptance, and behaviour.
problems. They provided clear support for the notion that both qualitative and quantitative aspects of social support have direct and indirect influences on parental, family, and child functioning. Such foundational results have contributed to a wealth of further research in this area that has validated the importance of considering social support and resources in any holistic model of family adaptation.

And lastly, a key contribution to current knowledge of caregiver burden and family adaptation, by Plant and Sanders (2007a), involved the identification of family variables that impacted on parenting stress associated with family caregiving. Author-designed checklists were used to gauge parents’ responses to items about stressfulness of caregiving tasks; caregiving tasks specific to parenting stress; difficulty of caregiving tasks; time involved in caregiving tasks; difficult child behaviour during caregiving tasks; and social support and caregiving. Three measures with established reliability and validity were used to assess some family variables. These were: The Ways of Coping Questionnaire – Revised (Folkman & Lazarus, 1988); the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 2002); and the Vineland Adaptive Behaviour Scale-Survey (Sparrow, Balla, & Cicchetti, 1984). Results showed a significant positive correlation between parent stress associated with caregiver tasks and (a) difficulty of tasks, (b) time involved in tasks, (c) difficult child behaviour during tasks, and (d) DBC total problem behaviour scores. These predictor variables accounted for 71% of variance in further analyses. Cognitive appraisals of caregiving responsibilities showed a significant relationship with the level of parent stress; difficulty of caregiving tasks, and difficult child behaviour during caregiving tasks. Testing for mediating effects, Plant and Sanders hypothesised that the relationship between predictor variables (difficulty of tasks and child behaviour) and parent stress would not be significant if entered into hierarchical regressions with
cognitive appraisals as the second step or mediating variable. Because this was unsupported, they concluded that all these variables made a unique contribution to parent stress but were not mediated by parents’ cognitive appraisals of caregiving responsibilities. When tested for significant moderating effects, they found that partner/family support buffered the effects of level of child disability on parent stress; friend support buffered the effects of difficult child behaviour during caregiving tasks on parent stress; and external/professional support buffered the effects of DBC total problem behaviour on levels of parent stress.

This study provides an important contribution to understanding the interrelationship between variables that have been shown to have an impact on family coping and stress. It provides links between a sub-set of variables and can be seen to eliminate the hypothesis that cognitive appraisals mediate the effects of predictor variables (e.g., difficulty of tasks and difficulty of child behaviour during caregiving tasks) on parent stress. Having used self-designed checklists without psychometrically established construct, discriminative or concurrent validity, or reliability, is a short-coming of this study. Designing checklists to measure observed variables brings into question the nature of the constructs being tapped. It may have been improved with the use of latent variables to reduce the dimensionality of data. That way, a large number of observable variables could be aggregated into a model to represent an underlying concept. Some of the significant correlations between observed variables in the Plant and Sanders (2007a) data may have been better understood as latent variables, which together describe a theoretical model.

Inductive inquiries such as these contribute to an understanding of how family variables relate to each other and influence outcomes for families. An alternative approach to model building relies on deductively testing current theoretically models.
Original psychometric evaluations of the Double ABCX model. Lavee, et al. (1985) made five basic propositions about variable interactions to evaluate the Double ABCX model using structural equation modelling which is considered to be the most appropriate analysis for models with large numbers of latent and observed variables (Baron & Kenny, 1986). These were (a) strain on a family related to a particular event is positively associated with other sources of demands, (b) the level of adaptation that a family achieves is negatively related to their pile-up of demands, (c) a family’s resources positively influence their adaptation to their piled-up demands and stressors, (d) a family’s resources negatively influences the severity of strain and stress created from their piled-up demands and stressors, and (e) a family’s perception and coherence positively influence their adaptation.

Their modelling included data from 288 families who were employed by the US Army. These families had been relocated to West Germany in May 1983, and had a broad range of experiences and attitudes about family relocation and adaptation to lifestyle in a foreign country.

Latent variables in their model consisted of Relocation Strain (Factor aA); Family Life Events (Factor aA); Social Support (Factor bB); Family System Resources (Factor bB); Coherence and Meaning (Factor cC); and Family Adaptation (Factor xX). Fifteen observed variables were measured using a range of unpublished Likert-type scales presenting items thought to relate to demands in a foreign country. Some more established measures such as the FACES-II; the Family Inventory of Life Events (McCubbin, Patterson, & Wilson, 1982); and the Social Support Index (McCubbin, Patterson, & Glynn, 1981) were also used. They conceptualized part of the resources variable (Factor bB) as family cohesion, adaptability and communication. The family adaptation variable (Factor xX) was conceptualised as
general well-being, satisfaction, and family distress. Pre-travel strains data was gathered from husbands only and post-arrival hardship data was collected from wives only. All other data was collected from both and mean family scores were used for analysis.

Their initial goodness-of-fit analyses yielded a questionable fit of the data to model due to family life events (aA) data being significantly related to relocation strain (aA), coherence (cC) and adaptation (xX). The goodness-of-fit index (GFI) for the model was 187.8 with 79 degrees of freedom ($p < .01$). They addressed this by freeing these relational parameters and improving GFI slightly. In addition to a moderate model fit to the data, some observed variables loaded onto more than one latent variable, some data points were not sufficiently accounted for by the model’s specifications, and first-order derivatives and correlation of estimates indicated that the fit to data may have been improved if residuals of some measures were allowed to correlate.

Their confirmatory factor analysis revealed fairly well-defined constructs and the structural model indicated significant positive direct pathways from both family system resource (bB) and coherence (cC) to family adaptation (xX). The model also produced a direct significant negative pathway from relocation strain (aA) to family adaptation (xX). That is, the more family system resources and coherence, the more positive family adaptation; the more relocation strain, the less positive family adaptation. Direct effects of social support (bB) and life events (aA) on adaptation (xX) were not significant. Over 90% of variance was explained by the relations between family adaptation and other latent variables. A significant positive pathway from social support (bB) to coherence (cC) showed that as social support improved, so did family coherence. A significant negative pathway from relocation strain (aA)
to coherence (cC) showed that as strain increased, family coherence decreased. Family life events (aA) formed a positive significant pathways to relocation strain (aA) showing that as families experienced more stressful life events, their experience of relocation strain increased. A significant negative pathway from social support (bB) to relocation strain (aA) showed that families with fewer supports experienced higher levels of strain.

Lavee, et al. (1985) concluded support for the hypothesis that the severity of strain of relocation was increased when there were previous piled-up sources of family strains and the more strain, the worse adaptation was likely (pile-up of strains and demands directly impacted on family adaptation). They also found that the negative effect of strains on adaptation was buffered in a mediating way by family resources (bB), and sense of coherence (cC). These variables themselves had positively-directioned and direct effects on family adaptation but did not affect the experience of strain per se. Social support (bB) was found to have a significant indirect, or moderating, effect on family adaptation. It was related positively to meaning and sense of coherence (cC) but not family adaptation (xX) directly. They suggested further empirical investigation of the function of coherence (cC) on family adaptation.

Lavee et al. (1985) provided a good foundation for further research along these lines with a need to adjust methodological limitations such as: variable definitions that were inconsistent with original theory (i.e., family system resources (bB) defined as family cohesion, family adaptability and family supportive communication, rather than these being outcome variables (xX)); small sample size and no indication of power analysis; devised measures without evidence of item analysis, content validity, or reliability; and exclusion of some of the model constructs
such as personal resources and coping. Although Lavee et al.’s. (1985) evaluation of the model provided a good example of theory testing, it was applied to the experience of the US Army families relocating in Germany – an experience that has little in common with raising a child who has a disability.

Bristol (1987) took a sample of 45 mothers of children with autism (aged 2 – 9 years) to evaluate the Double ABCX model. She operationalised Factor (aA) as severity of autism and the extent to which a family had to pass up opportunities because of the child, measured by a subscale, *Limits on Family Opportunity* of the QRS. Family cohesion, social support, and coping comprised Factor (bB). Measures of ‘maternal self-blame’ and ‘catastrophe/burden was used to measure Factor (cC). Family adaptation (Factor xX) was operationalised as parental depression, marital satisfaction, and home harmony/quality of parenting. The limitation here is that family adaptation, as defined by well-established models of normative family functioning such as the McMasters model (Epstein, et al., 2003) and the Circumplex model (Olson & Gorrall, 2003), is indicated to be only partially defined by these three variables; they do not represent the total construct of family adaptation. Bristol (1987) concluded through separate multiple regression analyses that the total model accounted for 55% ($R = .55, p < .01$) of variance in quality of parenting; 33% ($R = .33, p < .05$) variance in depressive symptoms; and 53% ($R = .53, p < .01$) of variance in marital adjustment.

Another key early evaluation of the Double ABCX model (Orr, Cameron, & Day, 1991) tested mediating effects of family resources (Factor bB) and the perception of stressor event (Factor cC) on the relationship between child behaviour (aA) and family stress and coping (xX). Orr and colleagues used path analysis to determine the causal ordering of variables related to family stress and coping. A
small sample of 86 mothers of children and adults (aged 5 – 21 years) with intellectual disability provided data. They used a behaviour problem score taken from parent report of frequency of common behaviour problems only to represent the stressor in the model (Factor aA) and the Parenting Stress Index to represent family stress and coping (Factor xX). This is a limitation because the stressor represents only one aspect of family caregiving burden and ignores all others. The researchers concluded that their data suggest that child behaviour (aA) is directly related to the perceptions of the stressor event (cC), the use of resources (bB), and the level of parental stress and coping (xX); that there was a significant interaction between Factors (bB) and (cC); and there was a direct relation between Factor (bB) and the outcome of parenting stress and coping (Factor xX). From these directional relationships between factors, they deleted the non-significant C-X pathway and assumed a linear ACBX pathway. Their statistical manipulations then revealed a significant fit to their original data and they concluded support for the mediating model in the direction of A-C-B-X. They concluded that this study adds support to the model but also conclude that assuming a moderating effect of Factors (bB) and (cC), rather than a mediating effect, may yield more meaningful results.

Further research on the model (re-labeled as the Resiliency Model of Family Adjustment and Adaptation) as it related to Native Hawaiian families of preschool-aged children who were educationally and socially at risk ($n = 150$) was then completed with original authors (McCubbin, Thompson, Thompson, Elver, & McCubbin, 1998). Family adaptation in this case was defined as a family’s level of dysfunction, manifested by having members abusing substances, their emotional difficulties, and their interpersonal abuse. Respondents were mostly mothers or female caregivers (92.3%). The authors used a range of measures that were
developed specifically for the study to measure family dysfunction, family schemas (or appraisals), family problem solving communication, family coherence, community support, and family hardiness, all with reported reliability indexes between .71 and .87. Through stepwise regression analysis the research team identified family problem-solving and family hardiness as independent variables, with coherence and family schemas and appraisals as having indirect influences upon family adaptation. A theory-trimming approach whereby all non-significant paths ($p < .05$) were deleted, confirmed the model and revealed that appraisal processes, coherence and family hardiness combined could explain the variability in family problem-solving communication. Family appraisals, as a variable, were found to be causally related to coherence which was in turn causally linked to family hardiness. Social support was linked significantly to family appraisals and hardiness and indirectly related to family dysfunction (through coherence, hardiness, and problem-solving communication). In sum, the model was said to be affirmed with some variables playing a mediating role and some with moderating effects. Although this investigation was promising in that relations were established through appropriate multi-variant analysis, the sample size was small ($n = 150$) and the population again was not defined by the presence of caregiving burdens imminent in families who have a child with a disability. Respondents’ age, income, number of children, and marital status were controlled due to significant correlations with some model variables and no direct measure of demands or strains was accounted for in the model.

**Subsequent psychometric investigations into the Double ABCX model.**

Further attempts to replicate validation of the model have occurred periodically since 2000 to the present. Examples include the Saloviita, Itälinna, & Leinonen (2003) study. They looked specifically at how family variables (Factors aA, bB, and cC)
predicted the single dependent variable of parental stress (Factor xX). Principal component and regression analysis was conducted on data from 258 families of children with intellectual disabilities (aged 1 to 10 years). Respondents were both mothers and fathers ($n = 647$; 55% mothers and 48% fathers completed the survey). They used the short version of the QRS (QRS-F; Friedrich, Greenberg, & Crnic, 1983), which essentially is a version from which two confirmed factors (Child Characteristics and Physical Incapacitation) were removed. The remaining items that load onto factors named Parent and Family Problems and Pessimism were used as the outcome variable (Factor xX). The QRS was designed to assess family strains, stress and needs, not family adaptation. Therefore although this study provides interesting insights into related variables, it does not evaluate the Double ABCX model of family adaptation as claimed. They measured family demands (Factor aA) with measures specifically constructed where parents estimated levels of some adaptive behaviours, challenging behaviours, and severity of intellectual and functional disability. Factor (bB), family adaptive resources, was measured using some well-established and reliable instruments targeting marital adjustment (Marital Adjustment Test; Locke & Wallace, 1959), family support (FSS) and coping (using an adapted version of the Ways of Coping Checklist; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) and a constructed item-set put to a Likert-type scale prompting responses to measure parent support, social acceptance of the child, and perceived control over life events.

Factor (cC), labelled as family definition and meaning, was measured by parents’ ratings of their level of readjustment required from having a child with a disability compared to 27 other stressful situations from the Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967). Although a logical induction, such a
rating is empirically arbitrary and its relation to the theoretical notion of family perceptions is questionable. They also used the Definition Scale (Bristol & DeVellis, 1980) which measured meaning/purpose, self-blame, and catastrophe/burden. This was confirmed by factor analysis after the removal of one item that did not yield communality.

Saloviita et al. (2003) then rolled these 20 independent variables into uncorrelated principal components obtaining a factor matrix that was rotated into varimax-criterion where variables in each factor were minimized. Eight rotated orthogonal factors then became the independent variables applied in a stepwise regression analysis with parental problems and pessimism (relabelled as parent stress, Factor xX) as the criterion variable. The assumption here is that factors are uncorrelated. Results showed that for their sample 72% of maternal stress variance was accounted for by these components (excluding positive coping strategies and locus of control components due to unfulfilled entry criteria) and 78% of paternal variance in stress could be accounted for in this way (again excluding one component - positive coping strategies). Their measure of the stressor variables (aA) predicted only 2% and 8% of variance of stress for mothers and fathers respectively. Mediating effects of family resources (bB) (42% stress variance for mothers and 33% for fathers) and family definition of the situation (cC) (explaining 29% variance for mothers and 37% for fathers) were reported. They argued support for a mediating model whereby family resources and definitions of the situation predict parental stress more than stressors or demands relating to the child. The measures and analysis used in this study are disadvantageous since construct validity of latent variables was not established and interactions between aspects of the proposed model are not revealed, making it not possible to infer directional causality. In addition, the outcome variable
chosen, parent stress, is fundamentally different from the concept of family adaptation presented in the Double ABCX model.

Pakenham, Sofronoff and Samios (2004) have also examined the model relating to families of children with Asperger syndrome. They set out to investigate the role of ‘making meaning’ as a coping process related to parental adaptation to caring for a child with Asperger syndrome. They looked at interrelations between both ‘benefit finding’ and ‘sense making’ with other family variables which were thought to represent aspects of the Double ABCX model. These included: the extent of initial and pile-up of demands; appraisals; social support; coping; and adjustment. Their sample of 59 parents (47 mothers and 12 fathers) of children with Asperger syndrome attending an anxiety management intervention, completed self-report measures of child behaviour problems, social readjustment, social support, parental stress, parental self efficacy, coping strategies, depression/anxiety/stress, social adjustment, and subjective health. Some of the instruments used were well-established in the psychological literature (e.g., Eyberg Child Behaviour Inventory; Eyberg & Pincus, 1999; SRRS; Coping Orientations to Problems Experienced; DASS-21; Social Adjustment Self-report Questionnaire, Weissman, 1986) while others were constructed or adapted for the study. No reliability or validity data was reported for a number of the measures used (including the Parental Stress in the Management of Asperger Syndrome; Parental Self Efficacy Scale; a global rating [1 – 5] of health status; a narrative description of ‘benefits found from having a child with Asperger syndrome’; a rating [1 – 4] of how much belief there is, or will be, about positive benefits; a narrative description of ‘sense-making’; and a rating [1 – 4] of how much belief there is in their ability to make sense of the situation now or in the future). The dependent variables were measured with semi-structured interview-type
questions which were analysed for content and a self-report on a 4-point scale of whether parents considered that they (a) believed they would eventually be able to make sense of having a child with Asperger syndrome, and (b) believed that there would be some eventual benefits of having a child with Asperger syndrome.

The researchers report identifying eight ‘benefit themes’ from their qualitative content analysis and 12 themes related to ‘a sense of order and/or direction in life’. Their correlational analyses revealed significant covariance between measures. Some of these included associations between measures of ‘benefit finding’ with the pile-up of demands and stressors; and coping strategies, social support satisfaction, and self-efficacy, with positive re-interpretations. ‘Sense making’ measures were reported as being significantly related to variables such as approach-related coping strategies, acceptance and positive re-interpretations. Pakenham, et al. (2004) have highlighted some important links between family variables related to the Double ABCX Model of family adaptation. Their study provides further rationale for model-testing using more sophisticated statistical analyses, a wider unbiased sample, and inclusion of all family variables theoretically founded within the Double ABCX model.

Stuart and McGrew (2009) used bivariate and multivariate analyses to examine variables relating to the Double ABCX model for families of children diagnosed with autism over the last 6 months. Their dependent variables (Factor xX) were identified on three levels: (a) caregiver burden (measured by the Caregiver Strain Questionnaire; Brannan & Heflingser, 1997), (b) marital burden (measured by the Dyadic Adjustment Scale), and (c) family burden (measured by the Impact on Family Scale; Stein & Reissman, 1980). Factor (aA) was measured using the Gilliam Autism Ration Scale (Gilliam, 2006) and the SRRS. Factor (bB) was measured with an adapted version of the Multidimensional Scale of Perceived Social Support (Zimet,
1998) for primary caregivers of children with autism. Respondants were mostly mothers (98.7%). The authors measured Factor (cC) (caregiver appraisals) with the Family Implications of Childhood Disability Scale (Trute & Hiebert-Murphy, 2002) and the Brief Coping Orientations to Problems Experienced (Carver, 1997).

Using simple correlations, from a mostly online sample ($n = 78$), they found symptom severity (aA) to be moderately correlated with caregiver burden ($r = 0.28, p = 0.013$) and family burden ($r = 0.34, p = 0.002$) (xX), such that higher levels of symptoms were positively related to increased burden. The SRRS scores (aA) had a strong positive relationship with all levels of burden, individual ($r = 0.43, p = 0.001$), marital ($r = 0.54, p = 0.001$), and family ($r = 0.51, p = 0.001$) (xX). Higher levels of social support (bB) showed a significant correlation with lower levels of individual ($r = -0.69, p = 0.001$), marital ($r = -0.45, p = 0.001$), and family ($r = -0.59, p = 0.001$) burden. More negative caregiver appraisals (cC) was associated with higher levels of individual burden ($r = 0.82, p = 0.001$), marital ($r = 0.52, p = 0.001$), and family ($r = 0.83, p = 0.001$) and positive appraisal was not correlated to any outcome variable. They also found that problem-focused or emotional approach coping strategies (cC) were unrelated to outcomes but passive avoidant coping strategies were related to higher levels of individual ($r = 0.60, p = 0.001$), marital ($r = 0.39, p = 0.001$), and family ($r = 0.39, p = 0.001$) burden.

They tested all variables from the Double ABCX model to predict Factor (xX) on the three separate levels (individual, marital, and family). They reported that the model accounted for 81% of variance in individual burden ($F(8, 77) = 37.186, p < 0.001$), 52% of marital burden variance ($F(9, 69) = 7.078, p < 0.001$), and 77% of variance in family burden ($F(7, 77) = 32.86, p < 0.001$). Again these finding give credence and support to aspects of interrelated variables within the Double ABCX
model and the researchers have chosen some sound empirically supported measures. Their conceptualisation of Factor (xX) incorporated aspects of family adaptation but were only partially consistent with that of the theoretical model. Unfortunately, elements of construct contamination between measures (e.g., negative appraisals and the experience of individual burden) were experienced, suggesting non-discrete constructs and potentially confounding interpretation of the model. Testing the measurement model as part of a structural equation modelling process may have been useful. Other limitations of this study were the disclosed sample bias and the small sample size for multivariate analysis. Also the sample was of families likely to be in the initial stage of adjustment to diagnosis, rather than longer term adaptation as suggested by the FAAR model. As discussed earlier, FAAR is a derivative of the Double ABCX model that focuses on pre- and post- crisis family variables and describes how a family continues to adapt through multiple events or situations over time. It distinguishes between the early adjustment phase of having a child with a disability and the longer term adaptation phase.

A more recent evaluation by Benzar (2009) tested the Double ABCX and the linear ACBX (Orr et al., 1991) models for data fit from parents of 495 children with autism (aged 1-17 years). Trained telephone surveyors asked standard questions to family caregivers (78% mothers; 17% fathers; 4% grandparents) that related to (a) indictors of extent of disability, pile-up of caregiving demands and parental concerns, (b) utilization of resources (c) parental sense of burden of the disorder on the family and (d) aspects of family functioning (family activities, parental health, parental coping, and disagreements). No standardised measured were used in this evaluation. The pile-up of stressors were conceptualised as causal indicators (indicators caused by the latent variable) rather than effect indicators (such that the latent variable is caused
by the indicator) and the difference was argued to be conceptual in nature. Predictions were made that all three indicators would predict family functioning as specified in the Double ABCX model. Also it was hypothesized that data would fit the ACBX model as reported by Orr et al. (1991) such that (a) the pile-up of stressors would predict utilization of resources and perceived burden on the family, (b) the perceived burden on the family would predict utilization of resources, and (c) the pile-up of stressors and utilization of resources would predict family functioning.

The strength of this study lies in the meticulous detail provided in respect to how its structural equation modelling techniques were completed. Benzar (2009) observed through her confirmatory factor analysis that all latent variables were comprised of their respective indicator (observed) variables and that latent variables were freely correlated. Attention was given to meet the assumption that variables needed to be continuous in nature. Variables with low factor loadings were either set to zero or removed from the model and added as independent variables, directly related to family functioning. Then to meet acceptable goodness-of-fit estimates (CFI = .893, TLI = .902, RMSEA = .075, SRMR = 1.276) and improve the measurement model, the family activities variable was removed from the latent variable of family functioning (Factor xX) due to its poor factor loading. With some other minor adjustments it was concluded that the Double ABCX model was supported by the Tucker Lewis index (or non-normed fit index; NNFI) and the comparative fit index (CFI) which indicated a good fit with the data and precluded it from the need for modifications. After testing the alternative linear ACBX model, Benzar concluded that statistical findings did not support it with Root Mean Square Error of Approximations (RMSEA) equal to 0.085, demonstrating less accurate goodness of fit than the original model. Benzar (2009) concluded that the original conceptualisation
of the Double ABCX model was empirically supported. The analysis was well
constructed and could only have been improved by the use of standardised measures.

Another quality evaluation of the model involved hierarchical linear
regression analysis with data from 195 families of children with autism (Manning,
Wainwright, & Bennett, 2011). Family adaptation (xX) was defined as family
functioning and parent stress (measured with the Family Environment Scale, Moos &
Moos, 1986; and the Parenting Stress Inventory) and held as outcome variables. The
model accounted for family functioning (28%) ($F(9, 157) = 6.88, \ p < .001$) and
parental stress (46%) ($F(10, 142) = 11.89, \ p < .001$). Three variables in particular
emerged as moderating predictors of family functioning. These included (a) child
behaviour problems, (b) coping by getting support from family and friends, and (c)
subjective social status. They also demonstrated that variables that moderated family
functioning and parenting stress were independent and high levels of stress were not
significantly associated with poor family functioning.

And lastly, the most current evaluation of the Double ABCX model (Pozo, et al., 2014) recognised the explicit need for a multidimensional and holistic approach to
modelling so that the influence of many family variables on family adaptation could
be examined simultaneously. The researchers refer to a family quality of life
conceptualisation of the original Double ABCX model. Drawing on the concept of
family quality of life, they defined the Factor (xX) variable in terms of a family’s
sense of wellbeing and the extent to which individual- and family- needs are met.
They measured this concept using the Beach Centre Quality of Life Scale (Poston, et
al., 2003) which records parent perceptions of family interaction, emotional well-
being, parenting, physical/material well-being and disability-related support. Also the
Brief Psychological Well-being Spanish Version (Diaz, et al. 2006) was used. This
instrument is reported to measure self-acceptance, positive relations, autonomy, environmental mastery, purpose in life, and personal growth). Factors (aA) involved measures of the severity of autism symptoms and behaviour problems, (bB) involved a checklist of social supports available, and (cC) was measured with the *Sense of Coherence Questionnaire* (Antonovsky, 1987; 1998b). Most measures used were well constructed and evaluated with good psychometric properties. Their interpretation of the model also included a Factor (BC) which was measured with the *Brief Coping Orientations to Problems Experienced*.

Using a relatively small survey sample (n = 118; 59 mothers and 59 fathers), separate path analyses were performed to compare predictive values of each factor, and to discriminate between mothers and fathers. Due to the small sample size, only separate models for each outcome variable could be constructed (two models to explain family quality of life and two to explain psychological well-being). The primary fit statistic used was chi-squared degree ration ($\chi^2$/d.f). Non-significant relationships between variables were dropped to gain improved data fit to the model (for example, these included active avoidance coping strategies with quality of life and social support with sense of coherence for mothers; for fathers, behaviour problems and family quality of life was dropped). Pozo et al. (2014) report that behaviour problems had an indirect effect on family adaptation in all models such that it was significantly negatively related to sense of coherence which in turn was significantly positively related to psychological well-being and family quality of life. Parents with a better sense of coherence had higher levels of well-being and quality of life. They also reported that social support had a positive causal relation with quality of life for both mothers and fathers. Severity of the disorder was negatively causality related to quality of life for mothers, such that the higher severity led to lower quality.
The reverse was found for fathers; increased severity was causality related to higher quality of life for fathers. Also for fathers, active avoidance coping strategies were positively causally related to quality of life, and were negatively determined by sense of coherence (lower scores related to higher levels of active avoidance coping). Conversely for mothers, positive problem-focused coping was significantly positively related to psychological well-being, and not determined by sense of coherence. The authors note, that the novelty of these findings should lead to cautious interpretation.

Overall, the analysis revealed a mediating causal pathway from behaviour problems (aA) through sense of coherence (cC) to family quality of life (xX) and psychological wellbeing (xX) for both mothers and fathers. Although an appropriate interpretation of the original Double ABCX model was conceptualised in this study and some well-established measures were used to operationalise constructs, the reliability of its results falls short due to extremely small sample size and the split between data for mothers and fathers. Statistical power could not be produced so the model had to be compartmentalised by splitting the Factor (xX) latent variable into its observed components. Therefore, how exogenous variables interact when they are influencing the endogenous latent variable could not be tested. In addition, the concept of family quality of life is currently in theoretical development stage. It is premature to assume it relates to the original Double ABCX concept of family adaptation which stemmed directly from the well-established McMasters and Circumplex models of normative family functioning. Substituting a new construct for Factor (xX) in the model, limits comparability of research results. Other issues that limit this study are the lack of a measure for Factor (A), life stresses; the inclusion of another factor (BC) which was originally described in the diagrammatic version of the model as a suggested interaction between (bB) and (cC) rather than a measurement factor in itself; and
measures used for the proposed (BC) factor combine those that are typically used to measure the separate constructs, thus making the (bB) and (cC) factors non-distinct.

**Summary of empirical inquiries.** In summary of the empirical inquiry into the relationship between family variables and the impact of disability on family adaptation, there have been three approaches. A large body of literature, of which only key examples have been discussed here, has been dedicated to uncovering associations between sub-sets of family variables that may influence family outcomes. Another approach has been to attempt to build models from the bottom-up by assembling family variables statistically into predictive models. The third approach has been to attempt to empirically validate the Double ABCX model, from top-down by establishing measurement of constructs and comparing data sets to make predictive and causal pathways between variables to family adaptation. After 30 years of research in this field, a clear, concise, replicable, predictive model of family adaptation has only partially been achieved due to recurrent, methodological limitations. There is a strong need for consolidation of a model that has been empirically validated using relevant and large enough samples to satisfy power statistics; sophisticated statistical procedures to account for a large number of family variables that affect family adaptation; clear operationalised definitions of latent variables that are consistent with a sound theoretical framework; and construct measures with good psychometric properties. Despite insufficient modelling there has been development and trials of family support programs that effect a range of family variables related to family adaptation. These are discussed next.

**Family Support Programs and Family Adaptation to Disability**

Early childhood development and family support programs generally focus on various aspects of child and family functioning that may contribute to family
adaptation but do not target it specifically. Child educational programming to improve child learning has been shown irrevocably to improve cognitive and adaptive skills, at least in the short term (Guralnick, 1997; 2011). The value of educational programming is unquestionable. The focus of this review, however, is the broader context of family adaptation. This section outlines applications of family adaptation theory and research into practice. It begins with recognised principles that are generally considered to comprise appropriate and effective family support programs. It then reviews the limited literature there is on the effectiveness of these principles when specifically applied. Australian research comparing effectiveness of entire family support programs is then presented and outcomes from programs targeting families of children with disabilities are outlined. Efficacy and effectiveness trials of Stepping Stones Triple P (SSTP; Sanders, et al., 2004), a positive parenting program for parents of children with disabilities, is then discussed in detail, showing positive effects on a range of family variables.

Dunst and Trivette (1994) have traced social and political movements from the 1960s in the US that have affected the development of child and family support services, relating to children with disabilities. These movements have increasingly focused on embedding child-related services into a broad ecological and family context. The resulting policies and principles provide a framework of family-centred practice to strengthen family functioning. They identify and provide detailed descriptions of the implementation of six principles. These include: enhancing a sense of community; mobilising resources and supports; providing shared responsibility and collaboration; protecting family integrity; strengthening family functioning; and providing proactive human services. A number of measures of family resources and service processes have been derived but do not measure family
adaptation per se. (e.g., FSS and Family Resources Scale [FRS]; see Dunst, Trivette, et al., 1994; Measures of Processes of Care, see King, Rosenbaum, & King, 1995).

In a report for the US National Association of State Units on Aging (Research Brief #10), five key focus areas of family support programs and their effectiveness have been described (Whittier, Coon, & Aaker, 2001). The areas included: providing information about services to families; helping families access services; individual counselling and support groups that assist with family problem solving; providing respite care; and supplemental short-term services to complement caregiver care. Again, family adaptation is not directed targeted. Generally, reported outcomes relating to implementation of these areas of focus was reported to be scarce. Information-only based services were reported to not show evidence of positive mental or physical health-related outcome. Increasing access to services was reported to have been shown to decrease caregiver burden and time-off from work due to caregiving demands. Counselling in various individual, group, and family forms was reportedly related to positive mental health outcomes, particularly for caregivers with high levels of emotional distress, depression and anxiety. Support groups were reported as having been related to improved informal peer support networks but not caregiver mental or physical health or shifts in caregiver burden. Education and training, especially related to family problem solving and behaviour management, was reported to be associated with improved caregiver management of depressive symptoms, mood management, problem solving, and decreases in caregiver burden. Respite was reported to be associated with lower levels of caregiving-related stress, reduced feelings of burden, and better psychological well-being. And supplementary services such as home modifications, homemaker services, legal advice, etc. were reported to generally strengthen informal caregiving. General findings are discussed
in relation to specific programs and cited papers but do not refer to formal evaluations that measure family adaptation or report clinical effect sizes.

The Australian Government (Australian Institute of Family Studies) commissioned a specific review of the evidence on the effectiveness of early childhood interventions that considered child outcomes and cost effectiveness for families of children at risk of poor developmental outcomes (Wise, Da Silva, Webster, & Sanson, 2005). Early childhood public programs that attempt to improve child and family health and development up to the age of 6 years were compared for costs and benefits. Thirty two programs that were already well-evaluated were selected and compared for effect sizes. Overall, the report concluded that interventions produced improvements across a wide range of outcome domains, with greatest improvement in children’s cognitive skills and child-related outcomes in general. Parent-related outcomes showed least improvement. Studies with reported effect sizes on parent and family outcomes showed negligible to small effects only, except for the Triple P program (Sanders, 1999; 2012). This program demonstrated positive and large effects on child behaviour, parenting style, and parent conflict over childrearing.

In a review of positive behaviour support programs for families commissioned for the Department of Ageing, Disability, and Home Care by the Centre for Developmental Disability Studies (Wiese, Stancliffe, & Henley, 2005), four of the most prominent programs operating in New South Wales, Australia were compared. These included Triple P (Sanders, 1999; 2012), Stepping Stones Triple P (SSTP; Sanders, et al., 2004), Signposts for Building Better Behaviour (Hudson, et al., 2003), and Apex Behaviour Management (Sigafoos, 2002). Comparisons were made on a range of variables relating to child outcome, being evidence-based, and being related
to early intervention and positive behaviour themes. All programs met criteria on these benchmarks with SSTP being rated strongest due to available evidence. They were also compared on aspects of being embedded in a broader family centred approach and demonstrating both child and family outcomes. Wiese, et al. (2005) reported that this meant that the program should recognise the goal of intervention is one of improving the well-being of the whole family since family centred approaches and family quality of life were thought to be inherently linked. For this, the benchmark required measurement of multiple outcomes reflective of the whole family, including: family satisfaction with program; improved parental self-efficacy; decreased feelings of stress and increased coping; and improved family relations. The Apex Project had, at the time, produced only child-related set of evidence; Signposts for Building Better Behaviour had reported on a single trial that demonstrated a decreased maternal stress, increased self-efficacy, less hassles, and improved child behaviour; SSTP had produced multiple trials demonstrating positive child-related and family-related outcomes including decreases in family stress and coping, and marital conflict. SSTP was argued to be the preferred approach to service provision through its highest contribution to family resources.

Although Signposts and SSTP met benchmarks for impacting a sub-set of family variables in families of children with disabilities, family adaptation was not considered. Indeed, program evaluations that consider a broad range of family variables and/or family adaptation are very scarce. The aforementioned two, and The Parents Plus Programme (Coughlin, et al., 2009) developed in Ireland for typically-developing children with conduct issues, but also trialled with families of children with disabilities, appear to hold most promise. But can any of these programs, which
have used comparative and psychometrically sound measures, be said to effectively facilitate positive family adaptation?

**Does the Parents Plus Program facilitate positive family adaptation?** The Parents Plus programme, applied to families of children with disabilities has been reported to yield significant shifts toward positive improvement in parent-reported child behaviour (measured with the *Strengths and Difficulties Questionnaire*; Goodman, 1997) compared to a waitlist condition, which was maintained over a 10-month period (Quinn, et al., 2007). This group-based program also saw significant shifts from pre- to post-test for treatment group families on measures of parenting satisfaction (measured with the *Kansas Parental Satisfaction Scale*; Schumm, Kennedy, Grigby, Shectman,& Nichols, 1985) and family resources and stress (measured with the QRS) but these changes did not yield statistically significant differences from the waitlisted control group. Other aspects of family life showed no significant within-group or between-group changes. These areas included parental adjustment (measured by the *General Health Questionnaire – 12 [GHQ]*; Goldberg & Williams, 1988); family functioning (measured by the FAD); social support (measured by the *Perceived Social Support Scale*; Carr & O’Reilly, 2000); life events (measured by the *Family Inventory of Life Events and Changes*); and parenting stress (as measured by the *Parental Stress* subscale of the *Parenting Stress Index*).

Coughlin, et al. (2009) also reported significant positive intervention effects, compared with a non-randomised treatment-as-usual control group, on reports of child behaviour (using the *Strengths and Difficulties Questionnaire*) and parenting stress (using the *Parental Stress Scale*; Berry & Jones, 1995) which were maintained at 5 month follow-up. Effects on conduct problems were more significant ($p < .01$) than for parental stress ($p < .05$). The authors compared the effects for parents of children
with and without developmental disabilities; they concluded that although both groups appeared to have benefitted in these areas, there were significantly more positive outcomes for families of children without disabilities.

In sum, the Parents Plus Program has been shown to improve child behaviour and may improve parent satisfaction, and resources and stress, but further evaluation is required for verification. It has not been found to have significant effects on theoretical or empirical conceptualisations of family adaptation using specifically related measures of family adaptation (FAD), general health (using the GHQ) perceived social support (using the Perceived Social Support Scale), or family life events (Family Inventory of Life Events).

**Does Signposts Building Better Behaviour facilitate positive family adaptation?** As referred to above, Hudson, et al., (2003) developed and evaluated Signposts in New South Wales, Australia. The program was developed with a family-centred framework and addressed eight distinct modules of treatment (i.e., *Introduction, Measuring your child’s behaviour, Systematic use of everyday interactions, Replacing difficult behaviour with useful behaviour, Planning for better behaviour, Teaching your child new skills, Dealing with stress, and Your family as a team*). One hundred and fifteen families of children with intellectual disabilities were openly recruited and mostly allocated (some made a choice) to either, group support \((n = 46)\), telephone support \((n = 13)\), self-directed resources \((n = 29)\), or a control group \((n = 27)\). Attrition saw 67 families complete post-tests so the sample was diminished. Yet, combining intervention groups and contrasting to control group means, analysis showed medium effects sizes for improved parent stress levels (using the *Stress* subscale of the DASS) and improved sense of parent needs being met (using the *Parental Needs* subscale of the Parenting Hassles Scale [PHS], Gavidia-
Payne, Richdale, Francis, & Cotton, 1997; Gavidia-Payne, Matthews, Hudson, Richdale, & Nankervis, 2003). Small-medium effects (\(\eta = 0.06\)) were also detected on parents’ sense of competence (using the Parent Sense of Competence Scale [PSoC], Efficacy subscale; Johnston & Marsh 1989). For a subsample (\(n = 28\)), effects on the DASS, PSoC and the PHS were maintained at 4 – 6 month follow-up. Reported also was a significant difference between pre-test and follow-up scores for child disruptive behaviour change (using the DBC, Disruptive subscale) (\(t_{26} = 2.69, p = 0.013\)), and child antisocial behaviour change (using the DBC, Antisocial subscale (\(t_{26} = 2.31, p = 0.0028\)), but no group differences for either subscale.

For a subsequent trial (Hudson, Cameron, & Matthews, 2008), outcomes of a nationwide implementation were constructed in accordance with benchmarks from the Wiese, et al (2005) evaluation and comparison of programs. Accordingly, child and parent outcomes were aggregated for some 2,119 families (with post-tests completed by 889 families) that participated in either group, individual, telephone, or self-directed versions of Signposts, over 18-months. Using pre-post comparisons of mothers data, small effect sizes (0.2 – 0.5; Cohen, 1992) were reported for depression, anxiety and stress (using the DASS), efficacy and satisfaction (using the PSoC) (effects were moderate for the Efficacy subscale), child behaviour and parent needs (using the PHS), child behaviour problems (using the DBC and a Likert-type scale of child aggression and obedience).

In sum, the Signposts program has been shown to improve child behaviour as well as a range of other family variables that relate to family adaptation. There is some preliminary evidence of positive effects on parental adjustment, efficacy, satisfaction and a decreased sense of parent hassles. The effects need to be verified
through further evaluation. As to whether family adaptation is facilitated, no specific measurement has been made.

**Does Stepping Stones Triple P improve family adaptation?** SSTP is a well established and evidence-based program developed by Professor M. Sanders, Dr T. Mazzucchelli, and the current author, Ms L. Studman (2004). It integrates applied behavioural analysis, social learning theory and developmental research into a range of parenting strategies for children with developmental disabilities. It is based on seven principles of positive family life that contribute to positive developmental outcomes for children with disabilities. These include: a safe engaging environment; a responsive learning environment; assertive discipline; realistic expectations; being part of the community; family adaptation to disability, and parental self care (Sanders, et al., 2004). SSTP has a number of specifically targeted aims and is designed to:

- increase parents’ competence in managing common behaviour problems and developmental issues found among children with disabilities;
- reduce parents’ use of coercive and punitive methods of disciplining children;
- improve parents’ personal coping skills and reduce parenting stress;
- improve parents’ communication about parenting issues and help parents support one another in their parenting roles; and
- develop parents’ independent problem solving skills.

Family adaptation is not directly targeted. However, with increased competence in child management and improved family resources, effects on family adaptation in general are implied.

The intervention is implemented either in a self-directed way, in a group format, or individually as a brief-targeted or broad-based intervention. Resources consist of written parent workbooks (Sanders, Mazzucchelli, & Studman, 2003a;
an instructional video tape (Sanders, Mazzucchelli, & Studman, 2003b); practitioner’s manuals and session presentations (Sanders, Mazzucchelli, & Studman, 2003c; 2009d; 2009e; 2009f; 2009g) and a series of booklets that outline template behaviour support plans for a range of high risk situations or child behaviours (Sanders, Mazzucchelli, & Studman, 2009b). Enhanced Triple P interventions consist of 3 – 6 sessions of cognitive-behavioural based skills development in the areas of parent mood/stress management and partner support (Sanders, Markie-Dadds, & Turner, 1998).

SSTP is commercially disseminated and over 2,100 practitioners internationally have been trained and accredited to provide the program (McWilliam, 2010). It is implemented as one of the dominant family support programs within the Western Australian (WA) public sector (Education and Disability agencies), and is currently being rolled-out through New South Wales, Queensland, and Victorian government sectors (details at: http://www.triplep-steppingstones.net/au-en/stepping-stones-triple-p/the-stepping-stones-triple-p-project/).

Since its inception, SSTP has undergone a number of evaluations. The early WA trial (Roberts, et al., 2006) used a randomised control design to answer the broad research question, “Does SSTP improve parenting and child behaviour for families with children who have a disability?” The initial analysis from the SSTP WA trial focused on treatment effects of targeted variables including child behaviour and parenting. Treatment effects of non-targeted variables related to family adaptation were not analysed since they addressed the specific research questions related to this present thesis on family adaptation.

The initial analysis revealed positive and significant effects. Significant reductions in problem behaviour (using the DBC) from pre- to post-intervention,
(t[16] = 3.67, p < 0.1) and from pre-intervention to 6-month follow-up (t[14] = 3.19, p < .05) were reported by mothers. The analysis revealed no significant changes for control group parents. On a parent report measure of dysfunctional parenting style (Parenting Scale [PS]; Arnold, O’Leary, Wolff, & Acker, 1993) there was a significant Group x Time effect. On subscales of the PS, intervention group mothers reported less Overreactivity (t[13] = 3.34, p = .01) after the intervention and these lower levels were maintained from pre-intervention to follow-up (t[11] = 3.97, p < .01). Time effects for Laxness, (F[1,27] = 6.24, p < .05, η² = .19) and Overreactivity, (F[1,27] = 9.72, p < .01, η² = .27) were also reported. There were no significant shifts for control group mothers. Intervention group fathers reported less Laxness, (t[9] = 4.47, p < .01) and Verbosity, (t[9] = 3.24, p = .01) from pre- to post-intervention, which were maintained at follow-up. Control group fathers reported increased dysfunctional parenting styles. Roberts et al. (2006) reported that SSTP had limited effects on reducing family stress (measured with the Stress subscale of the DASS). No group treatment effects were found, possibly because normative levels of stress at pre-intervention phase for both groups were noted.

Since the initial evaluation of SSTP, other studies have produced similar findings. Plant & Sanders (2007b) analysed variance of similar measures of effects of SSTP comparing a standard delivery SSTP intervention, an enhanced delivery SSTP intervention (i.e., six extra sessions focusing on coping with caring; reactions to child disability; grief and loss; developing effective coping skills; strengthening social support; enhancing teamwork and partner support), and a waitlist control group. They reported significant treatment and control group differences at post-test for child behaviour (DBC-Disruptive subscale, F(3,73) = 4.62, p = .013); and parenting style (PS, F(3,73) = 5.72, p = .005) with behaviour improving in a positive direction for
families in the standard delivery treatment group, without having had additional family issues directly targeted. Parenting satisfaction and competence (using the PSoC) improved for both treatment groups significantly (PSoC, $F(3,73) = 5.59, p = .006$) compared to the waitlisted families. When treatment groups were compared at 12 month follow-up, the enhanced-delivery group showed lower rates of child behaviour problems (DBC-Disruptive subscale, $F(1,39)=5.10, p=.03$) and no differences on any other measure. No significant differences between groups on measures of parental adjustment (DASS) or dyadic adjustment (*Abbreviated Dyadic Adjustment Scale*; [ADAS]; Sharples & Rogers, 1984) were found at any time-point. Again, program effect sizes may have been influenced by pre-intervention scores on the DASS and the ADAS being within normal ranges. At any rate, it may point to the possible maintenance effects of an enhanced intervention that taps into aspects of family adaptation.

Other relevant studies that have added to the evidence-base supporting SSTP, on targeted variables of parenting and child behaviour, include a randomised trial of 59 families of children with autism spectrum disorder (aged 2 to 9 years). It demonstrated improved child behaviour, parenting, and parent satisfaction (Whittingham, Sofronoff, Sheffild, & Sanders, 2009a). It showed effects that were again consistently positive on measures of child behaviour (*Eyberg Child Behaviour Inventory*) and parenting style (PS, all subscales) for parents of children with autism compared to a waitlist condition. Parent satisfaction, measured by the PSoC (*Satisfaction* subscale), was affected in a similar way, to a less but still significant extent at post-test. The PSoC, *Efficacy* subscale showed significant positive improvements only at 6 month follow-up, along with maintained effects for child behaviour, parenting and PSoC satisfaction scores.
This study was complemented with an embedded project that explored how parental attributions affect treatment outcomes. The Parental Attribution Questionnaire (Whittingham, Sofranoff, & Sheffield, 2006), based on Weiner’s attribution theory (Weiner, 1980) was developed for the study. Attributions about the cause and the stability of their child’s behavioural problems were reported to significantly predict change in the outcome measure of dysfunctional parenting. Following SSTP, parents were less likely to believe their child’s behavioural problems were caused by intrinsic, unchangeable factors such as the disability itself. They were more likely to believe that behaviour problems could change. Furthermore, parental attributions about child behaviour predicted some aspects of parenting style changes (Whittingham, Sofronoff, Shefield, Sanders, 2009b).

In a condensed SSTP program evaluation where the FAD-GF was included, the usual positive effects on child behaviour, and dysfunctional parenting styles (PS Over-reactivity and Verbosity) were reported (Sofronoff, Jahnel, & Sanders, 2011). No significant Group x Time differences were observed on measures of relationship quality (using the Relationship Quality Index, Norton, 1983), parent adjustment (DASS) or family adaptation (FAD-GF). Again, normative pre-intervention baseline means on these measures were reported and this again leaves results inconclusive. Interestingly the PSOC again yielded significant positively-directed improvements from pre-test to 3-month follow-up while not observed at post-test.

In the first systematic review of SSTP (Tellegen & Sanders, 2013), using meta-analytic procedures and involving 12 specific quantitative trials, significant improvements included: a medium effect size for child behaviour problems ($d = 0.537, 95\% \text{CI}(0.372, 0.702), p < .001$); a large effect size for parenting style ($d = 0.725, 95\% \text{CI}(0.553, 0.896), p < .001$); a moderate effect size for parental sense of
competence \((d = 0.523, 95\% \text{ CI}(0.315, 0.730), p < .001)\); a small effect size for parental adjustment \((d = 0.264, 95\% \text{ CI}(0.115, 0.414), p < .001)\); and a moderate effect size for parental relationship \((d = 0.421, 95\% \text{ CI}(0.214, 0.628), p < .001)\). With replicated effects demonstrated on some family variables, it is likely that family adaptation is also improved. However, it has generally not been targeted for intervention or measured as an outcome.

In sum, ongoing international evaluations of SSTP repeatedly demonstrate positive medium to large effects for improved child behaviour and less dysfunctional parenting interactions. To a lesser extent, it yields effects on parents’ sense of competency (PSoC), and inconsistent, but apparent, small to medium effects on measures of parental adjustment and relationship quality. As to whether family adaptation is improved, only one study included a specific measure for it (FAD), and non-significant results were reported.

**Summary of Theoretical, Empirical, and Applied Inquiries**

Theoretical, empirical, and applied inquiries into the relationship between family variables and impact of developmental disability on family adaptation can be summarised in three key points. Firstly theoretically, the Double ABCX model was initially construed from well-established and validated models of individual stress and coping, ecology of human development, and family systems theory. It integrates proposed, and partially validated, interactions between latent family variables related to family care-giving burden, family support and resources, and family perceptions, to predict family adaptation. The construct of family adaptation comprises physiological and psychological aspects of functionality of all members; it involves family communication, family coherence and family problem solving style and can be
measured in accordance with the Circumplex and/or Masters models using either the FACES-IV or the FAD-GF, respectively.

Secondly, empirical inquiries have provided clear direction for further research in terms of remedying recurrent methodological flaws related to conceptualisation of the Double ABCX model, small sample sizes and poor measurement. Through structural equation modelling there has been some support for direct and mediating causal relationships of between family variables and adaptation.

And thirdly, inquiries into applied family support principles and practices have demonstrated a definite focus on reducing caregiver burden through improving child behavioural problems and parenting styles. There have also been documented positive, yet inconsistent, effects on a range of other family variables such as parental and relationship adjustment and sense of competence, but no definitive inquiry into the effect of family support programs on family adaptation.
Chapter 4

Scope and Specifications of the Current Inquiry

Aims and Rationale

The overall aim of this thesis was to advance understanding of evidence-based models of family adaptation to disability. Specifically, the first aim was to describe family adaptation as it relates to the impact of family behavioural intervention. The second aim was to describe family adaptation as it relates to the evaluation of a theoretically sound model, thereby determining how latent family variables interact to predict the impact of family caregiving burden on family adaptation. Achieving these aims would lead to better informed treatment designs and targets, for families adapting to the caregiving burden of having a child with a developmental disability.

The rationale for this inquiry was that there is increasing need for family support programs that target family adaptation. This need arises from several observations. Firstly, prevalence rates of developmental disability are high (8.8% for boys; 5.0% for girls) (ABS, 2012) and generally poor behavioural and emotional outcomes for these children are on the increase (40% of the population being afflicted) (Emerson, 2003). Secondly, there is increased scientific acknowledgement and community awareness of the impact of developmental disability on mental health and social outcomes for both children with disabilities and their families (Edwards, 2008). Children with developmental disabilities whose families are overburdened with caregiving demands develop lower levels of adaptive behaviour and are at higher risk of developing secondary psychiatric impairments than those with well-functioning families (Wallander, et al., 2006). This is reflected in policy-informing reviews that implore family support programs take a family centred approach (Dunst & Trivette, 1994; Wiese, et al., 2005)
The need for research in this area also stems from literature that provides strong evidence of a range of impacts of disability. The caregiving impact on members of the family include those that arise from practical burdens (e.g., daily hassles of physical care, managing behaviour, and providing educational/medical treatment programs at home), psychological burdens (e.g., grief, stress, health problems, and effects on siblings), and burdens on the family unit (e.g., marital relationships, family functioning, and social networks). The financial costs of raising a child with a disability can also impact negative on families and come from non-normative associated expenses, such as therapeutic/educational equipment, mobility/communication devices, specialised dietary needs and procedures, and support from health professionals. There are also impacts of family caregiving on the wider community in relation to financial burdens associated with providing intensive behavioural interventions to curb challenging behaviour, providing family respite and out-of-home care supports, and out-of-home permanent placements in cases of family breakdown. When families do not achieve a positive level of family adaptation that supports the optimal development of all of its members, the impact resonates for the child with a disability, their family and the community in general. Therefore, advancing scientific understanding and promoting evidence-based family support programs is paramount.

In addition to the need for evidence-based models of family support, the rationale for the current inquiry relates to the current state of scientific knowledge in the area. The recognition of the impact that family caregiving can have on children and families, has lead to a plethora of inquiry into factors that contribute to how families cope and adapt to ongoing caregiving demands and stressors. Theoretical, empirical and applied fields of inquiry have emerged. All acknowledge and validate
the supposition that there is a range of family variables that act as risk and protective factors which influence the level of positive family adaptation that a family achieves. These family variables relate to (a) the extent and nature of stressors and demands, (b) the availability of family resources, both practical and emotional, and (c) the perceptions that a family holds about how they cope, what they believe about their situation, and their sense of coherence. However, there have been few comprehensive quantitative and well-designed inquiries into how these family variables interact to predict family adaptation.

The result has been only a limited range of family support programs for families of children with disabilities that involve empirically-supported models of family adaptation. It is not known if existing behavioural family interventions that target specific variables, such as child disruptive behaviour patterns and parenting styles, impact positively on family adaptation. Also, there is only inconclusive support for conceptual models of family adaptation, such as the Double ABCX model, that could inform the development of programs specifically targeting family adaptation to developmental disability.

The Double ABCX model theoretically attempts to group the many observed variables that are recognised as risk factors into the aforementioned latent variables (stress and demands; resources and supports; and parent perceptions). The model posits that family adaptation to enduring stress and non-normative change (Factor xX) is affected by the nature of the event or situation (Factor a), acquired resources (Factor b), and perceptions of current coping ability and positive contributions of child disability (Factor c) as well as family variables that are pre-existing. These may include pre-existing aspects of personal or family stress (Factor A), resources and supports (Factor B), and global perceptions or beliefs (Factor C) that exist before, or
irrespective to, the birth of a child with a developmental disability and any associated family caregiving burden. Empirical validation of this model has revealed inconclusive results and has failed to clarify the mechanisms of change. Whether family variables have a direct and additive, mediating, or moderating effect on family adaptation remains unclear.

The interrelationships between family variables are important to understand since they give insight into what, how, and when specific targets for intervention should be applied. If family variables have a moderating effect then it would suggest that a program to target adaptation would directly target a family’s caregiver burden (Factor aA) along with other family risk factors that are interacting, such as family resources and perceptions (Factor bB and cC variables). If family variables have a mediating effect then it would suggest that family caregiver burden could be targeted indirectly by providing services that target mediating variables only (Factors bB and cC). If family variables have additive effects then all family variables including caregiving burden; resources and supports; and parent perceptions, have an additive and cumulative effect on family adaptation, and can be targeted directly as needed in a family centred context. Ultimately, an evidence-based model can inform the most efficacious intervention since variables that are not impacting on a particular family’s adaptation would not be targeted for intervention. Family variables that mediate, moderate, or have a direct causal impact on family adaptation could be specifically targeted and prioritised over those that do not.

The current state of scientific knowledge in this area has been complicated by methodological inconsistencies that relate to the definitions of key terms, conceptualisations of the Double ABCX model, and measurements of family variables. Family researchers are interested in complex, dynamic processes that occur
both within and between individuals in families over a long period of time. These processes are present in everyday life/family activities and routines. Experience Sampling Methods involve family members recording their experience at random or specified times, when signalled by a ‘beeper’. More recent applications of this method broaden the unit of analysis to include not only internal states, but behaviours, social and physical contexts, and other variables. Known as Ecological Momentary Assessment, this method enables the collection of large amounts of information from family members in natural environments and reduces retrospective memory bias in responders (Smyth & Heron, 2014). However, this type of assessment can be impractical when samples are moderate or large in size. In addition to usual methods of family assessment that may include self-report questionnaire completion, and interviewing, the use of multiple methods of assessment are recommended (Cummings, Bergman, & Kuznicki, 2014).

Methodological limitations in this field of study also extend to the use of statistical procedures that are unable to account for the wide range of family variables that impact on family adaptation. Many studies have employed correlational and simple analysis of variance (such as MANOVA) methods which are appropriate for assessing group differences by creating a linear composites of measured variables. However, this does not allow for latent variables which are theoretically error-free covariates derived from measured variables (Hancock, 2004). Few studies have employed structural equation modelling procedures that allow more sophisticated analyses that can account for a wide range of observed variables.

Specific Research Questions

This thesis poses two specific questions. The first is: Does behavioural family intervention produce significant effects on targeted and non-targeted family variables
related to family adaptation? This is important because as family systems theory suggests, change in part of a family system may instigate changes in the broader context of the system. If this is the case, then targeting family adaptation specifically may not be an advantage since existing family support programs that target child behaviour and parenting may be the most parsimonious and cost-effective intervention to provide. If not, then it is important to consolidate clear definitions and measures of family adaptation, and to validate existing theoretically sound models, as a way to understand the mechanisms of change toward positive family adaptation.

The second research question is: How does the Double ABCX model of family adaptation best describe the relationship between family caregiving burden and family adaptation? Such an inquiry is needed as it might inform how more complex family interventions can be developed to complement existing behavioural family interventions that target child behaviour and parenting only. This is important as it can lead to greater efficiency of services through targeting specific family variables that either have direct and additive, mediating, or moderating effects on family adaptation.

Goals and Hypotheses

Study 1 – Differential effect sizes of a parent support program on targeted and non-targeted family variables. The primary goal of the first study was to quantify the relative effects of behavioural family intervention on a range of family variables that theoretically relate to family adaptation. Standard Stepping Stones Triple P (SSTP; Sanders, et al., 2004), a parenting program adapted for families of children with disabilities, from the original Standard Triple P manual (Sanders, Marker-Dadds, & Turner, 2001), was to be evaluated with a focus on comparing effect sizes on targeted variables (i.e., child behaviour and parenting) and non-
targeted variables (i.e., parent depression, anxiety and stress; family resources and stress; parent sense of competence; relationship adjustment; and general family functioning). The investigation was to form part of a general evaluation of clinical effectiveness that reported significant effects on targeted variables (Roberts, et al., 2006). The inquiry into the relative effects on non-targeted variables relates to the first distinct research question of this thesis. The secondary goal of Study 1 was to assess relative impact on both targeted and non-targeted variables over time to check for maintenance of any significant effects of SSTP.

Using a waitlist control designed with four time-points (pre-test, post-test, follow-up 1 at six months, and follow-up 2 at 12 months), generalised linear mixed modelling procedures were to be applied and eta (or eta squared) statistics were to be compared to test hypotheses. It was hypothesized that (a) the treatment group would show significant positive changes from pre-test to post-test on both targeted and non-targeted variables while the control group would not, and intervention effects would be stronger for targeted (child behaviour and parenting) over non-targeted variables (family resources and stress, family adaptation, parent sense of competence, parental dyadic adjustment, and parental mental health), (b) significant pre-test to post-test changes would be maintained at follow-up 1 and follow-up 2, and (c) the treated control group would show pre-test to post-test changes on targeted and non-targeted variables at time-point 3 and 4 after the program had been implemented.

Study 2 – Evaluation of the Double ABCX model of family adaptation to disability using structural equation modelling. The primary goal of study 2 was to apply structural equation modelling to evaluate the Double ABCX model. This method would allow for latent variables which are theoretically error-free covariates derived from measured variables. It allows more flexibility than other analyses of
variance, such as MANOVA, since covariance adjustments can be made both at the
construct and the individual level, such that individual variables’ residual may covary
above and beyond their latent variable’s common construct. This analysis
accommodates such relations (Hancock, 2004). Specific hypotheses related to this
primary goal are outlined subsequent to the secondary goal.

The secondary, embedded goal of Study 2 was to consolidate the
centralisation of key terms in the Double ABCX model for further research by
developing a reliable measurement model using latent variables to accommodate a
wide range of observed variables that theoretically pertain to family adaptation.
Factor (aA) from the model was conceptualised as Family Stress & Demands (aA)
and was to comprise two measures used to reflect child/family-related caregiver
burden and general life stressors that build-up over time. Factor (bB) was
conceptualised as Family Resources & Stress (bB); it was to comprise indications of
general family resources, formal and informal practical supports, and internal family
emotional resources, or hardiness. Factor (cC) was conceptualised as Family
Perceptions (cC) and was to comprise variables related to both positive perceptions
that parents make about having a child with a disability, and general family problem
solving style over time. Factor (xX) was conceptualised as Family Adaptation (xX).
Lazarus and Folkman’s theory of stress and coping has suggested that outcome
measures should include physiological, social, and psychological outcomes. Olson, et
al. (1988) has suggested that previous research has shown that an indication of family
adaptation should include personal well-being and family adaptation. This is
important since in past attempts to evaluate the Double ABCX model, a common
methodological flaw has been to select endogenous variable measures for family
adaptation, that are in fact, measures of family stress. For these reasons, in the
present inquiry, the construct Family Adaptation (xX), was to comprise indications of general physical and psychological health of parents, and family adaptation in relation to dimensions of the McMaster model (Epstein, et al., 2003). To create and validate the measurement model through confirmatory factor analysis, various measures of each of these variables were to be chosen according to their psychometric properties, including construct validity, and their use in previous research into family adaptation. Table 1 outlines the rationale for each measure used to construct the measurement model. It specifies each of the Double ABCX latent variables, observed variables that were used to comprise each component, and which specific subscales were to be included. It also outlines points of rationale for inclusion, which incorporates the psychometric properties of each inventory.
<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
</table>
| **Family Stress & Demands (Factor aA)**  
*Parenting Hassles Scale (PHS; Gavidia, et al., 1997; Gavidia-Payne, Matthews, Hudson, Richdale, & Nankervis, 2003)* | Measures stress in parents of children with disabilities in terms of ‘hassles’, which are characterised as the distressing demands of everyday transactions with the environment for families of children with disabilities (Richdale, Francis, Gavidia-Payne, & Cotton, 2000).  
Subscales used:  
(a) **Child Behaviour & Needs**  
(b) **Parent Needs & Characteristics**  
(c) **Education & Child Development** | • Targets specifically child/family-related caregiver burdens.  
• Locally devised from Australian research.  
• Covered most identified areas of impact of disability as discussed in Chapter 2.  
• Good psychometrics, including (a) concurrent validity with the DBC-Total Problem Score, (b) convergent validity with the DASS, (c) divergent validity with the PSoC (satisfaction subscale) and, (d) internal consistencies of Cronbach’s alpha coefficients of .94 (total scale), .75 (education and child development subscale), .86 (parental needs/characteristics subscale), and .89 (child behaviour/needs) (Gavidia-Payne et al., 2003).  
• The original version of 87 items included 8 further subscales (equipment, personal care of child, medication/health needs, siblings, resources, dealing with others, finances, and schedule) (Gavidia-Payne, et al., 1997, May) The short form was used since it was more succinct and maintained good psychometric qualities (Gavidia-Payne, personal and email communication). Also it was less likely to conceptually overlap other variables in the Double ABCX model.  
• The intensity scale was used rather than the frequency scale due to strongest validity and brevity as suggested by primary author (S. Gavidia-Payne, personal communication).  
• Disadvantage of no confirmatory factor analysis available at time.  
• Permission to reprint the scale and use in the project obtained from primary author, S. Gavidia-Payne.  
• Precedential use with parents of children with disabilities (Hudson, et al., 2003; 2008). |
| **Life Distress Inventory (LDI; Thomas, Yoshioka, & Ager, 1994)** | Assesses level of distress associated with 18 general areas of life. A total score for general distress is derived in addition to subscale scores indicating level of stress in four or five areas. Subscales used:  
(a) **Social Functioning**  
(b) **Life Satisfaction**  
(c) **Finance & Employment**  
(d) **Marital Distress** | • Targets longer term or ‘pre-existing’ family burdens.  
• Good psychometrics reported by (Yoshioka & Shibusawa, 2002), including (a) test-retest reliability over 6 months ($r = .66$), (b) high internal consistency ($\alpha = .85$) with a range of subscale consistencies from $\alpha = .55 - .84$, (c) high level of construct and concurrent validity established through factor analysis (52% of variance accounted for by 5 factors, with average of .63) (ref) and 77% of variance for 4 factors (social functioning, $\alpha = .89$; life satisfaction, $\alpha = .82$; finance and employment, $\alpha = .77$; marital distress, $\alpha = .80$) with total score $\alpha = .89$ (Yoshioka & Shibusawa, 2002), (d) good convergent and discriminative validity with high correlation with the Global Severity Index of the Brief Symptom Inventory (Derogatis, 1993) and low correlation with measures or socio-economic status, education, and religion (Thomas, Yoshioka, & Ager, 1994).  
• Permission to reprint the scale and use in the project obtained from author (personal communication).  
• Precedential use with populations including clinical and non-clinical samples (Yoshioka & Shibusawa, 2002). |
Table 1
(Continued)

<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Resources &amp; Supports (Factor bB)</td>
<td>Measures the adequacy of resources in households with young children.</td>
<td>• Targets basic practical resources following Maslow’s hierarchy of needs (Maslow, 1943) from money for food and housing, to resources such as time for holidays and family outings, and to socialise. Authors concede it assesses both intrafamilial and extrafamilial resources in accordance with Bronfenbrenner’s ecological theory. • Originally validated by authors with samples of mothers of children with developmental disabilities. • Item selection and ordering, from most to least basic, compiled by 28 experienced professionals. • Psychometric properties appropriate. Total score test-retest reliability (over 2 months), ( r = .7 ); coefficient alpha, .92, and split half reliability, .95 (Dunst &amp; Leet, 1998). Factor analysis revealed eight subscales related to (a) growth and financial support, time for interpersonal relationships, money for necessities, luxuries and the future, (b) health and necessities such as money for food, shelter, utilities, income work health/dental care, (c) nutrition and communication items such as food, clothing and transport, (d) physical shelter, heat and plumbing (e) intra-family support and time to be with family (f) communication and employment such as telephones, income and dependable transportation (g) child care and special equipment for the child, and (h) independent source of income. Predictive validity for all subscales was established for outcome variables of personal well-being and maternal commitment to carrying out professionally prescribed, child-level interventions (Dunst &amp; Leet, 1988). Further analysis revealed a four-factor structure (Herman &amp; Thompson, 1995), used in the current project, with Cronbach’s alphas equal to .92, .91, .89, and .57 respectively. Subsequent factor analytic research on a large, low-SES sample of families with children receiving early educational programs, not necessarily with developmental disabilities (HeadStart families) (van Horn, Belis, &amp; Snyder, 2001). It revealed 3 items with a greater than 10% response rate of “does not apply” were eliminated. The three items (public assistance, childcare/day care for your children, and babysitting for your children) seem relevant to families of children with disabilities. A fourth item (money to buy special equipment supplies for children) was dropped from the analysis because it was deemed relevant to families with children with disabilities but not the broader population. Although the psychometric validation studies were thorough and produced a reliable and valid revised FRS with fewer items (20), the revised FRS was not used in this research due to the deletion of relevant items for families of children with disabilities; Herman and Thompson’s (1995) original FRS factor structure was used. The original structure and internal and construct consistency has been verified with further confirmatory factor analysis and regression analysis (Brannan, Manteuffel, Holden, &amp; Heflinger, 2006). • The FRS may be reproduced without permission (email communication with primary author, Carl Dunst). • Precedential use with populations including disadvantaged children (van Horn, et al., 2001); children with emotional and behavioural disorders (Brannan, et al., 2006); and children with disabilities (Dunst &amp; Leet 1988; 1994). • Precedential use as a Factor bB variable in the Double ABCX model (Clark, 1999).</td>
</tr>
</tbody>
</table>

Family Resources Scale (FRS; Dunst & Leet (1988; 1994) | Measures the adequacy of resources in households with young children. | |

Subscales used:
(a) Basic Resources  
(b) Time Resources  
(c) Money Resources  
(d) Child-related Resources
Table 1
(Continued)

<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Support Scale</strong> (FSS; Dunst, Trivette, &amp; Jenkins, 1988; Dunst, Trivette, &amp; Hamby, 1994)</td>
<td>Measures how helpful a range of people have been to the respondent in terms of raising their child.</td>
<td>• Targets social supports that have been identified as helpful when raising children with disabilities.</td>
</tr>
<tr>
<td></td>
<td>Subscales used:</td>
<td></td>
</tr>
<tr>
<td>(a) <em>Informal Kinship</em></td>
<td></td>
<td>• Include informal social supports such as kin as well as formal supports from health professionals.</td>
</tr>
<tr>
<td>(b) <em>Social Organisation</em></td>
<td></td>
<td>• Adequate and appropriate psychometric properties. With a sample of 139 parents of preschool children with disabilities or developmental risk, the authors of the FSS reported a Cronbach’s alpha of .77. Split-half reliability was .75, and test-retest reliability was .75. Also an 18-month test-retest reliability of .47 has been reported for the total scale score (Dunst, Trivette, &amp; Jenkins, 1988). Through principle components analysis, the authors obtained a six component solution that accounted for 62% of inter-item variance which was used for the current project. Further analysis by Hanley, Tasse, &amp; Aman (1998) revealed five factors that accounted for 61% variance. These included community (30.6%), spouse and in-laws (11.5%), friends (7.1%), specialized/professional (5.7%), and own parents and extended family (5.7%). However, the sample used involved socioeconomically determined HeadStart families, rather than families of children with disabilities; hence their factor structure was not used in this study.</td>
</tr>
<tr>
<td>(c) <em>Formal Kinship</em></td>
<td></td>
<td>• It can be reproduced without permission (email communication with primary author, C. Dunst)</td>
</tr>
<tr>
<td>(d) <em>Immediate Family</em></td>
<td></td>
<td>• Precedential use to investigate the effect of social support on parent health and well-being, family integrity, parental perceptions of child functioning, and styles of parent-child interaction (e.g., Oelofsen &amp; Richardson, 2006; Littlewood, Swank, Strozier &amp; Kondrat, 2013) and with families of children with disabilities (Dunst, et al., 1986; Hastings, et al., 2002; Greer, Grey, &amp; McClean, 2006).</td>
</tr>
<tr>
<td>(e) <em>Specialized Professional Services</em></td>
<td></td>
<td>• Precedential use as a Factor bB variable in the Double ABCX model (Oelofsen &amp; Richardson, 2006; Salovita, et al., 2003; Woodman, 2014).</td>
</tr>
<tr>
<td>(f) <em>Generic Professional Services</em></td>
<td></td>
<td>• Precedential use with populations including children with disabilities (Chen &amp; Clark, 2007; Dunst, et al., 1986; McCubbin, McCubbin, &amp; Thompson, 1991).</td>
</tr>
<tr>
<td><strong>Family Hardiness Index</strong> (FHI; McCubbin, McCubbin, &amp; Thompson, 1991)</td>
<td>Measures the internal strength and durability of the family as characterised by a sense of control over the outcomes of life events and hardships. Specifically, items relate to a family’s: dependability and ability to work together; endurance of hardship and experience of meaningfulness; innovative efforts to experience new things and learn; and sharing of a sense of being in control of life rather than being determined by outside events or circumstances.</td>
<td>• Targets hardiness as a stress-resistance and adaptation resource in families (McCubbin, McCubbin, &amp; Thompson, 1991).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Appropriate and adequate psychometric properties. Authors report both a 3-factor and 4-factor solution, each with good psychometric properties. Subscales from the four-factor solution were used in this study. Authors report the FHI has an overall good internal consistency with a Cronbach’s alpha of .82, and a test-re-test reliability of .86. They also report low but significant concurrent validity with measures of family flexibility such as the FACES-II (Olson, et al., 1982), and the Family Time and Routines Index (McCubbin, McCubbin, &amp; Thompson, 1986).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Permission to use in the project and clarified verbal descriptions of reported direct and moderating effects (stress x hardiness) on health outcomes (email communication with Marilyn McCubbin).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Precedential use with populations including children with disabilities (Chen &amp; Clark, 2007; Dunst, et al., 1986; McCubbin, McCubbin, &amp; Thompson, 1991).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Precedential use as a Factor in the Double ABCX model (Judge, 1998; Failla &amp; Jones, 1991; McCubbin, et al., 1998).</td>
</tr>
</tbody>
</table>
Table 1

(Continued)

<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>FHI (continued)</td>
<td>(a) Co-oriented Commitment</td>
<td>• Targets specific aspects of parenting a child with a disability.</td>
</tr>
<tr>
<td></td>
<td>(b) Confidence</td>
<td>• This is one major scale of the KIPP which measures four dimensions of perceptions related to having a child with a disability (positive contributions [PCS], social comparisons, causal attributions, and mastery/control). The entire inventory contains 97 items and would have been too laborious to include. It was recommended through personal communication with authors (Jean Anne Summers and Anne Turnbull) that just the PCS (50 items) be used since evaluations had suggested most variance in parental perceptions measured by the KIPP loaded onto this one subscale.</td>
</tr>
<tr>
<td></td>
<td>(c) Challenge</td>
<td>• Appropriate and adequate psychometric properties. The authors report good validity coefficients using a sample of 1,262 parents of children and adults with an intellectual disability. The nine subscales of the PCS showed Cronbach’s alpha coefficients ranging from .56 to .86, and six-week test-retest reliabilities ranging from .30 to .74. (Behr, et al., 1992). In a sample of mothers, Hastings, Beck, and Hill (2005) obtained a Cronbach’s alpha of .92 for the PCS Total Score and between .63 to .83 for the subscale scores. Behr et al. (1992) report that the measure does not correlate with measures of social desirability.</td>
</tr>
<tr>
<td></td>
<td>(d) Control</td>
<td>• Permission from primary authors to use in project (email communication with Jean Anne Summers).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Precedential use as a Double ABCX Factor cC variable (Behr, 1990; Behr &amp; Murphy, 1993). This scale was developed specifically to measure the Factor (cC) component of the Double ABCX model (Behr, et al., 1992).</td>
</tr>
<tr>
<td></td>
<td>(a) Learning Through Experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>with Special Problems in Life</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(b) Happiness and Fulfilment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(c) Strength of Family</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(d) Understanding of Life’s purpose</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(e) Awareness about Future Issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(f) Personal Growth and Maturity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(g) Expanded Social Networks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(h) Career/job Growth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(i) Pride and Cooperation</td>
<td></td>
</tr>
</tbody>
</table>

Family Perceptions (Factor cC)  
*Positive Contributions Scale*  
(PCS; Behr, et al., 1992)

This scale is part of an inventory based on indices of cognitive adaptation identified by Taylor (1983). It measures perceived positive contributions made to family life from having a child with a disability.

Subscales used:

(a) Learning Through Experience with Special Problems in Life
(b) Happiness and Fulfilment
(c) Strength of Family
(d) Understanding of Life’s purpose
(e) Awareness about Future Issues
(f) Personal Growth and Maturity
(g) Expanded Social Networks
(h) Career/job Growth
(i) Pride and Cooperation
<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
</table>
| **Family Crisis Oriented Personal Evaluation Scales (FCOPE; McCubbin, Olsen, et al., 1991; McCubbin, Thompson, et al., 1996)** | Identifies problem solving and behavioural strategies used by families in difficult or problematic situations. It assesses a family’s capability to redefine stressful events in order to make them more manageable; and their ability to accept problematic issues minimizing reactivity. | • Targets global aspects of family coping that are likely to be ‘pre-existent’ to having a child with a disability.  
• The total FCOPE scales comprise 5 subscales. Only the 3 were included here for sake of brevity and being relative specifically to raising children with disabilities. Reframing as a cognitive coping strategy used by parents of children with disabilities has been verified by Hastings, et al. (2002). Seeking spiritual support has also been verified as a significant cognitive coping family strategy (Bayat, 2007; McCubbin & Patterson, 2001; Walsh, 2003 a). And research into passive vs. active appraisal and coping styles has been verified as a risk factor for family adaptation (Bayat, 2007; Hastings, 2002).  
• Appropriate and adequate psychometric properties. A Cronbach’s alpha for the total scale of .87 has been reported in a sample of 2740 families. Cronbach’s alpha for the subscales were reported to be .82 (reframing), .80 (seeking spiritual support), and .63 (passive appraisal); corresponding 4-5 week test-retest reliabilities were reported to be .61, .95, and .75 (McCubbin, Olsen, et al., 1991).  
• Permission granted for use in research via editors of source through online application (McCubbin, Thompson, & McCubbin, 1996).  
• Precedential use with populations including children with disabilities (Hastings, et al., 2002; Burke, et al., 2012; Greer, et al., 2006).  
• Precedential use as a Factor cC variabe in the Double ABCX model not found. However, Minnes (1988) used this inventory as a measure of Factor (bB). |
| **Family Adaptation (Factor xX) General Health Questionnaire - 12 (GHQ-12; Goldberg & Williams, 1988)** | Measures the general health of a respondent and is related to both physical and psychological indicators. It assesses patterns of adjustment during periods of distress or change and can be used to determine severity of psychological distress experienced over the past few weeks. | • Targets both physical and psychological aspects of parental adaptation, identifying  
• Appropriate and adequate psychometric properties. The GHQ was originally designed with 60 items. Various versions have been validated including the GHQ-30, GHQ-28, and GHQ-20. The GHQ-12 has been extensively validated throughout many countries and contexts (Werneke, Goldberg, Yalcin, & Ustun, 2000). In a review of validation studies in 1997, 17 studies from nine countries (n = 4031) reported a median sensitivity of 83.7% and a median specificity of 79% with a range of Cronbach’s alpha coefficients between .82 and .86 (Goldberg, et al., 1997). Further validation studies by the same authors using 15 worldwide patient centres (n = 25,916) revealed a mean Cronbach’s alpha of .88. Graetz’s (1991) 3-factor structure is considered to be the most suitable and was adopted for the current analysis. Although various solutions of one, two and three factors have been reported, a comparison of studies revealed the best fit data for Graetz’s 3-factor structure (Werneke, et al., 2000). This was confirmed further with reported factor loadings ranging between .55 and .83 and Cronbach’s alphas of .81 (anxiety and depression), .77 (social dysfunction) and .69 (loss of confidence) (Cheung, 2002). More recently, Shevlin and Adamson (2005) have reported factor loadings ranging from .38 to .78. The 3-factor structure has also now been confirmed with a large Australian sample (n = 8,732) (Campbell & Knowles, 2007). |

Subscales used:
(a) **Reframing**  
(b) **Seeking Spiritual Support**  
(c) **Passive Appraisal**

Subscales used:
(a) **Anxiety and Depression**  
(b) **Social Dysfunction**  
(c) **Loss of Confidence**
Table 1

<table>
<thead>
<tr>
<th>Measure and Source</th>
<th>Construct Description &amp; Subscales Used</th>
<th>Points of Decision for Inclusion in Measurement Model Including Psychometric Properties</th>
</tr>
</thead>
</table>
| GHQ-12 (continued) | • The instrument could be easily purchased online, for survey production, from ACER Publishing Company  (email communication with Rachel Atkinson, Publishing Assistant, nferNelson).  
  • It has been used as an outcome measure in passed family research (Coughlin, et al., 2009; Quinn, et al., 2007; Goncalves-Pereia, et al., 2013; Emerson, 2003; Emerson, Robertson, & Wood, 2004; Herring et al., 2006). |
| Family Assessment Device – General Functioning Subscale (FAD-GF; Epstein, Baldwin, & Bishop, 1983b) | • Targets aspects of adaptation that relate to families, rather than individuals and is likely to provide an indication of adaptation over time which represents post-crisis variables. It measures adaptation in relation to family functioning and is distinct from measures, and constructs, of family stress (which would be represented as a Factor aV variable).  
  • The entire FAD scale measures family adaptation and operationalises how families meet 3 tasks including basic tasks (providing food, shelter, money and transport), developmental tasks (meeting each members developmental needs), and hardardous tasks (handling non-normative crises). It measures these tasks along six dimensions of family life (problem-solving, communication, role-functioning, affective responsiveness, affective involvement, and behaviour control) (Byles, et al., 1988). Just the General Functioning scale was included for brevity and as recommended in previous research (Ridenour, Daley, & Reich, 1999) since most variance has been attributable to scores on the GF.  
  • It is claimed to be the oldest and most widely used instrument to assess family functioning and it is translated into 16 languages (Epstein et al., 2003). Indeed a simple PsycINFO search (October, 2013) identifies some 18,665 articles with a keyword of ‘family assessment device’. It is available to be reproduced for research.  
  • In a comprehensive review of evidence-based family measures Alderfest, et al. (2008) identified in the literature, 13 most well-regarded measures that related to general family functioning and met stringent psychometric and peer-review criteria. Of the 7 that were self-report measures, only 3 qualified as ‘well-established’, including the FAD, while others such as the FACES-IV qualified for an ‘approaching well-established’ rating. They reported the FAD has been used in a broad range of pediatric samples such as families of children with asthma, cancer, cerebral palsy, and spinal cord injuries and that typically only the 12-item FAD-GF subscale was reported.  
  • Appropriate and adequate psychometric properties. Excellent internal consistency was reported by authors to be in the range of .85-.90. It has since been the focus of rigorous psychometric evaluation (Byles, 1998; Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990; Ridenour, et al., 1999; Shek, 2001; Barney & Max, 2005) that validates this claim. Normative data for a WA sample is available (Tomlin & Joyce, 2013).  
  • Precedential use as an endogenous variable in the Double ABCX model not found. |

Subscales used:  
(a) General Functioning
With an adequate measurement model established, the primary goal of Study 2 was to be operationalised by deriving four structural models from the Double ABCX model; structural equation modelling was then used to identify the most parsimonious model that adequately fit the data. A description of the models, and the predictions that each one makes in relation to the directions of its causal pathways, are provided in Figure 3. Model fit was to be evaluated statistically (in terms of a comprehensive set of fit statistics) and conceptually (in terms of model plausibility).

The first model, the additive model, treats the three family variables, Stress & Demands (aA), Resources & Support (bB), and Perceptions (cC) as exogenous variables, and Family Adaptation (xX) as the endogenous variable. The model was to propose a direct causal pathway from each of the exogenous variables to the endogenous variable. The model predicted Family Stress & Demands (aA) would produce a significant, negative pathway towards Family Adaptation (xX). That is, the more stress and demands, the poorer family adaptation. It predicted Family Resources & Supports (bB) would produce a significant, positive pathway towards Family Adaptation (xX). That is, the more resources and supports, the better family adaptation. The additive model predicted Family Perceptions (cC) would produce a significant and positive pathway towards Family Adaptation (xX). That is, the more positive family perceptions, the better family adaptation.

It was hypothesized in the second model, the single-mediator model, that Family Perceptions (cC) would partially or fully mediate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). The model made two fundamental predictions (see Figure 3). The first was that there would be a significant and positive causal relationship between (bB) and (xX); and that this relationship would be partially or fully mediated by (cC), such that the pathways from (bB) to (cC)
Figure 3. Theoretical models derived from the Double ABCX conceptualisation of family adaptation to be tested. Full mediation models are represented without the broken-line pathways. Partial mediation models include these pathways. The moderation model would be tested with and without controlled pathways indicated with broken lines.
and from (cC) to (xX) would both be significant and positive. That is, the more resources and supports, the better family adaptation and this would be improved further when a family had positive perceptions. The second hypothesis was that there would be a significant and negative relationship between (aA) and (xX); and that this relationship would be partially or fully mediated by Factor (cC), such that pathways from (aA) to (cC) and from (cC) to (xX) would both be significant, with the initial pathway (aA) to (cC) being negative and the final pathway (cC) to (xX) being positive. That is, the more caregiving burden, the poorer family adaptation and this relationship would be improved when a family had positive perceptions.

The third model tested, the two-mediator model, was to propose Family Resources & Supports (bB) and Family Perceptions (cC) would partially or fully mediate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). It predicted firstly, a significant negative relationship between (aA) and (xX). That is, the more caregiving burden, the poorer family adaptation. Secondly, it predicted that (bB) would partially or fully mediate this relationship, such that pathways from (aA) to (bB) and from (bB) to (xX) would both be significant and positive. That is, increased family caregiving burden would lead to improved family resources and supports, and this would produce improved family adaptation. Thirdly, it predicted, that (cC) would also partially or fully mediate this relationship, such that pathways from (aA) to (cC) would be significant and negative, and from (cC) to (xX) would be significant and positive. That is, increased family burden would lead to poorer parental perceptions and the better the parental perceptions, the better the family adaptation.

In the fourth model tested, the moderator model, it was proposed that Family Resources & Supports (bB) and Family Perceptions (cC) would moderate the
relationship between Family Stress & Demands (aA) and Family Adaptation (xX). That is, caregiving burden, resources and supports, and family perceptions would interact to determine the quality of family adaptation. It was hypothesized firstly, that there would be a significant negative relationship between (aA) and (xX). That is, the more caregiving burden, the poorer adaptation. Secondly, this relationship would be moderated by (bB) such that pathways from the (aA x bB) interaction term would be significant. That is, the extent to which caregiving burden led to poor adaptation would be less when family resources and supports were high. And thirdly, it was hypothesized that the predicted relationship between (aA) and (xX) would be moderated by (cC), such that pathways from the (aA x cC) interaction term would be significant. That is, the extent to which burden led to poor adaptation would be less when family perceptions of positive contributions of disability and coping were high.

**Summary of Scope and Specifications of the Current Inquiry**

The overall aims of the project were firstly, to describe family adaptation as it relates to the impact of family behavioural intervention on how families adapt to having a child with a disability. This would entail quantifying the relative effects of targeted and non-targeted variables of a behavioural family intervention and determining whether further empirical model-building was indicated. Secondly, it aimed to describe family adaptation by evaluating a theoretically sound model and determining how latent family variables, described as Family Stress & Demands, Family Supports & Resources, and Family Perceptions, interact to predict the impact of family caregiving burden on family adaptation. The proposed interactions were hypothesised in terms of four models tested that posed family variables as either direct and additive, moderating, or mediating in nature.
Chapter 5

Study 1: Differential Effect Sizes of a Parent Support Program on Targeted and Non-targeted Family Variables

This study specifically aimed to describe how family adaptation relates to the impact of family behavioural intervention. Family support programs typically focus on assisting parents to overcome the burden of child behavioural problems when children have a developmental disability. It is largely unknown if the result of behaviourally focused programs impact on family adaptation to disability.

This study comprised part of an evaluation project that primarily investigated the impact of SSTP, a behavioural family intervention, on parenting practices and child behaviour for families with a child who had a disability. Results of the broad evaluation, which included moment-to-moment observational assessment and analysis of parent-child interaction, have been published prior to this analysis. The current study aimed to demonstrate that the SSTP intervention had positive impacts on family adaptation even though it was not directly an intervention target and that these effects were not as large as directly targeted family variables.

The research question specifically relating to this study was concerned with quantifying the relative effects of SSTP, on targeted and non-targeted family variables that relate to family adaptation to disability. That is, although significant effects on targeted variables of parenting style and child behaviour have been reported, it was not known if SSTP has effects on non-targeted variables including parent depression, anxiety and stress; family resources and stress; parent sense of competence; relationship adjustment; and general family functioning. The implication of this research question involves understanding whether behavioural family intervention

3 Results of the broad evaluation of SSTP are published as Roberts, Mazzucchelli, Sanders, and
Studman (2006), parsimoniously impacts positively on family variables that comprise family adaptation. If the impact is non-significant, then it would be important to further assess the concept of family adaptation and to identify family variables that may need to be directly targeted in intervention.

Three main hypotheses (H) were made and applied to data from a randomised, waitlist-control designed intervention of SSTP. These hypotheses were:

H1a: The treatment group would show significant positive changes from pre-test to post-test on targeted variables while the waitlist control group would show no significant changes on these variables over this period.

H1b: The treatment group would show significant positive changes from pre-test to post-test on non-targeted variables whilst the waitlist control group would show no significant changes on these variables over this period.

H1c: Intervention effects for targeted variables would be stronger than the intervention effects for non-targeted variables.

H2: The significant pre-post changes predicted for the treatment group (H1a – H1c) would be maintained at the 6- and 12-month follow-ups.

H3: The treated control group would show pre-post changes on targeted and non-targeted outcomes similar to the pre-post changes shown by the intervention group.

Method

Participants. Fifty-three families of children with disabilities (aged 2 - 6 years) were recruited through referral from the Disability Services Commission (D.S.C.) early intervention teams in WA. Health professionals were implored to make
referrals when they considered intensive support for families with high levels of family stress was indicated. Twenty-seven families were randomly allocated to a treatment group and 26 to a control condition. Seven families from the control group exited the study before pre-test was complete, leaving 19 families in the control group and a total sample size of 46 families. According to G*Power (Faul, Erdfelder, Lange, & Buchner, 2007), 20 participants in each group (n = 40) are required for an 80% chance of detecting a large (η² = 0.15) Time x Group interaction (the effect that reflects an intervention effect in the present analysis) at a Bonferroni adjusted alpha-level of 0.025.

All children had developmental disabilities including Down’s syndrome (n = 8), other genetic conditions (n = 8), cerebral palsy (n = 5), accident or disease (n = 3), and intellectual disability, developmental delay or ‘unknown’ conditions (n = 22). All children were registered with D.S.C and had levels of intellectual or adaptive functioning that were more than two standard deviations below their age norms. Mean composite scores on the *Stanford Binet Intelligence Scales IV* (Thorndike, Hagen, & Sattler, 1986) and the *Vineland Adaptive Behaviour Scales* were 64.34 (SD = 16.39) and 60.77 (SD = 13.08) respectively.

The sample consisted of 21.4% girls and 78.6% boys with a mean pre-test age of 4.30 years (SD = 1.03). Most mothers reported their marital status as currently married or de facto (76.2%); 23.8% reported being single, widowed, currently separated or divorced. Mean mothers age at pre-test was 33.3 years (SD = 5.21).

Regarding parent education levels, 11.9% of fathers left school before completing Year 10. Most fathers completed 10 to 12 years schooling (40.5%), 21.4% completed vocational training after school, and 9.5% completed tertiary training. A similar pattern emerged for mothers with 20.5% leaving school before
completing Year 10; 43.6.8% completed 10 to 12 years of schooling, 25.6% completed vocational training, and 10.3% completed tertiary level training. Most mothers reported that they did not work outside the home (75.6%) while 24.4% reported being employed. For fathers, 17.2% were unemployed, 55.2% employed in a non-professional capacity, and 27.6% employed in a professional field.

Although father data were collected, there were fewer fathers than mothers in the study. The current analyses therefore focused only on the mothers’ data in order to optimise statistical power.

**Measures.**

**Family Biographical Information.** The *Family Background Questionnaire* (FBQ) was adapted from the Western Australian Child Health Survey (Zubrick, et al., 1995) and used to gather biographical data for the child (name, age, date of birth); parent information (marital status, relationship to child, employment, education level); and details of the child’s disability, health and development, respite services used, and health/education services received. The FBQ was also used to collect information on family members, family composition, and parent use of other health services.

**Parenting style.** The 30-item *Parenting Scale* (PS; Arnold, et al., 1993) was used to measure three dysfunctional discipline styles in parents: Laxness (permissive discipline); Over-reactivity (authoritarian discipline, displays of anger, meanness and irritability); and Verbosity (overly long reprimands or reliance on talking). The composite scale has adequate internal consistency (α = .84) and test-retest reliability (r = .84), as do the subscales (Laxness: α = .83, r = .83; Over-reactivity: α = .82, r = .82; and Verbosity: α = .63, r = .79). The scale has been found to discriminate between parents of clinic and non-clinic children. It correlates with self-report measures of child behaviour, marital discord, and depressive symptoms, and also with
observational measures of dysfunctional discipline and child behaviour (Arnold et al., 1993). A more recent factor analytic study has reconceptualised the factor structure of the scale as: Laxness (mothers’ α = .85, fathers’ α = 0.82); Over-reactivity (mothers’ α = .88, fathers’ α = .80); and Hostility (mothers’ α = .78, fathers’ α = .83) (Rhoades & O’Leary, 2007). Total scores were used in the current analysis with higher scores indicating higher levels of dysfunctional parenting styles.

**Child behaviour and adjustment.** The 96-item *Developmental Behaviour Checklist* (DBC; Einfeld & Tonge, 1992; 2002) was used to measure parental perceptions of behavioural and emotional problems in children. It shares the structure of the *Child Behaviour Checklist* (Achenbach, 1991) in that each behavioural description is scored on a 0, 1, 2 rating scale where 0 = “not true as far as you know”, 1 = “somewhat true”, and 2 = “very true or often true.” The 96 items describe common behavioural and emotional problems for children with developmental disabilities that were extracted from 664 case files and an initial pool of 1,093 items. Principal components analysis, reported by the authors, has yielded six factors that accounted for 32.6% of variance. Adding scores for each item in each of the six subscales provides a total score. The subscales and their respective internal consistencies (Cronbach’s alpha) include: disruptive behaviour (.905); antisocial behaviour (.670); self-absorbed behaviour (855); communication disturbance (.806); anxiety (.762); and social-relating behaviour (.732). Good inter-rater reliability of total scores between pairs of parents (.80); pairs of nurses (.83); and test-retest reliability (.83) has been reported. Standardisation norms were set from an epidemiological prevalence sample of 171,000 cases in New South Wales and Victoria, Australia. Validity has been demonstrated through a high correlation of .81 (p < .001) between total scores as rated by clinic staff and ratings from professional
assessors on three scales of behavioural deviance, distress to carers, and impairment to adaptive functioning \((n = 70)\). The DBC has good specificity and sensitivity to distinguish between psychiatric and non-psychiatric cases (i.e., 92\% using a Receiver Operating Characteristics analysis, ROC). Where ROC equalled 45\%, an optimal clinical cut-off score of 46 has also been reported. The higher the total score, the more problematic the behavioural and emotional problems (Einfeld & Tonge, 1995).

**Family adaptation variables.** The *Family Assessment Device - General Functioning* subscale (FAD-GF; Epstein, et al., 1983) was used since it was developed to assess family functioning along the dimensions of the McMaster model. The construct validity of the FAD-GF subscale as a measure of family functioning is supported and has been found to be the best predictor of a psychiatric diagnosis in a child. Half of the 12 items in this scale describe healthy functioning of the family and the other half describe unhealthy functioning to which respondents indicate whether they agree or disagree. It has high internal consistency \((\alpha = .86)\) and good construct validity (Byles, et al., 1988). The FAD-GF consists of 12 items which are answered on a 4-point scale. The sum of the item scores is divided by 12 to give a score ranging from 1 to 4. High scores indicate greater family pathology.

The *Questionnaire on Resources and Stress – Friedrich* (QRS-F; Friedrich, et al., 1983) is an abbreviated version of QRS (Holroyd, 1974; 1988). It is reported to be a measure of stress in families of developmentally delayed or disabled children. Friedrich et al. (1983) item analysed the original 289 items to arrive at the current 52 true/false items, being the most reliable. Their factor analysis revealed four factors: Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation. They reported the total scale and its subscales have acceptable internal consistency reliability coefficients above 0.7. A replicated factor analytic
study confirmed the factors identified by the authors and reported alpha-reliability coefficients between .77 and .85 for the four subscales (Scott, Thompson, & Sexton, 1989). They concluded that the measure has reasonable psychometric integrity and taps four important latent variables. Sample means or standard deviations do not appear to have been reported. A more recent 31-item adaptation of this measure has been developed but was not used in this study since data were collected before its development. The more recent version omits two subscales (child characteristics and physical incapacitation) and adds a subscale focusing on parental depression. The additional subscale has not been supported statistically (Honey, Hastings, & McConachie, 2005). For the current analysis, total scores were used and higher scores indicated higher levels of family stress.

The 16-item Parenting Sense of Competence Scale (PSoC; Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Marsh 1989) was used to assess parents’ views of their competence as parents on two dimensions: satisfaction with their parental role (reflecting the extent of parental frustration, anxiety, and motivation); and feelings of efficacy as a parent (reflecting competence, problem solving ability, and capability in the parenting role). The measure has acceptable internal consistency scores: Total score (16 items), $\alpha = .79$; Satisfaction subscale (9 items), $\alpha = .75$; and Efficacy subscale (7 items) $\alpha = .76$ (Johnston & Mash, 1989). Higher score reflect higher levels of satisfaction and efficacy.

The 7-item Abbreviated Dyadic Adjustment Scale (ADAS; Sharpley & Rogers, 1984) was used to measure relationship satisfaction. The ADAS is a shortened version of the 32-item Spanier Dyadic Adjustment Scale (Spanier, 1976). It measures the quality of dyadic relationship adjustment focusing on communication, intimacy, cohesion and disagreements. The ADAS reliably distinguishes between married, co-
habiting, separated and divorces couples \( (F[3,442] = 20.644, p < .0001) \). Sharpley and Rogers (1984) report an acceptable internal consistency reliability of .76, whereas Hunsley, Pinsent, Lefebvre, James-Tanner and Vito (1995) reported a higher internal consistency of .82. Scores can range from 0 to 36 with higher scores indicating higher levels of relationship satisfaction and adjustment. Normative data has yielded means of 23.2 for married couples (range = 2 - 36) and 23.7 for cohabitating couples (range =13 - 35) with an overall standard deviation of 5.4. Hunsley et al. (1995) reported a mean 25.6 \( (SD = 4.8) \) for a community sample.

The 42-item \textit{Depression, Anxiety, and Stress Scale} (DASS; Lovibond & Lovibond, 1995a) was used to assess symptoms of depression, anxiety and stress in parents. It has high reliability for the Depression \( (\alpha = .91) \), Anxiety \( (\alpha = .84) \), and Stress \( (\alpha = .90) \) scales; and good discriminant and concurrent validity (Lovibond & Lovibond, 1995a; 1995b). Each of these scales has a minimum score of 0 and a maximum score of 42. Means of a community sample have been reported as 7.19 \( (SD = 6.54) \), 5.23 \( (SD = 4.83) \), and 10.54 \( (SD = 6.94) \) for depression, anxiety, and stress respectively (Lovibond & Lovibond, 1995b). Total scores were used in the current study; higher scores indicated higher levels of parental symptomatology.

**Procedure.** Ethical approval for the study was granted through both the Institutional Review Board and the D.S.C Human Ethics Committee. Families were recruited through early intervention service providers over a three year period. They were referred as families who had not effectively engaged in regular family support services and who were considered to be multiply-stressed. Parents provided consent for family participation in accordance with the Australian National Health and Medical Research Council guidelines for working with minors. They were informed of the research and intervention procedures and received written and verbal
descriptions of both (see Appendix A for parent information and consent form). This included information about withdrawing from the research project if they so chose, without any disadvantage to their regular service provision. It was made clear that once recruited, they would have 50% chance of being assigned to either treatment or waitlist control group conditions; waitlist control group participants would receive the treatment after 4 months.

Participants were randomly allocated to the treatment and the waitlist control conditions by a university-based researcher who had no contact with families. Research assistants who were blind to individual participant group allocation, visited families to complete questionnaire assessments at 4 time-points. At time-point 1 (T1), both treatment and control group families completed the assessment. At time-point 2 (T2), both treatment and control group families completed the assessment but only the family in the treatment condition had received the program. At time-point 3 (T3) (6 months from T2), the treatment condition families took their follow-up 1 assessment; the (treated) control group families had received the intervention and took their post-treatment assessment. At time-point 4 (T4) (12 months from T2), the treatment group families completed their follow-up 2 assessment; the control group families took their follow-up 1 assessments.

The intervention consisted of Standard SSTP, a behavioural parenting intervention that was delivered in family homes by the author and one other specialist psychologist employed by D.S.C. Both interventionists were specifically trained by Professor Matt Sanders of the University of Queensland. The content of the program is outlined in Table 2.

Eight families received the Triple P Coping Skills Module (Sanders, Markie-Dadds & Turner 1998), a three-session cognitive behavioural intervention targeting
parent mood management. Eight families received the *Triple P Partner Support Module* (Sanders, Markie-Dadds, & Turner 1998), a three-session positive communication and conflict resolution couples intervention.

**Research design.** A randomised waitlist control design was used to evaluate the SSTP program. The design is illustrated in Table 3.

**Statistical analysis.** For all analyses, ‘Mother’ was treated as a categorical random effect; ‘Group’ (treatment versus control) was treated as a categorical fixed effect; ‘Time’ (T1, T2, T3, T4) was treated as an ordinal fixed effect; and the PS, DBC, FAD-GF, QRS-F, PSoC, ADAS, and DASS were treated as scale outcomes.

The relationships between fixed effects and outcomes were analysed with a maximum likelihood mixed effects linear regression model (Bryk & Raudenbush, 1987; Dimitrov & Rumrill, 2003; Hofman et al., 2007; Holden, Kelly, & Agarwal, 2008; Rabash, Steele, Browne, & Prosser, 2004) as implemented through SPSS’s Generalised Linear Mixed Models (GLMM: SPSS Version 19). The analysis was conducted within the context of a hierarchical data structure in which ‘Time’ was nested within ‘Mother’.

GLMM linked the normally distributed outcomes (PS, DBC, FAD-GF, QRS-F, and PSoC) to the fixed effects with an identity function. If the outcomes did not have normal distributions (ADAS and DASS), then the parameter estimates of the covariance matrix were computed with robust statistics. In order to optimise the likelihood of convergence, a separate GLMM analysis was run for each outcome. Outcomes were partitioned into two conceptually distinct groups: Targeted variables (PS and DBC), and non-targeted variables (FAD-GF, QRS-F, PSoC, ADAS, and DASS).
Table 2

Summary of the Content of Standard Stepping Stones Triple P

<table>
<thead>
<tr>
<th>Session Theme</th>
<th>Specific Content</th>
</tr>
</thead>
</table>
| 1 Initial Interview | • Nature and history of presenting problem  
• Associated problems  
• Developmental, social and relevant family history  
• Parent’s perceptions of the problem  
• Keeping track of children’s behaviour |
| 2 Observation and Sharing of Assessment Findings | • Completion of initial interview/s  
• Interview with child (if appropriate)  
• Observation of parent–child interaction  
• Review of assessment results  
• Factors influencing child behaviour  
• Goals for change and intervention negotiation |
| 3 Helping Children Develop | • Principles of positive parenting  
• Developing good relationships with children  
• Encouraging good behaviour  
• Teaching new skills and behaviours |
| 4 Managing Misbehaviour | • Managing misbehaviour  
• Developing parenting routines  
• Finalising behaviour charts |
| 5-7 Practice Sessions | • Practice task  
• Self-evaluation and feedback  
• Goal setting  
• Other issues  
• Goals for between-session practice |
| 8 Planning Ahead | • Update on progress  
• High-risk situations  
• Planned activities routines |
| 9 Planning Ahead Practice Session | • Planned activity routine for encouraging independent play  
• Further planning  
• Engaging fun activity  
• Planned activity routine for *getting ready to go out* |
| 10 Program Close | • Family survival tips  
• Phasing out the program  
• Progress review  
• Keeping up the good changes  
• Problem solving for the future  
• Future goals |
Table 3

*Research Design and Group Labels at Each Data Collection Time Point*

<table>
<thead>
<tr>
<th>Group</th>
<th>Data Collection Time Points</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Time 1</td>
</tr>
<tr>
<td>Intervention</td>
<td>Pre-test</td>
</tr>
<tr>
<td>(n = 27)</td>
<td></td>
</tr>
<tr>
<td>Waitlist control</td>
<td>Pre-test 1</td>
</tr>
<tr>
<td>(n = 19)</td>
<td></td>
</tr>
</tbody>
</table>

In order to maintain the Type I error rate within reasonable bounds, a Bonferroni correction was applied within each group giving a per-test alpha-level of .025 for the targeted variables and .01 for non-targeted variables. Finally, significant Group x Time interactions were analysed with least significant difference (LSD) contrasts, and eta-squared ($\eta^2$) or partial $\eta^2$ were used to estimate effect sizes.

GLMM was used for hypothesis testing because it is less sensitive to participant attrition than the traditional statistical procedures for analysing behavioural change (e.g., repeated measures ANOVA). GLMM does not rely on participants providing data at every assessment point; it uses all the data present at each assessment point thereby reducing the impact of subject attrition on statistical power. More specifically, it is the simultaneous modelling of the fixed effects and the random subject variables that allows for the accommodation of multiple missing data points (Edwards, 2000). Moreover, GLMM is robust to unequal group sizes, does not require equal variances at each time point, and is able to account for correlations among repeated measurements. Finally, relative to other techniques, GLMM more accurately estimates group means when group sizes are small.

Hypotheses were formulated in order to accommodate the ethically sound waitlist control group design in which the control group changes its status to a treatment group for the final two assessments (see research design above). H1a to H1c
were tested by analysing the T1 to T2 segment of the outcome trajectory for both the treatment and control groups. Hypothesis 2 was tested by analysing the T1 to T4 segment of the outcome trajectory for the treatment group only. H3 was tested by analysing the T1 to T2 segment of the outcome trajectory for the treatment group in conjunction with the T2 to T3 segment of the trajectory for the treated control group.

**Results**

**Attrition analysis.** Fifty-three families were recruited for the study. Seven families withdrew from the waitlist control condition before completing pre-test assessment, leaving 46 families at pre-test (27 treatment and 19 control). Thirty-two families responded at post-test (17 treatment, 15 control), 27 at the 6-month follow-up (15 treatment, 12 control), and 23 at the 12-month follow-up 2 (12 treatment, 11 control). Attrition rates are reported in a CONSORT diagram (Figure 4).

Rates did not differ significantly between groups at post-test ($\chi^2(1) = 1.35, p = 0.246$); at follow-up 1 ($\chi^2(1) = 0.266, p = .606$); or at follow-up 2 ($\chi^2(1) = 0.807, p = .369$). Families who withdrew post-intervention had significantly lower pre-test levels of PS, FAD-GF, and DASS and significantly higher pre-test levels of PSoC. That is, they had a significantly more positive parenting style, family adaptation, parental personal adjustment; and a stronger sense of parenting competence.

**Group equivalence.** There were no significant differences between control and treatment groups in terms of child female/male ratio, child age, child IQ, child adaptive behaviour, and maternal/paternal marital status, maternal/paternal age, maternal/paternal education and maternal/paternal occupation level (see Table 4).
Recruited and consenting participants 
\((n = 53)\)

Allocated to treatment group 
\((n = 27)\)

Allocated to waitlist control group 
\((n = 26)\)

Completed pre-test 
\((n = 27)\)

Completed pre-test 
\((n = 19)\)

Intervention

Post-test (T2)

Completed post-test 
\((n = 17)\)

37.03\% \((n = 10)\) attrition

Completed post-test 
\((n = 15)\)

21.05\% \((n = 4)\) attrition

Intervention

Follow-Up 1 (T3)

Completed follow-up 1 
\((n = 15)\)

44.44\% \((n = 12)\) attrition

Completed follow-up 1 
\((n = 12)\)

36.84\% \((n = 7)\) attrition

Follow-Up 2 (T4)

Completed follow-up 2 
\((n = 12)\)

55.56\% \((n = 15)\) attrition

Completed follow-up 2 
\((n = 11)\)

42.12\% \((n = 8)\) attrition

Figure 4. CONSORT diagram of participants' progress through the phases of the randomised control trial indicating attrition rates at each stage.
Table 4

**Baseline Demographic Data Comparing Intervention and Control Conditions**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention</th>
<th>Control</th>
<th>Group Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>n</td>
</tr>
<tr>
<td>Gender of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>14.8</td>
<td>23</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of child</td>
<td>4.44</td>
<td>1.23</td>
<td>27</td>
</tr>
<tr>
<td>Child IQ score</td>
<td>64.25</td>
<td>14.70</td>
<td>20</td>
</tr>
<tr>
<td>Child adaptive behaviour</td>
<td>62.85</td>
<td>16.58</td>
<td>26</td>
</tr>
<tr>
<td>Mat. marital stat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/defacto</td>
<td>19</td>
<td>73.1</td>
<td>7</td>
</tr>
<tr>
<td>Single/widowed/divorced</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mat. age</td>
<td>33.33</td>
<td>4.82</td>
<td>24</td>
</tr>
<tr>
<td>Mat. education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10yrs</td>
<td>6</td>
<td>15.4</td>
<td>9</td>
</tr>
<tr>
<td>10-12 yrs</td>
<td>7</td>
<td>17.9</td>
<td>7</td>
</tr>
<tr>
<td>Vocational</td>
<td>2</td>
<td>5.1</td>
<td>2</td>
</tr>
<tr>
<td>Tertiary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mat. occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>2</td>
<td>87.5</td>
<td>14</td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pat. education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10yrs</td>
<td>1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>10-12 yrs</td>
<td>11</td>
<td>55</td>
<td>6</td>
</tr>
<tr>
<td>Vocational</td>
<td>5</td>
<td>25</td>
<td>4</td>
</tr>
<tr>
<td>Tertiary</td>
<td>3</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>Pat. occupation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>5</td>
<td>35.7</td>
<td>3</td>
</tr>
<tr>
<td>Nonprofessional/Trades</td>
<td>6</td>
<td>42.9</td>
<td>10</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>21.4</td>
<td>2</td>
</tr>
</tbody>
</table>

Notes. IQ was measured using the *Standford Binet Intelligence Scales IV-4th Ed* (Thorndike, Hagen, & Sattler, 1986). Adaptive behaviour was measured using the *Vineland Adaptive Behaviour Scales*. Categorical variables were subjected to Chi² analyses. Continuous variables were subjected to T-test analyses. No significant group differences were found.
**Descriptive statistics.** Table 5 shows group means, standard deviations and sample sizes for each outcome variable across all assessments. The inferential statistics reported in Table 6 indicate that there were no significant between-group differences at pre-test on any of the outcome measures.

For both treatment and control groups, mean pre-test scores on the DBC were higher than that of a community sample of 454 parents reporting on their child with a disability, and above the clinical cut-off of 46 (Einfeld & Tonge, 1996). Pre-test means for both groups were within normal range (one standard deviation from their normative means) on the PS ($M = 2.6, SD = 0.6$; Arnold, et al. 1993); the FAD-GF (clinical cut-off > 2.17; Byles et al., 1988); the PSoC (normative $M = 62.48$ to 64.19, $SD$s from 9.72 to 10.48 depending on age and gender; Johnston & Mash 1989); and the ADAS (normative $M = 25.6, SD = 4.8$; Hunsley et al., 1995). Mean pre-test DASS scores for the treatment group (depression = 10.23, $SD = 11.21$; anxiety = 4.65, $SD = 4.90$; stress = 13.31; $SD = 10.31$) and the control group (depression = 6.90, $SD = 8.3$; anxiety = 3.44, $SD = 7.34$; stress = 9.12, $SD = 7.30$) were all within one standard deviation of means reported from a community sample (Lovibond & Lovibond, 1995b).
Table 5

Descriptive Data (adjusted Means, SDs, and Ns) Comparing Treatment and Control Conditions at all Measurement Points on Each Outcome

|                      | Treatment Group | | | | | | Control Group | | | | | |
|----------------------|----------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
|                      | Pre-test       | Post-test | Follow-up 1 | Follow-up 2 | Pre-test | Post-test | Follow-up 1 | Follow-up 2 |
|                      | M       | SD    | n | M       | SD    | n | M       | SD    | n | M       | SD    | n | M       | SD    | n |
| PS\(^1\)             | 3.17    | 0.63  | 26 | 2.64    | 0.62  | 17 | 2.62    | 0.58  | 15 | 2.60    | 0.47  | 12 | 3.10    | 0.63  | 17 | 3.08    | 0.72  | 15 | 2.31    | 0.65  | 12 | 2.29    | 0.61  | 11 |
| DBC\(^1\)            | 68.70\(^3\) | 16.18 | 27 | 50.42   | 24.53 | 17 | 54.09   | 25.45 | 15 | 51.71   | 29.78 | 12 | 62.05\(^3\) | 24.69 | 19 | 65.28   | 26.96 | 16 | 41.83   | 18.76 | 12 | 48.21   | 26.01 | 10 |
| FAD\(^1\)            | 1.97    | 0.47  | 26 | 1.84    | 0.49  | 17 | 1.96    | 0.49  | 15 | 1.90    | 0.49  | 12 | 1.93    | 0.40  | 16 | 1.96    | 0.53  | 15 | 1.90    | 0.60  | 12 | 1.79    | 0.59  | 11 |
| QRSF\(^2\)           | 25.73   | 10.36 | 26 | 20.06   | 12.12 | 17 | 18.67   | 12.73 | 15 | 17.75   | 14.16 | 12 | 25.41   | 7.76  | 17 | 24.60   | 6.03  | 15 | 18.50   | 8.43  | 12 | 15.36   | 8.58  | 11 |
| PSoC\(^2\)           | 60.73   | 12.57 | 26 | 64.20   | 13.09 | 17 | 66.71   | 9.50  | 15 | 68.64   | 9.18  | 12 | 60.19   | 9.62  | 17 | 60.80   | 11.90 | 15 | 72.81   | 8.81  | 12 | 71.50   | 8.02  | 11 |
| ADAS\(^3\)           | 22.71   | 5.57  | 23 | 24.70   | 6.63  | 16 | 23.00   | 5.81  | 14 | 22.74   | 6.95  | 9  | 22.53   | 6.70  | 15 | 22.12   | 4.71  | 12 | 23.96   | 6.97  | 12 | 25.23   | 5.58  | 10 |

Notes:
1. By convention, item scores were averaged within participants; these averages were then averaged across participants to produce a mean outcome score.
2. By convention, item scores were summed within participants; these sums were then averaged across participants to produce a mean outcome score.
3. Represents baseline means in clinical range.
Table 6

Statistical Group Comparison of Baseline Means

<table>
<thead>
<tr>
<th>Variable</th>
<th>Contrast ($t$-statistic)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PS</td>
<td>$t(40)= 0.341, p=0.735$</td>
</tr>
<tr>
<td>DBC°</td>
<td>$t(40)= 0.793, p=0.433$</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>$t(40)= 0.290, p=0.773$</td>
</tr>
<tr>
<td>QRS-F</td>
<td>$t(40)= 0.200, p=0.842$</td>
</tr>
<tr>
<td>PSoC</td>
<td>$t(40)= 0.046, p=0.964$</td>
</tr>
<tr>
<td>ADAS</td>
<td>$t(35)= 0.101, p=0.920$</td>
</tr>
<tr>
<td>DASS</td>
<td>$t(40)= 1.184, p=0.243$</td>
</tr>
</tbody>
</table>

Notes. No significant differences between baseline treatment and control group means were found on any of the outcome measures using $t$-tests.

°: Represents baseline means in clinical range for both groups.

Assumption testing. GLMM selects the appropriate probability distribution for the outcomes (normality is therefore not a requirement) and will link them to the fixed effects with an appropriate linkage function (linearity was therefore not a requirement). The tests were conducted within the context of a hierarchical data structure in which in which ‘Time’ (four levels) is nested within ‘Mother’. The covariance matrix for ‘Time’ changed from the default of compound symmetry to auto-regressive (sphericity was therefore not a requirement). Finally, the ‘robust statistics’ option was selected (homogeneity of variance was therefore not a requirement). In order to optimize the likelihood of convergence, a separate GLMM analysis was run for each outcome (multicollinearity among outcomes was therefore not an issue).

Testing hypothesis 1. The first hypothesis had 3 components. These were:

H1a: The treatment group would show significant positive changes from pre-test to post-test on targeted variables (DBC and PS) while the waitlist control group would show no significant changes on these variables over this period.
H1b: The treatment group would show significant positive changes from pre-test to post-test on non-targeted variables (FAD-GF, QRS-F, PSoC, ADAS, and DASS) whilst the waitlist control group would show no significant changes on these variables over this period.

H1c: Intervention effects for targeted variables (DBC and PS) would be stronger than the intervention effects for non-targeted variables (FAD-GF, QRS-F, PSoC, ADAS, and DASS).

The relationships between the fixed effects (Group, Time, Group x Time) and the outcomes (PS, DBC, FAD-GF, QRS-F, PSoC, ADAS, and DASS) were analysed with a maximum likelihood mixed effects linear regression model (see Table 7 for results). H1a and H1b predicted a significant Group x Time interaction for all outcomes. Figure 5 graphs the interactions for each outcome. At the Bonferroni adjusted alpha levels, the Group x Time interaction was non-significant for the five non-targeted outcomes (QRS-F: \( F[1,71] = 4.52, p = .037, \eta^2 = .0598 \); FAD-GF: \( F[1,70] = 0.94, p = .336, \partial \eta^2 = 0.0132 \); PSoC: \( F[1,69] = 0.642, p = .426, \partial \eta^2 = 0.0092 \); ADAS: \( F[1,62] = 4.60, p = .036, \partial \eta^2 = 0.0691 \); DASS: \( F[1,69] = 4.46, p = .038, \partial \eta^2 = .0512 \)). The interaction was significant for the two targeted outcomes (PS: \( F[1,69] = 6.93, p = .010, \partial \eta^2 = .0913 \); DBC: \( F[1,75] = 9.41, p = .003, \partial \eta^2 = .1149 \)).

Least significant difference tests were conducted to locate the source of the interactions for the targeted outcomes. There was a significant pre-post reduction in PS for the treatment group \( (p < .001, \eta^2 = .1852) \), but no change for the control group \( (p = .960, \eta^2 = .0000) \); there was a significant pre-post reduction in DBC for the treatment group \( (p < .001, \eta^2 = .1604) \), but no change for the control group \( (p = .520, \eta^2 = .0055) \) (see Table 8). The results support H1a but not H1b.
Table 7

Results of the Omnibus Maximum Likelihood Mixed Effects Linear Regressions for Each Outcome

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Source</th>
<th>Num-erator df</th>
<th>Denom-erator df</th>
<th>F-value</th>
<th>Significance</th>
<th>Partial $\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Targeted outcomes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PS</td>
<td>Group</td>
<td>1</td>
<td>69</td>
<td>0.96</td>
<td>.330</td>
<td>.0137</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>69</td>
<td>7.32</td>
<td>.009*</td>
<td>.0959</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>69</td>
<td>6.93</td>
<td>.001**</td>
<td>.0913</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DBC</td>
<td>Group</td>
<td>1</td>
<td>75</td>
<td>0.53</td>
<td>.525</td>
<td>.0070</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>75</td>
<td>4.52</td>
<td>.037</td>
<td>.0568</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>75</td>
<td>9.41</td>
<td>.003**</td>
<td>.1149</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Non-targeted outcomes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QRS-F</td>
<td>Group</td>
<td>1</td>
<td>71</td>
<td>0.74</td>
<td>.393</td>
<td>.0103</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>71</td>
<td>6.03</td>
<td>.016</td>
<td>.0783</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>71</td>
<td>4.52</td>
<td>.037</td>
<td>.0598</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FAD-</td>
<td>Group</td>
<td>1</td>
<td>70</td>
<td>0.10</td>
<td>.752</td>
<td>.0014</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>70</td>
<td>0.78</td>
<td>.381</td>
<td>.0110</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>70</td>
<td>0.94</td>
<td>.336</td>
<td>.0132</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSoc</td>
<td>Group</td>
<td>1</td>
<td>69</td>
<td>0.34</td>
<td>.564</td>
<td>.0049</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>69</td>
<td>1.39</td>
<td>.243</td>
<td>.0197</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>69</td>
<td>0.64</td>
<td>.426</td>
<td>.0092</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADAS</td>
<td>Group</td>
<td>1</td>
<td>62</td>
<td>0.74</td>
<td>.393</td>
<td>.0118</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>62</td>
<td>0.80</td>
<td>.376</td>
<td>.0127</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>62</td>
<td>4.60</td>
<td>.036</td>
<td>.0691</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS</td>
<td>Group</td>
<td>1</td>
<td>69</td>
<td>0.15</td>
<td>.696</td>
<td>.0022</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>69</td>
<td>5.16</td>
<td>.026</td>
<td>.0696</td>
</tr>
<tr>
<td></td>
<td>Group x</td>
<td>1</td>
<td>69</td>
<td>3.72</td>
<td>.058</td>
<td>.0512</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Targeted outcomes:
* $p < \text{Bonferroni corrected alpha-level of } 0.025$
** $p < 0.01$

Non-targeted outcomes:
* $p < \text{Bonferroni corrected alpha-level of } 0.01$
Figure 5. Mean outcome scores at pre-test and post-test for each group. Error bars, which represent 95% confidence intervals, are offset horizontally to make them visible.
Both of these targeted variables showed large effect sizes. LSDs were also calculated for non-targeted variables even though interactions were non-significant at Bonferroni corrected alpha levels so that comparisons of effect size ($\eta^2$) could be made. Moderate effect sizes were found for the QRS-F ($p = .001, \eta^2 = .1397$); the ADAS ($p = .034, \eta^2 = .0705$); and the DASS ($p = .003, \eta^2 = .1231$). Small effect sizes were found for the FAD-GF ($p = .168, \eta^2 = .0269$); and the PSoc ($p = .147, \eta^2 = .0303$). The effect size estimates are consistent with H1c. Effects for all variables were in directions that indicated positive improvements.

**Testing hypothesis 2.** The second hypothesis was stated as:

H2: The significant pre-post changes predicted for the treatment group (H1a – H1c) would be maintained at the 6- and 12-month follow-ups.

Significant treatment effects were found for two of the outcomes (PS and DBC). LSD comparisons, post-hoc to the maximum likelihood mixed effects linear regression analysis, were used to determine whether these effects were maintained (see Figure 6). The significant pre-post reduction in PS was maintained at the 6-months follow-up (T1 - T3, $p < .001, \eta^2 = .2797$; T2 – T3, $p = .707, \eta^2 = .0010$) and at the 12-month follow-up (T1 - T4, $p < .001, \eta^2 = .2412$; T2 – T4, $p = .640, \eta^2 = .0014$; T3 – T4, $p = .843, \eta^2 = .0001$). The significant pre-post reduction in DBC was maintained at the 6-months follow-up (T1 - T3, $p = .003, \eta^2 = .1242$; T2 – T3, $p = .460, \eta^2 = .0082$) and at the 12-month follow-up (T1 - T4, $p = .002, \eta^2 = .1395$; T2 – T4, $p = .806, \eta^2 = .0009$; T3 – T4, $p = .665, \eta^2 = .0028$). H2 was supported.

Maintenance effects were not calculated for non-targeted variables as they showed non-significant Group x Time interactions from pre-test to post-test.
Table 8

Least Significance Difference Tests of the Simple Main Effects of Time for the Group x Time Interactions With Pairwise Contrasts of Pre-test and Post-test for All Variables.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Treatment</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contrast estimate</td>
<td>Std. error</td>
</tr>
<tr>
<td>PS</td>
<td>0.509</td>
<td>0.129</td>
</tr>
<tr>
<td>QRS-F</td>
<td>5.807</td>
<td>1.710</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>0.165</td>
<td>0.118</td>
</tr>
<tr>
<td>PSOC</td>
<td>-3.405</td>
<td>2.319</td>
</tr>
<tr>
<td>ADAS</td>
<td>-2.069</td>
<td>0.954</td>
</tr>
<tr>
<td>DASS</td>
<td>11.582</td>
<td>3.720</td>
</tr>
</tbody>
</table>

Notes:

*** p < .001. Both targeted variables result in significant simple main effects.

- P-values for non-targeted variables here are not relevant since Omnibus Maximum Likelihood Mixed Effect Linear Regressions were non-significant at Bonferroni corrected alpha levels.
- Conventions for defining eta-squared values: .01 = small; .06 = moderate; .15 = large (Kirk, 1996).
Testing hypothesis 3. The third hypothesis was stated as:

H3: The treated control group would show pre-post changes on targeted and non-targeted outcomes similar to the pre-post changes shown by the intervention group.

Intervention effects had been established for the targeted variables (PS and DBC). H3 predicted that these effects would be replicated in the treated control group. Results are reported in Table 9. The absence of a Group x Time interaction for PS ($F[1,66] = 0.730, p = .396, \eta^2 = .396$) indicates that the significant main effect of Time ($F[1,66] = 10.60, p = .002, \eta^2 = .1382$) and the significant main effect of Group $F(1,66) = 0.81, p = .371, \eta^2 = .0122$) are equivalent across the two groups.

Similarly, the absence of a Group x Time interaction for DBC ($F[1,67] = 0.50, p = .482, \eta^2 = .0074$) indicates that the significant main effect of Time ($F[1,67] = 35.73, p < .001, \eta^2 = .3477$) and the significant main effect of Group $F(1,67) = 0.74, p = .393, \eta^2 = .0110$) are equivalent across the two groups.

For non-targeted variables all Group x Time interactions were non-significant at Bonferroni adjusted alpha levels (QRS-F ($p = .984, \eta^2 = .0000$); FAD-GF ($p = .572,
$\eta^2 = .0049$; PSoC ($p = .058, \eta^2 = .0535$; ADAS ($p = .850, \eta^2 = .0006$); and the DASS ($p = .163, \eta^2 = .0292$), again indicating group equivalence. These results supported H3.

Table 9

Results of the Omnibus Maximum Likelihood Mixed Effects Linear Regressions
Comparing Intervention to Treated Control Groups on Each Outcome

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Source</th>
<th>Num-erator df</th>
<th>Denom-enator df</th>
<th>F-value</th>
<th>Significance</th>
<th>Partial $\eta^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Targeted outcomes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PS</td>
<td>Group</td>
<td>1</td>
<td>66</td>
<td>0.813</td>
<td>.371</td>
<td>.0122</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>66</td>
<td>10.59</td>
<td>.002**</td>
<td>.1382</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>66</td>
<td>0.730</td>
<td>.396</td>
<td>.0109</td>
</tr>
<tr>
<td>DBC</td>
<td>Group</td>
<td>1</td>
<td>67</td>
<td>0.742</td>
<td>.393</td>
<td>.0110</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>67</td>
<td>35.73</td>
<td>.000***</td>
<td>.3477</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>67</td>
<td>0.500</td>
<td>.482</td>
<td>.0074</td>
</tr>
<tr>
<td><strong>Non-targeted outcomes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QRS-F</td>
<td>Group</td>
<td>1</td>
<td>66</td>
<td>0.101</td>
<td>.752</td>
<td>.0015</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>66</td>
<td>9.233</td>
<td>.003*</td>
<td>.1226</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>66</td>
<td>0.000</td>
<td>.984</td>
<td>.0000</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>Group</td>
<td>1</td>
<td>66</td>
<td>0.056</td>
<td>.814</td>
<td>.0008</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>66</td>
<td>3.008</td>
<td>.088</td>
<td>.0436</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>66</td>
<td>0.323</td>
<td>.572</td>
<td>.0049</td>
</tr>
<tr>
<td>PSoC</td>
<td>Group</td>
<td>1</td>
<td>66</td>
<td>1.170</td>
<td>.283</td>
<td>.0174</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>66</td>
<td>11.77</td>
<td>.001*</td>
<td>.1513</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>66</td>
<td>3.735</td>
<td>.058</td>
<td>.0535</td>
</tr>
<tr>
<td>ADAS</td>
<td>Group</td>
<td>1</td>
<td>59</td>
<td>0.294</td>
<td>.396</td>
<td>.0049</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>59</td>
<td>3.832</td>
<td>.055</td>
<td>.0610</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>59</td>
<td>0.036</td>
<td>.850</td>
<td>.0006</td>
</tr>
<tr>
<td>DASS</td>
<td>Group</td>
<td>1</td>
<td>66</td>
<td>0.241</td>
<td>.625</td>
<td>.0036</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>1</td>
<td>66</td>
<td>7.117</td>
<td>.010</td>
<td>.0973</td>
</tr>
<tr>
<td></td>
<td>Group x Time</td>
<td>1</td>
<td>66</td>
<td>1.988</td>
<td>.163</td>
<td>.0292</td>
</tr>
</tbody>
</table>

Targeted outcomes:
* $p <$ Bonferroni correct alpha-level of 0.025
** $p < 0.01$
*** $p < 0.001$

Non-targeted outcomes:
* $p <$ Bonferroni correct alpha-level of 0.01

Conventions for defining partial eta-squared values: .01 = small; .06 = moderate; .15+ = large
Discussion

This study aimed to quantify relative effect sizes of SSTP on targeted and non-targeted family variables that contribute to how families of children with disabilities adapt. It was hypothesized that targeted variables, parenting style and child behaviour, would yield larger effect sizes than that for measures of resources and stress, family adaptation, parental sense of competence, dyadic adjustment, and parental adjustment. The results provide evidence that SSTP yielded positive and significant, large effects on targeted variables; results also showed non-significant small to moderate effects on non-targeted variables related to family adaptation.

The first hypothesis comprised three parts. The first part, that the treatment group would show significant positive changes from pre-test to post-test on targeted variables (child behaviour and dysfunctional parenting styles) while the control group would not, was supported. The second part, that the treatment group would show significant positive change from pre-test to post-test on non-targeted variables (family resources and stress, family adaptation, parental sense of competence, parental relationship adjustment, and parental adjustment) while the control group would not, was not supported. Pre-post changes on all non-targeted variables were non-significant. The third part, that relative effect sizes would be stronger for targeted compared to non-targeted variables, was supported. According to conventions for defining eta-squared values (Kirk, 1996), effect sizes were large for both targeted variables (dysfunctional parenting styles and child behaviour); they were moderate for three of the non-targeted variables (resources and stress; parental adjustment; and relationship adjustment) and small for non-targeted variables of parental sense of competence and family adaptation. All effects were in the direction of improvement on the various aspects of family functioning.
The second hypothesis predicted that significant pre-post changes for the treatment group would be maintained at 6 month and 12 month follow up. The hypothesis was supported for significant targeted variables. Since significant changes were found for targeted variables (PS and DBC) only, no further analysis of non-targeted variables was statistically meaningful. If further analyses of non-targeted variables revealed significant effects, the intervention could not be said to have determined them, since it no longer was controlled as an independent variable. Comparisons between the treatment group effects at follow up stages and the control group could not be made since the control group had by this time been treated.

A comparison of pre-test to 6- and 12- month follow-up reports from parents on parenting style (PS) showed significant improvements with large effect sizes which implies a continued improvement and maintenance at both time points. Comparisons on the PS from post-test to 6- and 12- month follow-up showed no significant change, suggesting maintenance of effects. These remained for 6- month to 12- month follow-up comparisons also. It is interesting to note that compared to pre-test scores of parenting style, improvements increased at both future time points for the treatment group. Large treatment effect sizes on reports on child behaviour (DBC) from pre- to post-test were maintained as moderate effect sizes from pre-test to 6 month follow-up with no significant change from post-test to 6- or 12- months follow-up. From pre-test to 12-month follow-up, effect size was still moderate and there was no significant change from 6- to 12- month follow-ups. Overall, this means reports of dysfunctional parenting style decreased significantly and continued to decrease over time, suggesting a positive impact of SSTP on improved parenting. Reports of child behaviour problems also decreased significantly with large effect sizes that were maintained at a moderate level over time.
The third hypothesis was supported and demonstrated that replication effects could be shown if the control group, when treated, showed similar effects to that of the treatment group. Although the period of time in which intervention occurred was not controlled in this instance, the treated control group indeed did reveal no significant differences from the treatment group on reports of all targeted and non-targeted variables. The treated control group significantly improved on baseline means of dysfunctional parenting, child behaviour problems, resources and stress, and parental sense of competence. Measures of family adaptation, parental relationship, and personal adjustment showed no significant improvement from pre- to post-test. It is interesting also that although small to moderate effect sizes were produced for most non-targeted variables, the effect size of parent sense of competence was large.

These results support previous research which has shown significant effect of SSTP for a treatment group compared to control group, on parenting style and child behaviour (Plant & Sanders, 2007b; Whittingham, et al., 2009a; Sofronoff, et al., 2011). Plant and Sanders (2007b) found significant positive changes in parental sense of competence (using the PSoC) for treatment groups that had either (a) SSTP only, or (b) SSTP plus enhanced treatment modules to target additional family risk variables. These effects were not maintained but at follow-up, they found that the group who took SSTP plus enhanced modules maintained significantly lower rates of child behaviour problems. They also found no significant changes on DASS and ADAS measures at any time-point. Although maintenance effects were suggested, essentially family behavioural intervention was not demonstrated to affect significant changes in various other family variables apart from a short-term positive shift in parental sense of competence. Significant positive change in PSoC scores was apparent also in the Whittingham, et al. (2009a) study of SSTP, where the satisfaction
subscale yielded smaller significant effects at post test and the efficacy subscale showed significant effects only at follow-up. In the Sofronoff, et al. (2011) study, significant changes after a condensed SSTP intervention were generated on the same measures of parenting style and child behaviour, with no significant Group x Time difference observed on measures of dyadic adjustment, parental adjustment (DASS), and family adaptation (FAD-GF). Also in their study, positively-directed improvements from pre-to-3-month follow up on the PSoC were yielded.

Consistently, SSTP seems to result in significant effects on targeted variables and not on non-targeted family variables, except for parental sense of competence. It may be the case that the PSoC measures a construct not distinct from parenting style and the effects repeatedly reported point to parental satisfaction and efficacy related to changes in parenting style rather than any distinct non-targeted family variable.

The results of this study are also consistent with outcomes from other behavioural family intervention programs using similar measures. Significant reductions in DBC scores and parenting hassles (using the PHS) were observed after the implementation of Signposts for Building Better Behaviour (Hudson, et al., 2008). Again in this study non-significant shifts in the DASS and PSoC were apparent (Hudson, et al., 2003; 2008). Also in a trial of the Parents Plus program (Quinn, et al., 2007), significant effects on child behaviour (using the Strengths and Difficulties Questionnaire) were observed; no significant group differences were observed on measures of parental perceptions about disability, family resources and stress (using the QRS-F), parental adjustment, family adaptation (using the FAD), social support, life events and changes, or parenting stress.

It can be inferred from these findings that behavioural family intervention targeting parenting and child behaviour, and specifically SSTP, does not provide the
most parsimonious treatment for broader family variables that comprise family adaptation to disability. This provided good rationale for further exploration of the concept of family adaptation in a bid to identify specific variables that may be useful targets within family support programs.

**Limitations.** A number of unavoidable methodological limitations in this study should be acknowledged as potential sources of error. The sample size was small leading to the required use of Bonferroni corrected alpha levels. Families referred for this trial were identified by health practitioners who sought more intensive support for them due to high levels of family stress. Small sample size and high attrition rates are frequently found in research with stressed families of children with disabilities (Hudson, 1985; Quinn, et al., 2007). It is understandable that stressed families drop-out of research projects when positive effects are not immediate and other family issues take priority. The fact that families were allocated to either waitlist control or treatment conditions before completing their first assessments may have affected attrition rates. Highly stressed families are inclined to seek alternative supports when placed on waitlists simply because of their level of stress and need for immediate support. Interestingly, families who withdrew at post-test had significantly lower pre-test levels of dysfunctional parenting; family dysfunction; and depression, anxiety and stress, than those who remained in the study. They also showed significantly higher pre-test levels of satisfaction and competence. It may have been that families withdrew from the project when problems were not so significant. Regardless of why, the specific attrition pattern means that composition of the sample may have changed over time and influenced intervention effect sizes.

Another limitation of design is that group mean baseline scores were within normative ranges (except for the DBC), despite the sample being targeted as highly
stressed families. This is also a limitation of the research design since it means that there is less room for improvement and therefore less chance of showing significant changes over time. A better design to compare relative effect sizes would insist that group means at pre-test were within clinical levels on all measures. Ideal as this would be, such a group is difficult to practically establish.

For consideration in further study, using the QRS-F may have been a limitation as well since baseline means could not be determined because normative data do not appear to have been reported in psychometric studies to date. Also, the newer version of the instrument which omits two of its original four subscales and adds another focusing on parental depression may suggest some confusion about what it actually measures. The subscales dropped were thought to measure child characteristics and physical incapacitation as sources of family stress. To explore treatment effects, measures that tap into observable aspects of family stress may be better than those that include definitive aspects of a child or situation.

Finally, some families were identified as needing enhanced modules of intervention during treatment negotiation. This aspect of treatment was not controlled and could not be compared as a separate treatment group due to small sample sizes.

**Summary.** By quantifying relative effects of SSTP on targeted and non-targeted family variables that relate to family adaptation, this randomised, controlled trial has provided results that lead to a strong rationale for further investigation. This trial has produced significant large effects on measures of parenting style and significant moderate effects on measures of child behaviour problems. Small to moderate, but non-significant effects, were produced on measures of family resources and stress, family adaptation, parent sense of competence and, dyadic and parental adjustment. These effects were found to be all in positive directions. Since these
non-targeted variables are related to family adaptation, the importance of considering how they may interact to determine positive family adaptation to disability was established. With this in mind, further research to establish an empirically strong model of family adaptation was indicated, and therefore comprised the basis for Study 2.
Chapter 6

Study 2: Evaluation of the Double ABCX Model of Family Adaptation to Disability Using Structural Equation Modelling

The overall aim of this study was to produce evidence that could be used to describe family adaptation to developmental disability by evaluating the theoretical Double ABCX model (McCubbin & Patterson, 1983b). The model groups known family risk variables into conceptual latent variables and proposes interactional relationships which predict family adaptation, the endogenous variable. A minor aim of this study was to consolidate the conceptualisation of key terms in the Double ABCX model for further research by developing a reliable measurement model consisting of a wide range of observed variables that theoretically pertain to family adaptation. Latent variables of the Double ABCX model used in this study included:

(a) Factor aA - *Family Demands & Stress* (aA), child/family-related caregiver burden and general life stressors that build-up over time;

(b) Factor bB – *Family Resources & Supports* (bB), indications of general family resources, formal and informal practical supports, and internal family emotional resources or hardiness;

(c) Factor cC – *Family Perceptions* (cC), positive perceptions that parents make about having a child with a disability, and general family approach and problem solving style over time; and

(d) Factor xX – *Family Adaptation* (xX), indications of general physical and psychological health of parents and family adaptation in relation to dimensions of the McMaster model (Epstein, et al., 2003).

Proposed interactions were theoretically derived in terms of four competing models that posed family variables as direct and additive, moderating, or mediating in nature.
Evaluating the Double ABCX model is important since the results of Study 1 demonstrated that the behavioural family intervention, SSTP, did not yield significant positive effects on family variables that are related to family adaptation that were not directly targeted. This suggested that further inquiry to validate potential intervention targets when promoting family adaptation, was needed. This inquiry aimed to uncover treatment targets and important interactions between family variables that would provide insight into an appropriate service delivery model.

Structural equation modelling to test derived models, described in Chapter 4, (see Figure 3 for proposed causal pathways) was used. The proposed models and related hypotheses (H) are reiterated below.

(a) The *additive* model proposes direct causal pathways from each exogenous variable to the endogenous variable. For this model to be supported three hypotheses (H1a-c) would need to be met.

H1a. Family Resources & Supports (bB) will be positively and significantly related to Family Adaptation (xX), i.e., the pathway from (bB) to (xX) would be positive.

H1b. Family Stress & Demands (aA) would be negatively and significantly related to Family Adaptation (xX), i.e., the pathway from (aA) to (xX) will be negative.

H1c. Family Perceptions (cC) would be positively and significantly related to Family Adaptation (xX), i.e., the pathway from (cC) to (xX) would be positive.
(b) The *single-mediator* model proposed Family Perceptions (cC) partially or fully mediated the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). For this model to be supported four hypotheses (H2a-d) would need to be met.

H2a. There would be a significant positive relationship between Family Resources & Supports (bB) and Family Adaptation (xX).

H2b. Family Perceptions (cC) would partially or fully mediate the relationship predicted in H2a, i.e., the pathways from (bB) to (cC) and from (cC) to (xX) would both be significant and positive.

H2c. There would be a significant negative relationship between Family Stress & Demands (aA) and Family Adaptation (xX).

H2d. Family Perceptions (cC) would partially or fully mediate the relationship predicted in H2c, i.e., the pathways from (aA) to (cC) and from (cC) to (xX) would both be significant but this time the initial component of the mediating pathway (aA) to (cC) would be negative.

(c) The *two-mediator* model proposed Family Resources & Supports (bB) and Family Perceptions (cC) partially or fully mediate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). For this causal model to be supported three hypotheses (H3a-c) would need to be met.

H3a. There would be a significant negative relationship between Family Stress & Demands (aA) and Family Adaptation (xX).

H3b. Family Resources & Supports (bB) would partially or fully mediate the relationship predicted in H3a, i.e., the pathways from (aA) to (bB) and from (bB) to (xX) would both be significant and positive.
H3c. Family Perceptions (cC) would partially or fully mediate the relationship predicted in H3a, i.e., the pathways from (aA) to (cC) and from (cC) to (xX) would both be significant but this time the initial component of the mediating pathway (aA) to (cC) would be negative.

(d) The *moderator* model proposed Family Resources & Supports (bB) and Family Perceptions (cC) moderate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). For this model to be supported 3 hypotheses (H4a-c) would need to be met.

H4a: There would be a significant negative relationship between Family Stress & Demands (aA) and Family Adaptation (xX).

H4b: The relationship predicted in H4a would be moderated by Family Resources & Supports (bB), i.e., the pathway from the (aA x bB) interaction term will be significant.

H4c: The relationship predicted in H4a would be moderated by Family Perceptions (cC), i.e., the pathway from the (aA x cC) interaction term would be significant.

**Method**

**Participants.** The survey sample comprised 404 parents (or carers) of children with developmental disabilities (aged 2 – 12 years). Child, parent, and family characteristics are reported below.

**Child characteristics.** A summary of child biographical data can be found in Table 10. Most respondents had children with disabilities who were boys (67.1%) with a mean age of 7.6 years (SD = 2.9 years). A range of developmental disabilities were represented in the total sample, including cognitive/learning (3.7%), intellectual (93.6%), neurological (0.2%), physical (1.5%), psychiatric (0.5%), and sensory
Of those with intellectual disabilities, whose parents reported a specific level of impairment \(n = 217\), 30.8\% were described as having ‘mild’ intellectual disability, 50.6\% as ‘moderate’, and 18.4\% as ‘severe/profound’. In addition, almost half, (48\%) of the total sample reported their child to have autism/pervasive developmental disorder. Responders reported that 52\% of the children had more than one disability and that 34.4\% had health problems in addition to a developmental disability. The average number of siblings living at home was 1.41.

Table 10

Sample Biographical Information for Children

<table>
<thead>
<tr>
<th>Child Characteristic</th>
<th>% of respondents</th>
<th>N</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>boys</td>
<td>67.1</td>
<td>272</td>
<td></td>
</tr>
<tr>
<td>girls</td>
<td>32.5</td>
<td>132</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>boys</td>
<td></td>
<td>7.6 (2.9) years</td>
<td></td>
</tr>
<tr>
<td>girls</td>
<td></td>
<td>7.8 (2.7) years</td>
<td></td>
</tr>
<tr>
<td>Types of disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive/learning</td>
<td>3.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intellectual (inc PDD; GDD; and ID)</td>
<td>93.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PDD (Autism and other PDDs)</td>
<td>48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild ID</td>
<td>30.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate ID</td>
<td>50.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe/Profound ID</td>
<td>18.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td>0.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>1.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric</td>
<td>0.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensory</td>
<td>0.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary disabilities</td>
<td>52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional health issues</td>
<td>34.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of siblings</td>
<td>1.41</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: PDD- pervasive developmental disorders; GDD – global developmental delay; ID – intellectual disability.

**Parent (respondent) characteristics.** A summary of parent biographical data can be found in Table 11. Most respondents were mothers of identified children (88\%), with a small proportion being step/foster or ‘other’ types of carers (1.5\%). Most were in original biological/adoptive families with two parents (76\%) and fewer were in two-parent step/blended families (14.7\%). Sole-parent families comprised 17.6\% of the sample. This corresponds well with a report of most respondents being
married (74.3%), fewer being in defacto relationships (6.5%), and fewer again being either divorced (6%), separated (9.2%), never married/defacto (2.7%) or, widowed (1.2%).

Regarding education levels and employment, most of the sample respondents were educated to levels of Year 10 or 11 (27.5%), Trade (26.2%), or Tertiary (29.5%). Their partners were also reported to be educated to levels of Year 10 or 11 (19.3%), Trade (29.5%), or Tertiary (25.4%).

Respondents were mostly not working outside the home (53.7%) or working part-time (30.7%) and had partners who were working full time (64.1%).

Table 11
Sample Biographical Information for Families

<table>
<thead>
<tr>
<th>Respondent Characteristic</th>
<th>% of respondents</th>
<th>% of respondents’ partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents (or carers)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers</td>
<td>88</td>
<td></td>
</tr>
<tr>
<td>Fathers</td>
<td>10.5</td>
<td></td>
</tr>
<tr>
<td>Step/foster parents/ other</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Family type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sole parents</td>
<td>17.6</td>
<td></td>
</tr>
<tr>
<td>Original family</td>
<td>76.0</td>
<td></td>
</tr>
<tr>
<td>Step</td>
<td>14.7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1.2</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>74.3</td>
<td></td>
</tr>
<tr>
<td>Defacto</td>
<td>6.5</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>Never partnered</td>
<td>2.7</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1.2</td>
<td></td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10 years</td>
<td>4.7</td>
<td>13.9</td>
</tr>
<tr>
<td>10 – 11 years</td>
<td>27.5</td>
<td>19.3</td>
</tr>
<tr>
<td>12 years</td>
<td>12.1</td>
<td>11.9</td>
</tr>
<tr>
<td>Trade</td>
<td>26.2</td>
<td>29.5</td>
</tr>
<tr>
<td>Tertiary</td>
<td>29.5</td>
<td>25.4</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>14.6</td>
<td>64.1</td>
</tr>
<tr>
<td>Part-time</td>
<td>30.7</td>
<td>6.4</td>
</tr>
<tr>
<td>Not working</td>
<td>53.7</td>
<td>12.0</td>
</tr>
</tbody>
</table>
**Family social characteristics.** Total family income was broken into six categories of specific amounts from low-income to high-income brackets. Of 384 respondents, most reported family earning in the higher ranges (see Table 12).

Table 12

<table>
<thead>
<tr>
<th>Family Income Range</th>
<th>% of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowest to highest income range</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>

The reported high income earning skew of the sample was compared to socio-economic national data, using the ABS Socio-economic Indexes for Areas (SEIFA) (ABS, 2006) codes. Socio-economic levels could be compared by taking postcodes from respondent addresses and ranking them lowest to highest. SEIFA codes were then assigned and decile rankings from 1 to 10 (lowest to highest relative socio-economic advantage or disadvantage) are be reported. The ABS decile rankings are calculated by accounting for (a) the proportions of high and low income households in the area, and (b) the proportion of households with and without broadband internet connections. Decile 1 contains the lowest 10% of socio-economic indexes across Australia, including all metro and regional areas. Decile 2 contains the next higher 10%, and so on, (ABS, 2006). Figure 7 graphs the number of survey respondents who lived in each decile range and demonstrates a range across all socio-economic levels with a skew towards the higher levels.
Measures. Demographic and biographical information was collected using the Family Background Questionnaire (FBQ), which was adapted from the Western Australian Child Health Survey (Zubrick et al., 1995). It gathered biographical data for the child (name, age, date of birth); parent information (marital status, relationship to child, employment, education level); and details of the child’s disability, health and development, respite services used, and health/education services received. The FBQ was also used to collect information on family members, family composition, and parent use of other health services.

A range of other measures were selected for their psychometric strength, relevance to each of the components of the Double ABCX model, and precedential use with families of children with disabilities. Detailed rationale for selection, and psychometric properties, of each can be reviewed in Table 1 (see Chapter 4, pp. 100-105). The measures, subscales, and scoring details for each of the model latent constructs are described below. The assessment booklet can be seen in Appendix B.
**Family Stress & Demands (aA).** The 51-item *Parenting Hassles Scale* (PHS; Gavidia-Payne, et al., 2003) comprises three subscales that measures frequency and intensity of child/family characteristics associated with parent stress and demands. It measures stress in parents of children with disabilities in terms of ‘hassles’, which are characterised as the distressing demands of everyday transactions with the environment for families of children with disabilities (Richdale, et al., 2000). It includes subscales relating to (a) *child behaviour/needs*, (b) *parent needs/characteristics*, and (c) *education and child development*. Items are checked by parents of children with a disability on a 5-point scale (1 = no hassle; 5 = major hassle). A higher score on these subscales indicates a higher level of intensity of daily hassles.

The 18-item *Life Distress Inventory* (LDI; Thomas, et al., 1994) assesses level of distress associated with 18 general areas of life. It represents longer term or ‘pre-existing’ family burdens. A total score for general distress can be derived in addition to subscale scores indicating level of stress in four areas: (a) *social functioning* (item numbers 12, 5, 2, 11, 4, 10, 16, and 15), (b) *life satisfaction* (item numbers 17, 13, 18, 14, and 8), (c) *finance and employment* (item numbers 7 and 9), and (d) *marital distress* (item numbers 1, 3 and 6) (Yoshioka & Shibusawa, 2002). From the 7-point Likert-type scale items ranging from 1 (*most distress ever felt*) to 7 (*no distress*), total scores may range from 18-126. An item-mean score for healthy adults is considered to be 2.02 (*SD = .88; n = 179*). With code-reversal, higher scores reflect greater distress.

**Family Resources (bB).** This latent variable was assessed with three measures; one that focuses on general family resources, one that assesses child-related family supports, and one that assesses internal family emotional resources or hardiness. The *Family Resources Scale* (FRS; Dunst & Leet, 1988) has 31 items
measuring the adequacy of resources in households with young children. Each item is
rated on a 5-point scale ranging from 1 (not at all adequate) to 5 (always adequate).
Respondents could also indicate not applicable. In such cases, responses were coded
with a 0 so that total scores were not influenced. A four-factor structure was used
(Herman & Thompson, 1995) with subscales labelled as (a) basic resources (items 1,
2, 4, 5, 6, 8, 9, 11, 13, 19, 23), (b) time resources (items 12, 14, 15, 16, 17, 18, 24, 25,
26), (c) money resources (items 3, 7, 10, 22, 28, 29, 30, 31), and (d) child-related
resources (items 21, 22, 27). Mean total score in the Herman and Thompson study
was 110.05 (SD = 23.25, n = 223). Scores are summed and higher scores indicate
higher levels of family resources.

The 18-item Family Support Scale (FSS; Dunst, Trivette, & Jenkins, 1988;
Dunst, Trivette, & Hamby, 1994) measures how helpful a range of people have been
to the respondent in terms of raising their child. Parents rate specific people, services,
and organisations on a 5-point scale (1 = not at all adequate; 5 = almost always
adequate) as to “how helpful each has been in terms of raising your child(ren)”. Parents
can also rate each item as ‘N/A’ if it does not apply to them. It has 6
subscales, including: informal kinship (items 6, 7, 8, 9, 13); social organisation
(items 10, 11, 12); formal kinship (items 1, 3, 4); immediate family (items 2, 5);
specialized professional services (items 15, 16, 17); and generic professional services
(items 14, 18). Scoring the FSS involves summing responses so that higher scores
indicate higher perceived levels of family support.

The 20-item Family Hardiness Index (FHI; McCubbin, McCubbin, et al.,
1991) measures the characteristic of hardiness as a stress-resistance and adaptation
resource in families. Parents rate examples of family hardiness on a 4-point scale (0
= false; 1 = mostly false; 2 = mostly true; 3 = true). Subscales include: co-oriented
commitment (items 4, 5, 6, 7, 9, 11, 13, 18), which involves a family’s dependability and ability to work together; confidence (items 2, 3, 8, 10), which specifies ability to plan ahead, appreciate family effort, endure hardship and experience meaningfulness; challenge (items 12, 14, 15, 16, 17), which looks at innovative efforts to experience new things and learn; and control (items 1, 19, 20), which refers to a family’s sense of being in control of life rather than being determined by outside events or circumstances (McCubbin, McCubbin, et al., 1991). Authors report the FHI has an overall normative mean of 47.4 (SD = 6.7). Scoring the FHI involves summing item responses after reverse coding items 1, 2, 3, 8, 10, 14, 16, 19, and 20. Higher scores indicate higher levels of family hardiness.

**Family Perceptions (cC).** The Positive Contributions Scale (PCS) of the Kansas Inventory of Parental Perceptions (KIPP) (Behr, et al., 1992) was used. Respondents were required to indicate agreement on a 4-point scale (1 = strongly disagree; 4 = strongly agree) with 50 items that described potentially perceived positive contributions that a child with a disability can make to his/her family. Mean mothers total scores has been reported as 134.69 (SD = 21.65) (Hastings, et al., 2005). Subscales within the PCS include: learning through experience with special problems in life (items 7, 16, 27, 41, 42, 43, 48); happiness and fulfilment (items 8, 11, 22, 29, 33, 49); strength of family closeness (items 36, 37, 44, 46, 47, 50); understanding of life’s purpose (items 1, 30, 34, 35); awareness about future issues (items 10, 17, 23); personal growth and maturity (items 3, 4, 5, 6, 18, 20, 21); expanded social networks (items 2, 14, 32, 38, 40); career/job growth (items 9, 19, 26, 31); and pride and cooperation (items 12, 13, 15, 24, 25, 28, 39). PCS items are summed such that higher scores are associated with a greater level of perceived positive contribution made to family life from having a child with a disability.
The 30-item Family Crisis Oriented Personal Evaluation Scales (FCOPE; McCubbin, Olson, et al., 1991; McCubbin, Thompson, et al., 1996) was used to identify problem solving and behavioural strategies used by families in difficult or problematic situations. Respondents mark their level of agreement (1 = strongly disagree; 5 = strongly agree) with positively stated strategies that promote family coping. Three (of five) most relevant subscales were used: reframing (items 1, 2, 3, 5, 7, 9, 10, 12), which assesses a family’s capability to redefine stressful events in order to make them more manageable; seeking spiritual support (items 6, 11, 14, 16); and passive appraisal (items 4, 8, 13, 15), which assesses ability to accept problematic issues minimizing reactivity. Several items on the passive appraisal subscale are reverse coded and then all items are summed so that higher scores represent more positive family coping and problem solving, and less passive appraisal.

**Family Adaptation (Factor xX).** The General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988) measures the general health of a respondent and is related to both physical and psychological indicators. There are 12 items asking respondents to rate the degree to which they have recently experienced a particular symptom or item of behaviour on a 4-point scale ranging from not at all to much more than usual. Assigning scores of 0 - 3 from positive to negative anchors means where lower total scores reflect higher general health. For the current analysis, total scores were reversed so that higher scores indicated better general health. Three subscales (Graetz, 1991) were used: anxiety and depression (items 2, 5, 9, 6); social dysfunction (items 1, 3, 4, 8, 7, 12); and loss of confidence (items 10, 11). An Australia national survey of mental health and well-being reported a community sample of women to give a mean item score of 1.07 (SD = 0.04, N = 5,936) (Korten & Henderson, 2000).
The 12-item *Family Assessment Device – General Functioning Subscale* (FAD-GF; Epstein, et al., 1983) assesses family functioning along the dimensions of the McMaster model. It is brief, easy to administer and score, and has a range from 0 - 48. Half of the twelve items in this scale describe healthy functioning of the family and the other half describes unhealthy functioning. Each of the 12 items are rated on a 4-point scale (1 = strongly agree; 4 = strongly disagree). Items 1, 3, 5, 7, 9, and 11 require reverse coding so that higher total scores indicate greater family pathology (as usually scored). For the current study, however, total scores were then reversed such that higher FAD-GF scores reflected greater family positive adaptation. The mean of a large random sample (N = 1868) was reported to be 1.75 (SD. = .44) (Byles et al., 1988). Poor family functioning, measured with the FAD-GF was described as a score below 2.25 (when reversed scored so that low scores represent poor family functioning) in a Western Australian population survey of families (Tomlin & Joyce, 2013) and this cut-off represented 13.9% of the sample (N = ~900) in 2012; and 14.8% in 2003. It was also reported that 14.6 – 16.1% of community families with children up to 15 years old, reported to be above a clinical cut-off score for poor family functioning.

**Procedure.** Ethical approval for the survey was granted by the Curtin University Institutional Review Board and the D.S.C., WA, Research and Ethics Committee. Access to the D.S.C client database (N = 1419), including identifying information of all registered children with developmental disabilities or delay (aged 2 – 12 years), was granted to the author as an employee. Since the survey included multiple measures, it was important to gauge the likelihood of a adequate response rate. From the total database, 50 were randomly chosen and sent an introductory letter with a short set of questions (Appendix C) to provide feedback about how the
survey was to be presented to families; the experience of completing the survey booklet (including how long it took, any difficulties understanding the task, and any indication of stress associated with responding to the survey items); and general issues such as whether the language level was appropriate/understandable and any suggestion to increase the chance that families would return it, when it was disseminated. They were requested to read and complete the entire survey booklet. A summary of pilot-group responses to reading and completing the survey is presented in Appendix C. A total of 15 families responded (30%). Pilot feedback suggested that it took an average of approximately 50 minutes to complete the survey; the language and layout was mostly acceptable (with a few minor changes suggested); that parents accepted that ‘stress is a part of everyday life!’ (qualitative comment) and completing the survey felt ‘emotionally fine’ (qualitative comment). Some respondents said that the items were emotionally hard and ‘brought up feelings...’ (qualitative comment). Also some suggestions about how to manage the incentives being offered were made.

During this initial preparatory survey stage, three 1-hour promotional presentations were delivered to D.S.C. specialist early intervention service providers and Local Area Coordinators (LAC) (case managers) informing them of research issues relating to family adaptation and developmental disability. They were encouraged to support the survey by assisting parents with requests and/or prompting them to return their survey booklets. Most families would have received at least one home-visit from a service provider or LAC within the survey-return period. A summary promotional flyer provided to all D.S.C. employees working with families of children under the age of 12 years and LACs can be found in Appendix D.
After feedback was incorporated into the final survey materials, 500 families were randomly selected from the D.S.C. database and sent a survey package including introductory letter (Appendix E), a research participant information sheet and summary of the nature of each questionnaire in the survey booklet, and the questionnaires. This process was repeated for the next 500 families selected from the database, and then again for the remaining 369 families. Information on support contacts that could be made if parents were stressed and needing immediate assistance were included. Parents were requested to complete the survey and return it to Curtin University in a pre-paid envelop within two weeks. Although parents were asked to provide their child’s identifying information, they were assured that participation in the survey would not impact at all on services they currently received and D.S.C. practitioners (apart from the researcher) would have no access to any raw data. They were informed that by sending back the completed survey they were consenting to participate in the research and that their responses would be de-identified and stored at Curtin University in locked filing cabinets for approximately 5-7 years before being shredded. Incentives provided to families in the hope of maximising response rates included a teabag attached to the introductory letter and their family name being entered into a draw for $50. Also, a follow up letter was sent to all families after two weeks (Appendix F), indicating the current response rate and reminding them to complete and send back their survey if at all possible. A total of 89 survey packages were returned unopened and marked as *not at this address*. It was assumed then that the other 1280 were received. Completed surveys from 416 families were returned, 12 were discarded due to excessive missing data. This amounted to a sample of 404; a response rate of 31.5%. A $50 voucher was provided to three families randomly
selected from those who participated in the research (one from each of the three mail-outs).

**Data analysis.** Structural equation modelling (SEM) techniques, implemented through LISREL (Version 8.54; Jöreskog, Sörbom, Du Toit, & Du Toit, 2003), were used to test the causal models presented in Figure 3 (see Chapter 4, pp. 107). This analysis comprised three stages.

**Stage 1: Confirmatory factor analyses (CFAs).** A CFA was conducted on each of the 10 scales – PHS1 (75-item version), PHS2 (51-item version), LDI, FRS, FSS, FHI, FCOPE, PCS, GHQ, and FAD-GF, in order to determine whether the multi-dimensional structure that had been proposed for each measure provided a better fit than a more parsimonious uni-dimensional structure. The CFA results were then used to refine the measurement component of the model.

**Stage 2: The measurement model.** A measurement model derived from the Stage 1 CFAs was tested. The model was identified because it satisfied the sufficient requirement for a standard multifactor measurement model, namely, that each of the four latent variables (Family Stress & Demands [aA], Family Resources & Supports [bB], Family Perceptions [cC], and Family Adaptation [xX]) had at least two indicators (the indicators are the total scores on the measurement dimensions identified at Stage 1).

**Stage 3: The structural models.** The four competing structural models (the additive model, the single-mediator model (partial and full versions), the two-mediator model (partial and full versions), and the moderator model (full factorial and reduced) were then tested and compared. The structural models were ‘identified’ because they are ‘recursive’. In a recursive model, the disturbances (D) are uncorrelated and all causal effects are unidirectional. The Stage 2 measurement model
was added to each of the structural models to create a hybrid model consisting of both measurement and structural components. Assuming that the Stage 2 measurement model provided an adequate fit for the data, any lack of fit in the hybrid model would be due to a lack of fit in the embedded structural model.

**Assumption testing.**

**Multivariate normality.** *SEM* with LISREL assumes that the measures being analysed are multivariate normal (Kline, 2005). At Stage 1, the assumption of multivariate normality applied to the questionnaire items. At Stages 2 and 3 the assumption applied to the indicators of the latent variables (i.e., the subscales, or measurement dimensions, that emerged at Stage 1). Multivariate normality was violated at the item level (all chi-square *p*-values < .001; see Table 13) and at the subscale level (chi-square *p*-value < .001; see Table 14). When multivariate normality is violated, it has been argued that the preferred data input to the *SEM* analysis is the Spearman (non-parametric) correlation matrix (Lebart, Morineau, & Warwick, 1984). Spearman’s correlations were therefore input to all *SEM* analyses.

**Linearity.** Linearity is satisfied when the relationships among the measures are essentially linear rather than curvilinear. At Stage 1, the measures in question were the questionnaire items. No obvious curvilinear trends were observed in a random selection of the 5250 scatterplots derived from the 75 PHS items (2775 scatterplots), the 18 LDI items (153 scatterplots), the 31 FRS items (465 scatterplots), the 20 FSS items (190 scatterplots), the 20 FHI items (190 scatterplots), the 16 FCOPE items (120 scatterplots), the 50 PCS items (1225 scatterplots), the 12 GHQ items (66 scatterplots), and the 12 FAD-GF items (66 scatterplots).
Table 13

Test of Multivariate Normality Across Items for Each Measure (N = 404)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Skewness Value</th>
<th>Skewness z-score</th>
<th>Skewness p-value</th>
<th>Kurtosis Value</th>
<th>Kurtosis z-score</th>
<th>Kurtosis p-value</th>
<th>Skewness &amp; Kurtosis Chi-square</th>
<th>Skewness &amp; Kurtosis p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHS-1</td>
<td>1936.022</td>
<td>121.858</td>
<td>.000</td>
<td>6927.793</td>
<td>33.223</td>
<td>.000</td>
<td>15953.371</td>
<td>.000</td>
</tr>
<tr>
<td>PHS-2</td>
<td>587.967</td>
<td>62.061</td>
<td>.000</td>
<td>3173.543</td>
<td>26.375</td>
<td>.000</td>
<td>4547.243</td>
<td>.000</td>
</tr>
<tr>
<td>GHQ</td>
<td>27.871</td>
<td>29.470</td>
<td>.000</td>
<td>243.878</td>
<td>18.180</td>
<td>.000</td>
<td>1198.991</td>
<td>.000</td>
</tr>
<tr>
<td>FSS</td>
<td>46.812</td>
<td>28.918</td>
<td>.000</td>
<td>409.093</td>
<td>12.209</td>
<td>.000</td>
<td>985.285</td>
<td>.000</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>26.755</td>
<td>28.523</td>
<td>.000</td>
<td>262.538</td>
<td>20.076</td>
<td>.000</td>
<td>1216.643</td>
<td>.000</td>
</tr>
<tr>
<td>FCOPE</td>
<td>38.365</td>
<td>28.396</td>
<td>.000</td>
<td>354.554</td>
<td>15.437</td>
<td>.000</td>
<td>1044.637</td>
<td>.000</td>
</tr>
<tr>
<td>FHI</td>
<td>50.517</td>
<td>25.179</td>
<td>.000</td>
<td>530.630</td>
<td>16.737</td>
<td>.000</td>
<td>914.069</td>
<td>.000</td>
</tr>
<tr>
<td>LDI</td>
<td>72.032</td>
<td>44.448</td>
<td>.000</td>
<td>522.584</td>
<td>23.019</td>
<td>.000</td>
<td>2505.506</td>
<td>.000</td>
</tr>
<tr>
<td>FRS</td>
<td>248.518</td>
<td>70.973</td>
<td>.000</td>
<td>1444.081</td>
<td>29.301</td>
<td>.000</td>
<td>5895.699</td>
<td>.000</td>
</tr>
<tr>
<td>PCS</td>
<td>541.441</td>
<td>57.266</td>
<td>.000</td>
<td>3029.394</td>
<td>25.508</td>
<td>.000</td>
<td>3939.030</td>
<td>.000</td>
</tr>
</tbody>
</table>

Table 14

Test of Multivariate Normality Across Subscales (N = 404)

<table>
<thead>
<tr>
<th></th>
<th>Skewness Value</th>
<th>Skewness z-score</th>
<th>Skewness p-value</th>
<th>Kurtosis Value</th>
<th>Kurtosis z-score</th>
<th>Kurtosis p-value</th>
<th>Skewness &amp; Kurtosis Chi-square</th>
<th>Skewness &amp; Kurtosis p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>224.844</td>
<td>55.335</td>
<td>.000</td>
<td>1363.429</td>
<td>21.192</td>
<td>.000</td>
<td>3513.279</td>
<td>.000</td>
</tr>
</tbody>
</table>
At Stages 2 and 3, the measures in question were the subscales of each measure. No obvious curvilinear trends were observed in a random selection of scatterplots derived from these subscales.

**Multicolinearity.** This exists when there are substantial correlations among measures. At Stage 1, the measures in question were the measure items. In order to determine whether there were substantial correlations among questionnaire items, a tolerance value for each item was computed. An item’s tolerance value indicates the degree to which the item does not correlate with the other items in the measure. If an item has a low tolerance value, then it is highly correlated with the other items in the questionnaire indicating a multicolinearity problem. It has been suggested that multicollinearity may be a problem if the smallest tolerance value is less than .1 (e.g., Bowerman & O’Connell, 1990, p. 447; Myers, 1990, cited in Stevens, 1992). For each of the questionnaires, item tolerance values were sufficiently high (see Table 15) to rule out any serious multicolinearity problems for the Stage 1 analyses.

**Table 15**

*Tolerance Values Across Items for Each Measure (N = 404)*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Range of item tolerance values</th>
<th>Mean item tolerance value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHS-S1 (75 items)</td>
<td>.17 - .68</td>
<td>.379</td>
</tr>
<tr>
<td>PHS-S2 (51 items)</td>
<td>.18 - .68</td>
<td>.401</td>
</tr>
<tr>
<td>GHQ</td>
<td>.34 - .65</td>
<td>.49</td>
</tr>
<tr>
<td>FSS</td>
<td>.43 - .90</td>
<td>.701</td>
</tr>
<tr>
<td>FAD-GF</td>
<td>.43 - .71</td>
<td>.581</td>
</tr>
<tr>
<td>FCOPE</td>
<td>.14 - .81</td>
<td>.590</td>
</tr>
<tr>
<td>FHI</td>
<td>.44 - .86</td>
<td>.586</td>
</tr>
<tr>
<td>LDI</td>
<td>.16 - .80</td>
<td>.440</td>
</tr>
<tr>
<td>FRS</td>
<td>.22 - .78</td>
<td>.460</td>
</tr>
<tr>
<td>PCS</td>
<td>.31 - .70</td>
<td>.504</td>
</tr>
</tbody>
</table>

At Stages 2 and 3, the potential multicolinearity problem applies to the indicators that were included in the measurement model, namely, the questionnaire
subscales. Tolerance values across the indicators ranged between .19 and .72 ($M = .466$) ruling out any serious multicolinearity problems for the Stage 2 and 3 analyses.

**Replacing missing values.** For each measure, the item with the greatest percentage of missing values was identified. These percentages are reported in Table 16. Item missing values were minimal and were therefore replaced by simple mean substitution (King, Fogg, & Downey, 1998).

**Determining adequate sample sizes.**

**Stage 1.** In order to reliably conduct individual CFAs, at least 5 participants are required for each parameter that needs to be estimated from the data; 10 - 20 participants per parameter would be ideal (Kline, 2005). There are four parameters estimated in a CFA. These are (a) an error variance for each item, (b) a factor loading for each item, (c) a variance for each factor, and (d) the bivariate correlations among the factors.

Table 16

<table>
<thead>
<tr>
<th>Measure</th>
<th>Item with most missing values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenting Hassles Scale (PHS)</td>
<td>2.38%</td>
</tr>
<tr>
<td>Life Distress Inventory (LDI)</td>
<td>2.78%</td>
</tr>
<tr>
<td>Family Resource Scale (FRS)</td>
<td>1.98%</td>
</tr>
<tr>
<td>Family Support Scale (FSS)</td>
<td>2.78%</td>
</tr>
<tr>
<td>Family Hardiness Index (FHI)</td>
<td>1.98%</td>
</tr>
<tr>
<td>Family Crisis Orientated Personal Evaluation Scale (FCOPE)</td>
<td>3.97%</td>
</tr>
<tr>
<td>Positive Contributions (PCS)</td>
<td>9.52%</td>
</tr>
<tr>
<td>Family Assessment Device (FAD-GF)</td>
<td>3.57%</td>
</tr>
<tr>
<td>General Health Questionnaire (GHQ)</td>
<td>1.19%</td>
</tr>
</tbody>
</table>

It can be seen from Table 17 that the present sample size of 404 is adequate for the majority of the CFAs. The CFAs for the PHS and the PCS may be underpowered.
Table 17

Sample Sizes Required for a CFA of Each Questionnaire

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Model</th>
<th>Sample size (5 participants per parameter)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHS (75 items)</td>
<td>1-Factor</td>
<td>755</td>
</tr>
<tr>
<td></td>
<td>9-Factors</td>
<td>975</td>
</tr>
<tr>
<td>PHS (51 items)</td>
<td>1-Factor</td>
<td>515</td>
</tr>
<tr>
<td></td>
<td>3-Factors</td>
<td>540</td>
</tr>
<tr>
<td>LDI (18 items)</td>
<td>1-Factor</td>
<td>185</td>
</tr>
<tr>
<td></td>
<td>4-Factors</td>
<td>230</td>
</tr>
<tr>
<td>FRS (31 items)</td>
<td>1-Factor</td>
<td>315</td>
</tr>
<tr>
<td></td>
<td>4-Factors</td>
<td>360</td>
</tr>
<tr>
<td>FSS (20 items)</td>
<td>1-Factor</td>
<td>205</td>
</tr>
<tr>
<td></td>
<td>5-Factors</td>
<td>275</td>
</tr>
<tr>
<td></td>
<td>6-Factors</td>
<td>305</td>
</tr>
<tr>
<td>FHI (20 items)</td>
<td>1-Factor</td>
<td>205</td>
</tr>
<tr>
<td></td>
<td>3-Factors</td>
<td>230</td>
</tr>
<tr>
<td></td>
<td>4-Factors</td>
<td>250</td>
</tr>
<tr>
<td>FCOPE (16 items)</td>
<td>1-Factor</td>
<td>165</td>
</tr>
<tr>
<td></td>
<td>3-Factors</td>
<td>190</td>
</tr>
<tr>
<td>PCS (50 items)</td>
<td>1-Factor</td>
<td>505</td>
</tr>
<tr>
<td></td>
<td>9-Factors</td>
<td>725</td>
</tr>
<tr>
<td>FAD-GF (12 items)</td>
<td>1-Factor</td>
<td>125</td>
</tr>
<tr>
<td>GHQ (12 items)</td>
<td>1-Factor</td>
<td>125</td>
</tr>
<tr>
<td></td>
<td>3-Factors</td>
<td>150</td>
</tr>
</tbody>
</table>

Stage 2. In order to reliably test the measurement model, at least 5 participants are required for each parameter that needs to be estimated from the data; 10 - 20 participants per parameter would be ideal. This the same rule-of-thumb used to estimate a sample size for the Stage 1 analyses (Kline, 2005). A CFA is used to test the measurement model. The parameters in the Stage 2 measurement model are therefore the same as the parameters in the Stage 1 CFA models are (a) an error variance for each indicator (35 parameters), (b) a factor loading for each indicator (35 parameters), (c) a variance for each factor (latent variable) (4 parameters), and (d) the bivariate correlations among the factors (6 parameters). A minimum sample size for
testing the measurement model would therefore be $5(35+35+4+6) = 400$. The present sample size of 404 was considered adequate for testing the measurement model.

**Stage 3.** Using the same rule-of-thumb as before, in order to reliably test the structural model, at least 5 participants are required for each parameter that needs to be estimated from the data; 10 - 20 participants per parameter would be ideal. Four parameters were estimated when testing the structural model. These were (a) a path coefficient for each pathway, (b) a disturbance (sources of variance external to the model) for each endogenous variable (c) a variance for each exogenous variable, and (d) the bivariate correlation between the exogenous variables. Table 18 shows the number of parameters in each of the competing structural models, and estimates sample size on the basis of 10 (rather than 5) participants per parameter. Provided the measurement model has been reliably tested, 400 participants were considered to be adequate for testing the structural models.

Table 18

<table>
<thead>
<tr>
<th>Model</th>
<th>No. of parameters</th>
<th>Sample size (10 participants per parameter)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additive model</td>
<td>10</td>
<td>100</td>
</tr>
<tr>
<td>Single-mediator model (partial)</td>
<td>10</td>
<td>100</td>
</tr>
<tr>
<td>Single-mediator model (full)</td>
<td>8</td>
<td>80</td>
</tr>
<tr>
<td>Two-mediator model (partial)</td>
<td>9</td>
<td>90</td>
</tr>
<tr>
<td>Two-mediator model (full)</td>
<td>7</td>
<td>70</td>
</tr>
<tr>
<td>Full-factorial moderator Model</td>
<td>36</td>
<td>360</td>
</tr>
<tr>
<td>Reduced moderator model</td>
<td>21</td>
<td>210</td>
</tr>
</tbody>
</table>

**Results**

**Descriptive statistics.** Sample comparisons made were between sample mean scores on inventories and reported means and standard deviations. The current sample generated a mean score within one standard deviation from the reported mean on the LDI compared to a sample of healthy adults (Yoshioka & Shibusawa, 2002);
the FRS compared to a community sample (Herman & Thompson, 1995); and the PCS compared to a sample of families with children with a disability (Hastings et al., 2005). The current sample showed a FHI score below one standard deviation of the mean (McCubbin et al., 1996) indicating that they reported relatively lower on family hardiness compared to a sample of community families (N = 304). Sample sizes, means, and standard deviations for each family variable are shown in Table 19.

Table 19

<table>
<thead>
<tr>
<th>Measure</th>
<th>Sample size</th>
<th>Sample mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHS</td>
<td>404</td>
<td>122.22</td>
<td>36.28</td>
</tr>
<tr>
<td>LDI total scores</td>
<td>404</td>
<td>30.02</td>
<td>18.76</td>
</tr>
<tr>
<td>*LDI item-mean scores</td>
<td>404</td>
<td>1.76</td>
<td>1.10</td>
</tr>
<tr>
<td>*FRS</td>
<td>404</td>
<td>104.48</td>
<td>28.05</td>
</tr>
<tr>
<td>FSS</td>
<td>404</td>
<td>36.09</td>
<td>13.62</td>
</tr>
<tr>
<td>**FHI</td>
<td>404</td>
<td>39.91</td>
<td>8.58</td>
</tr>
<tr>
<td>FCOPE</td>
<td>404</td>
<td>53.42</td>
<td>6.93</td>
</tr>
<tr>
<td>PCS*</td>
<td>404</td>
<td>129.71</td>
<td>18.96</td>
</tr>
<tr>
<td>GHQ total scores</td>
<td>404</td>
<td>14.12</td>
<td>6.11</td>
</tr>
<tr>
<td>GHQ item-mean scores</td>
<td>404</td>
<td>1.77</td>
<td>0.50</td>
</tr>
<tr>
<td>***FAD-GF total scores</td>
<td>404</td>
<td>36.31</td>
<td>5.80</td>
</tr>
<tr>
<td>***FAD-GF item-mean scores</td>
<td>404</td>
<td>1.97</td>
<td>0.48</td>
</tr>
</tbody>
</table>

Note: Some scale total score means are also reported as item-mean scores so that comparisons with reported item-mean scores can be made. Reverse coding of total GHQ and FAD-GF scores was undone so that comparisons with reported means could be made. Higher scores on these two measures represent higher levels of ‘unhealthy’ functioning in this table.

* sample mean within one standard deviation of reported mean
** sample mean more than one standard deviation of reported mean
*** statistically significant difference between sample mean and reported population mean

Endogenous variables were compared statistically with reported population means. For the GHQ, measuring general physical and psychological wellbeing of parents, a one-sample t-test comparing means with a community-based sample of Australian families (N = 5,936; mean = 1.07; SD = 0.04) (Korten & Henderson, 2000) generated a significant difference (t(403) = 4.218, p < .001). Families in the current sample reported poorer general health than families in the general community.
For the FAD-GF, measuring family adaptation in terms of cohesion, communication and closeness, a one-sample $t$-test comparing means with a community sample mean ($1.75; SD = .44; N = 1868$) (Byl et al., 1988), also generated a significant difference ($t(403) = 9.301, p < .001$). Families in the current sample reported significantly higher, indicating poorer family adaptation compared to a normative sample.

A comparison between the current sample FAD-GF results and that of a Western Australian sample in 2003 and 2004 can be made using data reported from the Health and Wellbeing of Children Survey (Thomlin & Joyce, 2013). A cut-off score of 2.25 or below was determined to represent families in the 'poor family functioning range'. In the 2004 annual survey ($N = \sim 900$), the percentage of families in W.A in this range was reported as 19.4%; in 2005, it was 12.8%. From the current research sample, when that cut-off score was applied, a total of 23.3% of the sample fell into the range of poor family functioning. Therefore, the current sample mean is higher than reported community means, indicating higher levels of poor family functioning.

**Stage 1: Dimensionality of measures.** Determining the dimensionality of each measure involved testing multifactor structures proposed in the literature (see Table 1, Chapter 4) and accepting the most parsimonious compared to one-factor structures. Results are summarised in Table 20.
Because different fit indices evaluate model fit from slightly different perspectives, more than one fit index is generally reported. The present study used the following fit statistics: The Satorra-Bentler chi-square divided by its degrees of freedom [χ²/df], the comparative fit index [CFI], the non-normed fit index [NNFI], the standardised root mean square residual [SRMR], and the root mean square error of approximation [RMSEA]. The cut-off criterion for the χ²/df statistic was set between 2 and 5 (Hooper, Coughlan, & Mullen, 2008). More specifically, Kline (1998) proposes that a value less than or equal to 3 indicates an acceptable fit. The CFI compares the null model, in which all latent variables are assumed to be uncorrelated, to the hypothesised model. The suggested criterion for a good fit is a CFI value greater than or equal to .85 (Benet-Martinez & Karakitapoglu-Aygun, 2003; Tabachnick & Fidell, 2007). The NNFI compares the chi-square values of the null and the hypothesised model, a value greater than or equal to .85 indicates a good fit.
The SRMR is considered to be one of the more meaningful fit indices to report in a CFA analysis (Hooper, et al., 2008). It measures the square root difference between the residuals of the null model and the hypothesised model. An SRMR of less than or equal to .1 is required for the SRMR to be considered a good fit (Marsh, Hau, & Wen, 2004). The RMSEA is considered an important fit index as it takes into account the number of parameters in the hypothesised models and selects the most parsimonious model to analyse (Hooper et al., 2008). A value of less than or equal to .08 on this index indicates a good fit (Benet-Martnez & Karakitapoglu-Aygun, 2003; Hu & Bentler, 1999). An examination of the fit indices in Table 21 indicates that, where previous research has indicated a multidimensional factor model, it fit the data better than the more parsimonious unidimensional model; and where previous research had indicated two alternative multidimensional factor models, the model with more factors fit better. The measurement model was derived from these best-fitting multidimensional solutions.

Stage 2: The measurement model. Indicators for the measurement model were the subscales from the best-fitting multidimensional CFA solutions obtained at Stage 1. The indicators were distributed across latent variables according to the rationale discussed in the Chapter 4 (see Table 1; pp 100-105). The three PHS and the four LDI subscales loaded on the Family Stress & Demands (aA) latent variable; the nine PCS and the three FCOPE subscales loaded on the Family Perceptions (cC) latent variable; the four FRS and the six FSS, and the four FHI subscales loaded on the Family Resources & Support (bB) latent variable; and the three GHQ and the FAD-GF subscales loaded on Family Adaptation (xX) latent variable. The fit statistics for this measurement model are presented in the top row of Table 21. According to
these statistics, the model was a poor fit for the data. In order to improve model fit, the indicators with small non-significant loadings on their respective latent variables (FCOPE: passive appraisal subscale; and FSS: Social organisation subscale) were dropped from the model and error covariances were added between the PHS indicators, between the FRS indicators, between the FSS indicators, and between the FHI indicators. These covariances are not only plausible, but their addition was suggested in the modification indices section of the LISREL output. The modified measurement model is presented in Figure 8, and the fit statistics for this model are reported in the bottom row of Table 21. According to these statistics, the modified measurement model was a good fit for the data.

Table 21

<table>
<thead>
<tr>
<th>Measurement model</th>
<th>$X^2$</th>
<th>$f$</th>
<th>$\chi^2/df$</th>
<th>FI</th>
<th>NFI</th>
<th>SRMR</th>
<th>RMSEA (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original</td>
<td>3468.60</td>
<td>623</td>
<td>5.57</td>
<td>.870</td>
<td>.861</td>
<td>.111</td>
<td>.106 (.103 - .110)</td>
</tr>
<tr>
<td>Modified</td>
<td>1892.08</td>
<td>535</td>
<td>3.54</td>
<td>.922</td>
<td>.913</td>
<td>.092</td>
<td>.079 (.076 - .083)</td>
</tr>
</tbody>
</table>

Having tested the measurement model, the structural models were tested and compared (see Figures 9 – 12). This was accomplished by testing the fit of the hybrid model. The hybrid model consists of the measurement model and the structural model. Because the measurement model provided an adequate fit for the data, any lack of fit in the hybrid model was considered to be due to a lack of fit in the embedded structural model.
Figure 8. The measurement model. Starting on the extreme left of the figure and moving across to the right, the curved double-ended arrows represent error covariances, the right pointing arrows represent measurement errors, the left-pointing arrows represent factor loadings, and the curved double-ended arrows represent factor correlations.
**Stage 3: Testing structural models.** Before testing the structural models that might have generated the correlations among the latent variables, it needed to be shown that the latent variables were in fact correlated. The correlations among the latent variables are reported in Table 22; all correlations are statistically significant.

Structural models were tested in order of conceptual complexity, from least to most, and compared using the Akaike Information Criterion (AIC; Akaike, 1974).

Table 22

*Correlational Matrix of Latent Variables*

<table>
<thead>
<tr>
<th>Latent variable</th>
<th>Family Stress &amp; Demands (aA)</th>
<th>Family Resources &amp; Supports (bB)</th>
<th>Family Perceptions (cC)</th>
<th>Family Adaptation (xX)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Stress &amp; Demands (aA)</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Resources &amp; Supports (bB)</td>
<td>-859***</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Perceptions (cC)</td>
<td>-.223***</td>
<td>.341***</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>Family Adaptation (xX)</td>
<td>-.714***</td>
<td>.692***</td>
<td>.151**</td>
<td>1.000</td>
</tr>
</tbody>
</table>

** p < .01
*** p < .001

*The additive model.* The additive model, depicted in Figure 9, proposed that Family Stress & Demands (aA), Family Resources & Supports (bB), and Family Perceptions (cC), act as correlated (see Table 22 for the correlations) exogenous variables that combine additively to predict Family Adaptation (xX).

**Figure 9.** The additive Double ABCX model showing Family Resources & Supports (bB), Family Stress & Demands (aA), and Family Perceptions (cC) as additive predictors of Family Adaptation (xX). Bold pathways indicate significance: thick = p < .001; thin = p < .05.
The fit indices for the additive model are reported in Table 23. The additive model fit the data on four of the five fit statistics (CFI > .9, NNFI > .9, SRMR < .1, 95% CI for RMSEA straddles .08; but $\chi^2/df > 3$). The Model AIC is only informative when compared to the AICs of other models. The significance of the path coefficients suggest that Family Stress & Demands (aA) and Family Resources & Supports (bB), but not Family Perceptions (cC), impacted Family Adaptation (xX).

Table 23

| Goodness-of-fit Indicators for the Additive Model (N = 404) |
|-----------------|-------|--------|------|------|-----|--------|
| $\chi^2$ df  $\chi^2/df$ CFI NNFI SRMR RMSEA (CI) Model AIC |
| Additive model | 1892.08 | 535 | 3.54 | .922 | .913 | .092 | .079 (.076 - .083) | 2082.08 |

The single-mediator model. While Family Perceptions (cC) might not have combined additively with Family Stress & Demands (aA) and Family Resources & Supports (bB) to predict Family Adaptation (xX), it was considered to possibly mediate the (bB) to (xX) and/or the (aA) to (xX) relationships. The mediation effect could be either partial (Figure 10a) or full (Figure 10b).

The fit indices for the two versions of the single-mediator model are reported in Table 24. The partial mediation version of the model fit the data on four of the five fit statistics (CFI > .9, NNFI > .9, SRMR < .1, 95% CI for RMSEA straddles .08; but $\chi^2/df > 3$). The full mediation version fit the data on just two of the fit statistics (CFI > .9, NNFI > .9). In addition, the Model AIC (where smaller values denote better fit) favoured the partial mediation model. The question was whether the partial mediation model fit the data significantly better. The $\chi^2$ difference test was significant ($\chi^2_{\text{diff}} = 214.21, df = 2, p < .001$) indicating that the $\chi^2$ value for the partial mediation model was significantly smaller than the $\chi^2$ value for the full mediation model.
Figure 10. The single-mediator Double ABCX model showing Family Perceptions (cC) as a partial and a full mediator for pathways between (i) Resources & Supports (bB) and Family Adaptation (xX), and (ii) Family Stress & Demands (aA) and Family Adaptation (xX). Bold pathways indicate significance: thick = $p < .001$; thin = $p < .05$.

The partial mediation model therefore fit the data significantly better than the full mediation model implying that the direct pathways from Family Stress & Demands (aA) and Family Resources & Supports (bB) to Family Adaptation (xX)
should be retained, and that Family Perceptions (cC) did not fully mediate the (aA) to (xX) or (bB) to (xX) pathways, although it could still have been a partial mediator.

Table 24

<table>
<thead>
<tr>
<th>Single-mediator model</th>
<th>$\chi^2$</th>
<th>df</th>
<th>$\chi^2$/df</th>
<th>CFI</th>
<th>NNFI</th>
<th>SRMR</th>
<th>RMSEA (CI)</th>
<th>Model AIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partial mediation</td>
<td>1866.55</td>
<td>535</td>
<td>3.51</td>
<td>.922</td>
<td>.913</td>
<td>.092</td>
<td>.079 (.076, .083)</td>
<td>2082.08</td>
</tr>
<tr>
<td>Full mediation</td>
<td>2080.76</td>
<td>537</td>
<td>3.87</td>
<td>.909</td>
<td>.900</td>
<td>.136</td>
<td>.085 (.081, .088)</td>
<td>2266.76</td>
</tr>
</tbody>
</table>

The $p$-values for the indirect pathways were subsequently examined to determine whether Family Perceptions (cC) was a partial mediator of the (aA) to (xX) and/or (bB) to (xX) relationships. An initial condition that would have to be satisfied in order for Family Perceptions (cC) to be a partial mediator of these relationships was the significance of each of the component pathways that comprise the mediation effects. One of these pathways, the (cC) to (xX) pathway, was non-significant ($p = .237$). Since this pathway is crucial to both mediation effects, its non-existence ruled out Family Perceptions (cC) as a partial mediator of the (aA) to (xX) and the (bB) to (xX) relationships.

**The two-mediator model.** The present data indicated that Family Perceptions (cC) did not combine additively with Family Stress & Demands (aA) and Family Resources & Supports (bB) to predict Family Adaptation (xX), nor did it mediate the (aA) to (xX) or the (bB) to (xX) relationships. It was then considered that possibly Family Perceptions (cC) and Family Resources & Supports (bB) mediate the (aA) to (xX) relationship. Once again, the mediation effect could be either partial (Figure 11a) or full (Figure 11b).

The fit indices for the two versions of the two-mediator model are reported in Table 25. The partial and full mediation versions of the model fit the data on four of the five fit statistics ($\text{CFI} > .9$, $\text{NNFI} > .9$, $\text{SRMR} < .1$, 95% CI for RMSEA straddles
.08; but \( \chi^2/df > 3 \). According to the \( \chi^2 \) statistic and the Model AIC, where smaller values are better, the partial mediation model provided the better fit. The question was however: Does the partial mediation model fit the data significantly better? In order to answer this question, a \( \chi^2 \) difference test was conducted. The test was significant (\( \chi^2_{\text{diff}} = 29.66, df = 1, p < .001 \)) indicating that the \( \chi^2 \) value for the partial mediation model was significantly smaller than the \( \chi^2 \) value for the full mediation model. The partial mediation model therefore fit the data significantly better than the full mediation model implying that the direct pathway between Family Stress & Demands (aA) and Family Adaptation (xX) should be retained, and that Family Resources & Supports (bB) and Family Perceptions (cC) were not full mediators of the relationship between (aA) and (xX) although they could still have been partial mediators.

Table 25

<table>
<thead>
<tr>
<th>Goodness-of-fit Indicators for the Two-Mediator Model (N = 404)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two-mediator model</td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Partial mediation</td>
</tr>
<tr>
<td>Full mediation</td>
</tr>
</tbody>
</table>

The \( p \)-values for the indirect pathways were subsequently examined to determine whether Family Resources & Supports (bB) and Family Perceptions (cC) were partial mediators of the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). An initial condition that must have been satisfied in order for (cC) to be a partial mediator was the significance of each of the two component pathways that comprise the mediation effect, namely, the (aA) to (cC) pathway and the (cC) to (xX) pathway. Figure 11 indicates that the (cC) to (xX) pathway was not significant (\( p = .485 \)). Family Perceptions (cC) could therefore be dismissed as a partial mediator of the relationship between (aA) and (xX). The other two mediating
pathways, (aA) to (bB) and (bB) to (xX), were both significant ($p < .001$ and $p = .041$ respectively) indicating that Family Resources (bB) could be a partial mediator.

Figure 11. The two-mediator Double ABCX models showing Family Resources & Supports (bB) and Family Perceptions (cC) as (a) partial, and (b) full mediators of the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). Bold pathways indicate significance: thick = $p < .001$; thin = $p < .05$. 
Two more conditions must be satisfied before concluding that Family Resources (bB) was a partial mediator of the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). Firstly, the overall indirect effect from (aA) to (xX) via (bB) must be significant. The strength of the indirect effect is given by the product of its two component path coefficients; -.85 multiplied by .26 equals -.22, which is significantly greater than zero (z = 1.997, p = .045). The indirect effect from (aA) to (xX) via (bB) was therefore significant.

Finally, before concluding that Family Resources (bB) was a partial mediator of the relationship between Family Stress & Demands (aA) and Family Adaptation (xX), it had to be shown that the strength of the direct pathway from (aA) to (xX) (-.50) was significantly less than the strength of this pathway when (bB) was removed from the model (-.71). The difference between the two path coefficients was significant (β change = .21, p < .001) indicating that the inclusion of Family Resources (bB) in the model significantly reduced the strength of the direct pathway from (aA) to (xX). Family Resources (bB) therefore satisfies all three requirements for a partial mediator.

However, there was a problem with the partial mediator model (Figure 11). The negative path coefficient for the causal pathway from Family Stress & Demands (aA) to Family Resources & Supports (bB) indicated that increases in family stress levels led to decreases in the levels of family resources and support. This is implausible. The implausibility arises from testing causal models with cross-sectional data. At a single point in time, it could be expected that stress and support are negatively related (higher levels of stress reflecting lower levels of support). Overtime however, it should be expected that high levels of stress lead to families acquiring increased resources and supports, making the causal pathway positive.
The moderator model. Family Perceptions (cC) did not combine additively with Family Stress & Demands (aA) and Family Resources & Supports (bB) to predict Family Adaptation (xX), nor did it mediate the (aA) to (xX) or the (bB) to (xX) relationships. Family Resources (bB), however, did partially mediate the (aA) to (xX) relationship. The final model to be tested proposed that (cC) and (bB) moderated (rather than mediated) the relationship between (aA) and (xX). There were two version of this model. One version (Figure 12a) is the full factorial model consisting of the three two-way and the three-way interaction; the other version (Figure 12b) focused on the moderation effects of interest as reflected in the Family Stress & Demands (aA) x Family Resources & Supports (bB) (aA x bB) interaction and the Family Perceptions (cC) x Family Stress & Demands (aA) (aA x cC) interaction. Each interaction term was the product of its centred main effects.

The fit indices for the two versions of the moderator model are reported in Table 26. The full factorial and the reduced versions of the model fit the data on four of the five fit statistics (CFI > .9, NNFI > .9, SRMR < .1, 95% CI for RMSEA straddles .08; but $\chi^2/df > 3$). The two version of the moderator model, unlike the two versions of each mediator model, are not nested models and therefore cannot be compared with a $\chi^2$ difference test. According to the $\chi^2$ statistic and the Model AIC (where smaller values are better), however, the reduced moderator model provides the better fit.

Table 26

<table>
<thead>
<tr>
<th>Goodness-of-fit Indicators for the Moderator Models (N = 404)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Moderation models</strong></td>
</tr>
<tr>
<td>-----------------------</td>
</tr>
<tr>
<td>Reduced</td>
</tr>
</tbody>
</table>
**a. Full Factorial Moderation Model (with Controlled Pathways)**

```
Bb
Family Resources and Supports

Aa
Family Stress & Demands

Cc
Family Perceptions

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Aa X Cc
Family Stress & Demands X Family Perceptions

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Cc
Family Perceptions

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Aa X Cc
Family Stress & Demands X Family Perceptions

Cc
Family Perceptions

Xx
Family Adaptation

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Xx
Family Adaptation

Bb X Cc
Resources & Supports X Perceptions

aA x Bb x Cc
Stress & Demands x Resources & Supports x Perceptions

.35, p = .014

.11, p = .024

.12, p = .064

-.01, p = .864

.06, p = .296

.09, p = .108

.04, p = .317

-.06, p = .231
```

**b. Reduced Moderation Model**

```
Bb
Family Resources and Supports

Aa
Family Stress & Demands

Cc
Family Perceptions

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Aa X Cc
Family Stress & Demands X Family Perceptions

Cc
Family Perceptions

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Aa X Cc
Family Stress & Demands X Family Perceptions

Cc
Family Perceptions

Xx
Family Adaptation

Aa X Bb
Family Stress & Demands X Family Resources & Supports

Xx
Family Adaptation

Bb X Cc
Resources & Supports X Perceptions

aA x Bb x Cc
Stress & Demands x Resources & Supports x Perceptions

.35, p = .014

.11, p = .024

.12, p = .064

-.01, p = .864

.06, p = .296

.04, p = .317

-.06, p = .231
```

*Figure 12.* The full factorial and reduced moderation models showing Family Resources & Supports (bB) and Family Perceptions (cC) as moderators of the relationship between Family Stress and Demands (aA) and Family Adaptation (xX) with and without controlling for interactions between, i) Family Resources and Supports (bB) and Family Perceptions (cC) and, ii) Family Stress & Demands, Family Resources & Supports (bB), and Family Perceptions (cC). Bold pathways indicate significance: thick = \( p < .001 \); thin = \( p < .05 \).
The $p$-values for the pathways from the two-way interactions in the reduced model were examined to determine whether Family Resources & Supports (bB) and Family Perceptions (cC) moderated the relationship between Family Stress (aA) and Family Adaptation (xX). The pathway for the (aA x cC) interaction was not significant ($p = .317$) indicating that Family Perceptions (cC) did not moderate the relationship between (aA) and (xX). The pathway for the (aA x bB) interaction, however, was significant ($p = .024$) indicating that Family Resources & Supports (bB) moderated the relationship between Family Stress & Demands (aA) and Family Adaptation (xX).

In other words, the significant (aA x bB) interaction indicated that the strength of the relationship between (aA) and (xX) varied as a function of (bB). In order to determine how the strength of the (aA) to (xX) relationship varied as a function of (bB), the present sample of 404 participants was split into high and low resources groups at the median split. A multi-group analysis was then conducted to test and compare the (aA) to (xX) relationship across the two groups; the results are reported in Figures 13.

The (aA) to (xX) pathway was significant in both groups; however, the global $\chi^2$ test was significant ($\chi^2 = 505.78, df = 108, p < .001$) indicating that the pathway was significantly stronger for the low resources group. Therefore, moderating effects were verified.

A plausibility problem arose with the moderator analysis. A moderator variable should not be strongly correlated with the predictor. According to Table 22, Family Resources & Supports (the moderator) and Family Stress & Demands (aA) (the predictor) are correlated -.859 ($p < .001$). In the presence of such a strong correlation between (aA) and (bB), what appears to be a significant (aA x bB)
interaction might actually be a significant non-linear effect of (aA) alone (Fairchild & MacKinnon, 2009).

![Diagram](image)

**Figure 13.** The relationship between Family Stress & Demands (aA) and Family Adaptation (xX) for median-split groups of ‘high’ and ‘low’ Family Resources & Supports (bB).

**Summary and comparison of models tested.** Stage 3 of the analysis tested and compared variations of the Double ABCX model to examine the mediating and moderating effects of Family Resources & Supports (bB) and Family Perceptions (cC) on the relationship between Family Stress and Demands (aA) and Family Adaptation (xX). Results are summarised and compared in Table 27.
## Table 27

**Summary Outcomes and Comparisons of Model Testing**

<table>
<thead>
<tr>
<th>Model</th>
<th>Model AIC</th>
<th>What the Pathways Indicate</th>
<th>Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additive</td>
<td>2082.08</td>
<td>Family Stress &amp; Demands (aA) and Family Resources &amp; Supports (bB), but not Family Perceptions (cC), predicted Family Adaptation (xX).</td>
<td>No problems.</td>
</tr>
<tr>
<td>Single-mediator (partial mediation version)</td>
<td>2082.08</td>
<td>Family Perceptions (cC) did not mediate the (bB) to (xX) or the (aA) to (xX) relationships.</td>
<td>The second component of the mediation effect (Family Perceptions -to - Family Adaptation) is not significant producing a model that conveys no more information than the additive model.</td>
</tr>
<tr>
<td>Two-mediator (partial mediation version)</td>
<td>2089.84</td>
<td>Family Resources (bB), but not Family Perceptions (cC), was a partial mediator of the relationship between (aA) and (xX).</td>
<td>The negative Family Stress &amp; Demands – to – Family Resources &amp; Supports pathway is implausible.</td>
</tr>
<tr>
<td>Moderator (reduced version)</td>
<td>2183.73</td>
<td>Family Resources &amp; Supports (bB), but not Family Perceptions (cC), moderated the relationship between (aA) and (xX) such that the relationship is stronger for individuals with fewer resources.</td>
<td>Predictor and moderator are highly correlated.</td>
</tr>
</tbody>
</table>
Discussion

The aim of this study was to examine the relationship between latent variables of the Double ABCX model of family adaptation (McCubbin & Patterson, 1983b), using survey data from a sample of caregiving mothers of children (aged 2 – 12 years) with a developmental disability. Four theoretically-driven versions of the Double ABCX model were tested. Each model represented a different perspective on the contributions and interactions of exogenous variables of Family Stress & Demands (aA), Family Resources & Supports (bB), and Family Perceptions (cC) on the endogenous variable, Family Adaptation (xX).

Each of the four models provided a good statistical fit for the data. In order to further compare the viability of models, Model AICs (Akaike, 1974) were computed. The Model AIC is useful for comparing non-nested models, such as those tested here. The additive model and the single-mediator model (the partial mediation version) provided the best statistical fit. The additive model provided evidence for direct predictive effects of family caregiving burden, and family resources and supports, on the outcome, family adaptation. Family perceptions did not predict outcomes. The single-mediator model showed partial mediating effects for family resources and supports but not family perceptions. Both the two-mediator model (the partial mediation version) and the moderator model (the reduced version) posed plausibility problems. Therefore, it is concluded that the additive model demonstrated best fit, conceptual plausibility, and was most parsimonious.

The additive model. This model proposed direct causal pathways from all three exogenous variables to Family Adaptation (xX). Two of three hypotheses (H1a-c) were supported. H1a was supported; the positive pathway from Family Resources & Supports (bB) to Family Adaptation (xX) was significant. The more family
resources and supports families reported having, the more positive their level of family adaptation was likely to be. H1b was also supported since the negative pathway from Family Stress & Demands (aA) to Family Adaptation (xX) was significant. That is, the higher families reported their level of family caregiving burden, the lower their level of family adaptation. In contrast, H1c was not supported. The pathway from Family Perceptions (cC) to Family Adaptation (xX) was not significant. How families reported on their level of coping and their extent of perceived positive contributions to family life, from having a child with a disability, was not causally related to the level of family adaptation they were likely to report.

**The single-mediator model.** This model proposed that Family Perceptions (cC) partially or fully mediate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). Two of the four hypotheses (H2a-d) were supported. H2a was supported; the positive pathway between Family Resources & Supports (bB) and Family Adaptation (xX) was significant. The more a family reported a high level of family resources and supports, the more they were likely to report a high level of positive family adaptation. H2b was not supported. Although the initial component of the mediating pathway (from bB to cC) was positive and significant, the latter component (from cC to xX) was non-significant. The non-significance of the latter component prevented mediation. The positive correlation between how families reported on their level of family resources and supports, and their level was positive family adaptation, was not likely to be mediated by their level of family coping or perceptions of positive contributions to family life from having a child with a disability. H2c was supported; the negative correlation between Family Stress & Demands (aA) and Family Adaptation (xX) was significant. The more families reported high levels of family caregiving burden, the more likely it was that
they reported low levels of positive family adaptation. Hypothesis 2d was not supported. The pathways from Family Stress & Demands (aA) to Family Perceptions (cC) was non-significant and that from (cC) to Family Adaptation (xX) was non-significant. The negative correlation between how families reported on the severity of family caregiving burden and their level was positive family adaptation was not likely to be mediated by their level of family coping or perceptions of positive contributions to family life from having a child with a disability.

**The two-mediator model.** This model proposed Family Resources & Supports (bB) and Family Perceptions (cC) mediated the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). For this model to have been supported, three hypotheses (H3a-c) had to be met; only one was supported. H3a was supported. There was a significant negative relationship between Family Stress and Demands (aA) and Family Adaptation (xX). The more families reported increased family caregiving burden, the more likely they reported negative family adaptation. Hypothesis 3b was not supported. Family Resources & Supports (bB) did not mediate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). The pathway between (aA) and (bB) was significantly negative. Although the pathway between (bB) and (xX) was positive and significant at a low confidence level, the model is implausible since it suggests that increases in family caregiving burden led to decreases in family resources and supports over time, rather than increases in acquired resources. This implausibility arises from testing causal models with cross-sectional data. At a single point in time, we can expect the two constructs to be negatively related (higher levels of family stress reflecting lower levels of resources and supports).
Hypothesis 3c was also not supported. Although the initial pathway (from aA to cC) was significant and negative as predicted, the path coefficient associated with the pathway from Family Perceptions (cC) to Family Adaptation (xX) was non-significant, suggesting no significant mediational effects between (aA) and (xX). How family reported relationships between family caregiving burden and family adaptation was not mediated by their experience of family coping or parent perceptions of positive contributions to family life from having a child with a disability.

**Moderator model.** This model proposed that Family Resources & Supports (bB) and Family Perceptions (cC) moderate the relationship between Family Stress & Demands (aA) and Family Adaptation (xX). Two of the three hypotheses (H4a-c) were supported. H4a was supported; a significant negative relationship between Family Stress & Demands (aA) and Family Adaptation (xX) suggested that the more family caregiving burden reported, the lower the level of family adaptation likely to be reported. H4b was supported at a low level of confidence. The pathway from the (aA x bB) interaction term to Family Adaptation (xX) was significant at \( p < .05 \), suggesting some level of moderating effects. That is, if this was a viable model, it would suggest that family caregiving burden combined with family resources and supports together could predict levels of family adaptation. H4c was not supported. The pathway from the (aA x cC) interaction term to Family Adaptation (xX) was not significant. This suggests that family caregiving burden combined with family coping and parental perceptions of disability did not predict levels of family adaptation.

The moderator model gave a plausible result for interactions between family caregiving burden and family resources and supports. That is, a significantly stronger relationship between Family Stress & Demands (aA) and Family Adaptation (xX) for
families with low levels of Family Resources & Supports (bB) compared to families with high levels of (bB) was confirmed. However, the reliability of this result is questionable since the predictor variable (aA) was highly correlated with the moderator variable (bB). This means that the apparent interaction may only be a non-linear effect of (aA).

**Comparisons with previous studies.** Inconsistencies in conceptualisation of latent variables, and differences in how measurement models have been constructed makes comparison between studies tenuous. However, consistencies in the observed direct effects of Factor (aA) on Factor (xX) in the model are apparent. For instance, Lavee et al. (1985) reported similar direct, negative effects from relocation strain (Factor aA) onto family adaptation (Factor xX). In the present study, family caregiving burden (Factor aA) had a direct, negative effect on family adaptation (Factor xX). Although different target groups meant different measures between this study and Lavee et al.’s study, it is theoretically plausible that increased strain will directly impact negatively on family adaptation, no matter what circumstance produces that strain. Measures for Factor (aA) tend to be indicators of actual demands and strains, rather than psychological constructs. Therefore, the current model evaluation result is somewhat comparable and consistent with the Lavee et al. study, regarding the relationship between Factor (aA) and Factor (xX).

Regarding Factor (bB), the Lavee et al. (1985) group reported a direct, positive effect of family system resources on family adaptation. Although this is theoretically consistent with the current findings, their conceptualisation of the (bB) latent variable was operationalised with measures tapping ‘family cohesion, adaptability and commitment’ (using FACES-II). In the current study, these constructs loaded clearly on to the Factor (xX) endogenous variable, family
adaptation. This makes logical comparisons between the causal relationship of Factors (bB) and (xX), between studies, implausible. In addition, the Lavee et al. study unravelled Factor (bB) into two latent variables – one denoting family resources mentioned above; one denoting family supports (measured with the *Social Support Index*). They found no significant, positive effect of social support on family adaptation. Instead, they reported mediating and moderating effects of social support (Factor bB); and direct and mediating effects of family coherence (Factor cC), on family adaptation (Factor xX). In the present study, where the additive model was superior over other proposed mediating and moderating models, Factor (bB) comprised measures of both resources and supports and the construct did produce significant, direct, positive effects on family adaptation, while Factor (cC) did not.

Comparisons between Factor (cC) results are also thwarted with differences in model conceptualisation and construction. The Lavee et al. group used measures specific to risk factors associated with their sample – families undergoing army relocation. Their measures tapped constructs related to ‘family army-fit’, ‘predictability of work and family schedules’, and ‘commitment to army life-style’. They found a significant, positive, direct effect from Factor (cC) to Factor (xX), as well as mediating effects. This effect was not found in the current study, Factor (cC) variables of ‘family coping style’ and ‘perceived positive contributions (of having a child with a disability)’ did not predict family adaptation. Results from both studies lead to a conclusion that further investigation into the construct of Factor (cC) and its function on family adaptation is needed.

In other research, indirect effects of Factor (cC) variables including coherence and family appraisal have been reported to moderate and mediate the relationship between family resources and stress (bB) and family adaptation (xX) (McCubbin et
al., 1998) or mediate it solely (Benzar, 2011). Again, the current research does not verify such functions and measures were conflicting. Benzar (2011) conceptualised Factor (cC) as *perceived burden* which here was conceptualised as, and loaded clearly onto, Factor (aA), Family Stress & Demands. In the present study Factor (bB) variables had a causal relationship with Factor (cC) variables but these did not carry forth to mediate effects on family adaptation. At any rate, a more parsimonious understanding of the function of Factor (bB) variables on family adaptation is demonstrated to be direct and additive in the current study.

The current results are somewhat consistent with those reported by Orr et al. (1991). Orr et al.’s analysis yielded direct effects from Factor (aA) and (bB) to Factor (xX) but no direct effects from Factor (cC). They then tested for mediating effects of (cC) and concluded no significant pathway from Factor (cC) variables to (xX). This is consistent with present findings. They suggested a linear model (ACBX) which was not tested here since no theoretical rationale could be established. Orr et al. also suggested further testing for moderating effects of (bB) and (cC), which was followed up here and yielded less support than a direct and additive model.

With regression equations based on observed variables, Manning et al. (2011) reported no significant predictive value of ‘*coping by seeking spiritual support*’ or ‘*reframing*’ (Factor cC) onto family functioning (Factor xX). Both the present study and the Manning et al. (2011) study found non-significant, causal relationships between these specific Factor (cC) variables and Factor (xX). Manning et al.’s. (2011) analysis did, however, show that these variables predicted parenting stress (another observed Factor xX variable in the Manning study). Again, since parenting stress was conceptualised in the present study as a component of Factor (aA), logical comparisons between studies cannot be made. Previous research has shown that high
levels of negative appraisals (e.g., self-blame, wishful thinking, avoidance) had significant, negative effects on individual, marital and family adaptation (Factor xX) (Saloviita et al., 2003). Positive coping strategies such as those measured in the present study and in Salovitta et al. study, had no significant impact on family adaptation.

**Strengths and limitations.** Considering the generalisability of the current results, there have been a number of advantages of the methodology used here that comprise key contributions to theoretical and empirical advancement of the model. Observed variables included in the current study were the result of a thorough literature review of impacts of disability on families and, both deductive and inductive family adaptation model building. Conceptualising latent variables of the Double ABCX model then depended on clear interpretations of original theory, and clear functional definitions of Factors (aA), (bB), (cC), and (xX). This, and having used valid and reliable measures, with confirmed factor analytic structures to devise an adequate measurement model with a moderate-large sample size, improves the generalisability of models that were then tested and supported.

There were also limitations that need to be taken into account when generating conclusions about how the Double ABCX model may inform policy and service delivery for families. Although the sample used in Study 2 was demographically homogeneous, i.e., families were reasonably well educated and financially positioned, this, of course, limits the generalisability of the findings. A more normative sample would provide more generalisable results and this may be achieved using a stratified random sampling technique with a stratum of socio-economic status.

Another limitation of the current study was satisfying criteria (covariation, directionality, and causal closure) for model testing. Before concluding that an
increase in Stress & Demands (aA) causes a decrease in Family Adaptation (xX), for instance, it would have to be shown that the two variables covary. This is the criterion of covariation. Secondly, it has to be shown that Family Stress & Demands (aA) precedes Family Adaptation (xX), rather than vice-versa. This is the criterion of directionality and can only be established with longitudinal data. Thirdly, the relationship between Stress & Demands (aA) and Family Adaptation (xX) would need to be shown to be closed to outside influences. This is the criterion of causal closure. If the relationship between Stress & Demands (aA) and Family Adaptation (xX) were not closed to outside influences, then there might be some third variable - income say - that causes Stress & Demands (aA) to increase and Family Adaptation (xX) to decrease. If this is the case, then the negative correlation between Family Stress & Demands (aA) and Family Adaptation (xX) (Figure 12-14) would be spurious. That is, it would not reflect an underlying causal relationship between the two variables; it would merely reflect the action of a third variable (income) that causes people to become stressed and experience lower levels of family adaptation.

*SEM* causal modeling operates on data generated by correlational designs. Cross-sectional correlational data can only satisfy the first criterion for causality (covariation); longitudinal correlational data can satisfy criteria one and two (covariation & directionality). Regardless of whether it is cross-sectional or longitudinal, however, correlational data can never satisfy the third criterion for causality (causal closure). The experimental design is the only design that satisfies all three criteria. Therefore, conclusions from the present *SEM* analysis can only mean that a particular causal model does a good job of accounting for the correlational data. And in terms of further research, taking data at two or more points in time would be advantageous.
Another area to focus further research efforts on may be that of how family perceptions function to impact on the relationship between family stress and adaptation. This Factor (cC), of the Double ABCX model, has been conceptualized in many different ways by researchers (e.g., reframing, personal coping style, coherence, definitions, positive contributions from child, locus of control, etc.) and from the papers reviewed, a conclusive role has not yet been described.

**Conclusion.** The support for the additive model tested here, means that both family caregiving burden (family stress and demands), and resources and supports, have a causal relationship with family adaptation. This demonstrated the importance of the direct effects of these family variables on family outcome, and what they may mean for developing a family support service based on this model. Specific ideas are elaborated in Chapter 7 but for now, suffice it to say that such a service targeting family adaptation would require two components. Firstly, support that sought to reduce sources of family caregiving burden in families would be needed. Reducing the level of family caregiving burden in a practical way, would likely weaken its negative association with family adaptation. Secondly, given that increased levels of family resources and social supports have been shown to improve the likelihood of positive family adaptation, family support programs would need to provide resources for families to use to strengthen their coping ability. For example, direct and indicated clinical interventions to teach a child communication and adaptive behaviour skills may decrease the level of family caregiving burden. In addition, empowering and teaching parents to build and extend support networks and a sense of family confidence and optimism would increase family resources and hardiness, and therefore likely again improve family adaptation.
In conclusion, this study has provided no compelling evidence that Family Resources & Supports (bB) or Family Perceptions (cC) either mediated or moderated the relationship between Stress & Demands (aA) and Family Adaptation (xX). While there was some evidence that Family Resources & Supports moderated the relationship between Family Stress & Demands (aA) and Family Adaptation (xX), the evidence was provided within the context of a structural model that (a) fit the data less well than the other models and (b) included a moderator that was highly correlated with the predictor. The additive model, which described direct causal relationships between (a) family caregiving burden, and (b) family resources and stress, with family adaptation to developmental disability, was most the most parsimonious, empirically supported, and conceptually plausible interpretation of the Double ABCX model tested. There was therefore no compelling reason to prefer any of the other models over the basic additive model. Family perceptions were not found to have significant causal effects on family adaptation.
Chapter 7
Discussion, Summary, and Conclusion

Well-informed support programs that target specific family variables to enable families to make positive adaptation, to the caregiving burden associated with having a child with a disability, are much needed. The overall aim of this inquiry was to advance understanding of evidence-based models for family adaptation to developmental disability. Specifically, the first goal was to quantify the relative effects of behavioural family intervention, on a range of family variables that theoretically relate to family adaptation. A previous report of the overall evaluation of Standard Stepping Stones Triple P (SSTP; Sanders, et al., 2004), a parenting program for families of children with disabilities, identified significant effects on targeted variables that were maintained over 12 months (Roberts, et al., 2006). In the present study, effect sizes on targeted variables (i.e., child behaviour and parenting) and non-targeted variables (i.e., parent depression, anxiety and stress; family resources and stress; parent sense of competence; relationship adjustment; and general family functioning) were compared. This would establish whether the intervention effectively targeted variables related to family adaptation or further inquiry into effective designs for treatment was required. The second goal was specifically to evaluate a theoretically sound model to determine how latent family variables interact to predict the impact of family caregiving burden on family adaptation. SEM was used to evaluate the Double ABCX model using data from a large sample of families of children with developmental disabilities. Direct and additive, mediating, and moderating conceptualisations of the model were compared for plausibility and tested on a range of fit statistics. A secondary goal of the evaluation was to consolidate the conceptualisation of key terms in the Double ABCX model for further research. This
has been important since past variations in interpretation and measurement of the model has contributed to inconclusive, and non-comparable, evaluation results. This chapter summarises the main findings of both studies, outlines key theoretical and empirical contributions, and discusses implications. Also clinical applications for positive family adaptation to developmental disability are suggested. Limitations of this research and recommendations for further research are also discussed.

**Key Findings and Research Comparisons**

**Effects of behavioural family intervention on family adaptation.** The results of Study 1 provided a clear indication of differential, relative effects of SSTP on targeted and non-targeted variables. While significant, large intervention effect sizes were demonstrated for dysfunctional parenting style and child behaviour problems, non-significant, small to moderate intervention effects were produced for other family variables related to family adaptation. All effects were in positive directions such that SSTP was associated with improvements on all child and family measures. As predicted, effect sizes were stronger for targeted variables. Although effects on non-targeted variables that represented aspects of family adaptation were in positive directions, they were not significant compared to the waitlist control condition. Significant effects on targeted variables were maintained at both 6-month and 12-month follow ups.

An interesting finding was that when the control group in this study was treated and measures compared pre- to post, there were significant, improvements in not only dysfunctional parenting style and child behaviour, but also in measures of parenting sense of competence, and parent reported resources and stress. Small to moderate, non-significant effects on other family variables were found. Again, all
effects were in positive directions indicating improvements in child and family variables.

These results are consistent with findings from other trials of SSTP where significant effects on dysfunctional parenting style and child behaviour problems have been reported (Plant & Sanders, 2007; Sofronoff, et al., 2011; Whittingham, et al., 2009), and where reports on the measure of parent sense of competence (PSoC) have been inconclusive. Plant and Sanders (2007) reported short term effects on the PSoC that were not maintained at follow-up. Whittingham, et al. (2009) reported one PSoC subscale (parental satisfaction) shifted significantly at post-test, with no maintenance, but with a potential sleeper effect on the other PSoC subscale (parental efficacy). There are also reports of non-significant SSTP effects on measures of depression, anxiety and stress (using the DASS) (Plant & Sanders, 2007; Sofronoff, et al., 2011); dyadic adjustment (using the ADAS) (Plant & Sanders, 2007) and family adaptation (using the FAD-GF) (Sofronoff, et al., 2011).

The current results also compare favourably with outcomes from trials of other behavioural family interventions that have yielded significant changes in parenting and child behaviour but not other family variables. For example, Gavidia-Payne, et al. (1997) reported non-significant shifts in parental adjustment and sense of competence. Also, Quinn, et al. (2007) reported non-significant shifts in parental perceptions about disability, family adaptation, social support, life events and changes, and parenting stress. These results suggested that behavioural family intervention, such as SSTP, does not provide a parsimonious treatment to facilitate change on a range of variables related to the broad context of family adaptation. SSTP targets only specific risk factors, dysfunctional parenting and child behaviour problems, which theoretically are a subset of family variables related to the broader
context of family adaptation to developmental disability. The results of Study 1 did, therefore, lead to a strong rationale for further investigation into the concept and nature of family adaptation, so that specific family variables and their interactional nature could be determined.

**Empirical support for the Double ABCX model of family adaptation.** The results of Study 2 provided partial support for the Double ABCX model of family adaptation (McCubbin & Patterson, 1983) when exogenous variables were considered to have direct and additive, predictive value. This conceptualisation of the model was the most parsimonious model which fit four, of the five specified fit-statistics. There was strong support for latent variables Family Stress & Demands (aA) and Family Resources & Supports (bB) being directly and causally related to Family Adaptation (xX). Support was not found for such a relation with Family Perceptions (cC) in this model.

A mediating version of the model examined whether family perceptions had an indirect effect on family adaptation by influencing the relationships between (a) levels of stress and demands, and (b) levels of family resources and supports, on family adaptation. Although increased levels of family resources and supports, were causally related to increased positive family perceptions in this model, the lack of significant causality from family perceptions to family adaptation, discounted the model as statistically or conceptually plausible. Another mediating version tested, examined (a) family resources and supports, and (b) family perceptions as mediators of the relationship between levels of family stress and demands, and levels of family adaptation. Although family resources and stress, but not family perceptions, could be accounted as a partial mediator of this relationship, the conceptualisation of this model was implausible since causality could not be assumed using a dataset from a
single time-point. Besides, even if causality could be assumed, this conceptualisation was statistically inferior and less parsimonious than the additive conceptualisation of the model.

In a similar way, the moderating version of the model generated some evidence for levels of family stress and demands combined with levels of family resources and supports, causally determining family adaptation. That is, fewer caregiving demands and higher levels of resources and supports led to more positive family adaptation. Conversely, a moderating effect of family caregiving demands combined with parental perceptions, on family adaptation, was not evident. The moderating version of the Double ABCX model was statistically inferior, and less plausible than, the direct, additive version of it.

An interesting finding from Study 2 was the consistent, non-significant role of the latent variable, Family Perceptions (cC), in explaining variations in family adaptation, in all conceptual versions of the model that were tested.

**Key Contributions and Implications of this Research for the Field of Family Adaptation and Developmental Disability**

This research provides several contributions to the body of scientific knowledge in the field of family adaptation and developmental disability. It has extended knowledge of the impact of behavioural family intervention on family variables that are associated with family adaptation. It has devised a consolidated conceptualisation and operationalisation of the Double ABCX model; the measurement model developed was derived from its theoretical and empirical basis and can be used in future research such that findings will be comparable. It has provided clarity and evidence that model variables (a) caregiving burden and, (b) family resources/supports, function in an additive and direct manner to influence
family adaptation. It supports previous ambiguous findings relating to how the model variable, parent perceptions, functions in relation to family adaptation. And this research has provided clear empirical support for the development of a family support program with specific targets to facilitate family adaptation. These theoretical and empirical contributions are considered below. Also applications of the findings are considered in relation to informing the development and evaluation of a family support program to facilitate positive family adaptation.

**Theoretical and empirical considerations.** The first key contribution was providing confirming evidence, from Study 1, that family behavioural intervention produces significant positive changes in parenting and child behaviour but not in other non-targeted aspects of family adaptation. Previous research has shown non-significant effects of behavioural family intervention on family variables that are not directly targeted such as parents’ personal and relationship adjustment, resources and stress, family adaptation, and parental sense of competence (Plant & Sanders, 2007; Sofronoff, et al., 2011). This was verified in the current research which demonstrated small to moderate non-significant group effects on these variables. This provided a strong rationale for further exploration into the broader context of family adaptation as an outcome of support programs. It also provided some indication of family variables that are important to consider in a model of family adaptation.

Secondly, this research has contributed significantly to how the Double ABCX model is theoretically conceptualised and operationalised. The development of clear and concise definitions of empirical terms associated with the Double ABCX model of family adaptation meant that 4 latent variables could be operationalised (comprising 9 observed variables measures with reliable instruments) and established through confirmatory factor analysis. This is a significant contribution to the
empirical body of knowledge in the area since latent variables of the Double ABCX model had previously been repeatedly misconceptualised. The model stemmed initially from early theory of individual stress and coping (Lazarus & Folkman, 1984) which highlighted the importance of cognitive resource, such as positive appraisals that individuals make to manage stress, as being a resource that mediates the effects of stress on coping. It was then theoretically influenced by ecological models, family systems theory, and long-standing empirically validated models of family functioning such as the McMasters (Epstein, et al., 2003) and the Circumplex (Olson & Gorall, 2003) models. Subsequently, attempts to empirically validate the Double ABCX model, and its derivate models, have resulted in diversions from the original definitions and theoretical underpinnings. Ill-defined and non-distinct latent variables in previous empirical investigations have resulted. Variations in interpretation, and operationalisation of the model, have traditionally made research results incomparable, and hence inconclusive. The rationale and development for the current measurement model contributes significant clarification around these issues.

The third key contribution of this research also came from Study 2. It verified that the W.A sample of parents of children with disabilities generally report poorer levels of general physical and psychological health, and lower levels of family adaptation, than community-sample families. Significant differences between mean sample scores, and reported community means, on measures of general health (GHQ) and family adaptation (FAD-GF), were detected for the current sample is consistent with past epidemiological research (Korten & Henderson, 2000; Byles, et al., 1988, and Thomlin & Joyce, 2013, respectively) and has been previously reported (Edwards, et al., 2008). Furthermore, the current investigation contributes to research in this field by providing normative data for a number of family measures from a
moderate-large sample of mothers with children who have a developmental disability. These include the GHQ-12, the FAD-GF, the PHS, and the PCS. Subscale and item-data from a number of measures from the measurement model can also be used to develop a screening device to detect families that may benefit from a family support program that facilitates positive family adaptation.

Study 2 also demonstrated confirming evidence that specific family variables have direct and additive predictive influences on how families adapt to the caregiving burden of raising a child with a disability. These direct and additive influences bring together a large and disperse body of literature, into an empirically supported conceptualisation of family adaptation. Specifically, it verified that family variables related to (a) family caregiving burden, and (b) family resources and stress, have significant, causal effects on family adaptation, and are therefore important targets for family intervention. It also clarified the correlational, but not causal, nature of the relationship between family perceptions with family adaptation. These main theoretical and empirical contributions and their implications are expanded below in the context of consolidating previous research.

**Family caregiving burden.** Family caregiving burden, in terms of practical demands or daily hassles, psychological and health burdens, and impacts on the family unit, have been demonstrated in this research to have a negative impact on how a family adapts over time. This is consistent with decades of individual studies that have reported on particular caregiving burdens. These have included family variables such as parent stress (Beckman, 1983; Crnic, et al., 1983; Haveman, et al., 1997; Wang, et al., 2004), financial burden (Emerson, 2003), severity of disability and related daily hassles (Coplan, et al., 2003; Davis & Gavidia-Payne, 2009), activities of daily life (self care, social interactions, learning, and behavioural/emotional problems),
educational/therapy services, consultations, advocacy, home programs, pain management and prognosis concerns (Plant & Sanders, 2007). Dealing with behavioural concerns and parenting (Plant & Sanders, 2007), and sibling maladjustment (Crnic & Leconte, 1986; Dyson, 1999; Giallo & Gavidia-Payne, 2006) have also been reported to be sources of family caregiving burden. Psychological and other family burdens have been found to include the experience of recurrent grief (Bruce & Schultz, 2001), parental pessimism (Dyson, 1993), excessive self-blame or guilt (Nixon 1993; Seligman, 1997), marital tension and self care capacity (Nixon & Singer, 1993), higher levels of stress/depression/anxiety than others (Gerstein, et al., 2009; Oelofson & Richardson), parent physical health problems such as migraine and pain (Murphy, et al., 2007), potential marital tension (Risdal & Singer, 2004), impacts on family functioning (Rutter, et al., 1994), and family/social isolation (Llewellyn & Gustavsson, 2010).

The current analysis confirmed many of these aspects of family caregiving have a direct negative effect on family adaptation. Caregiving burden was assessed in terms of child/parent/family factors with the PHS which incorporates ratings of child behaviour/needs; parent needs/characteristics; and education and child development. The current analysis also confirmed that family burdens unrelated to caregiving are associated with family adaptation to developmental disability, as proposed in the Double ABCX model. Parents’ burdens from general life experiences, as measured by the LDI were also found to be causally related to family adaptation. These included areas of social functioning, life satisfaction, finances and employment, and marital distress.

**Family resources and supports.** This research has also confirmed the predictive, additive, and causal impact of specific risk factors for poor family
adaptation. Family resources measured with the FRS in the current study were verified as a significant risk factor for family adaptation. This was consistent with reports from Dunst, Trivette, and Deal (1988; 1994). Resources that pose specific risk when low, included basic provisions (e.g., food, home, amenities, clothes), time resources (e.g., quality time, social time, alone time, partner time), money resources (e.g., bills, necessities, equipment, entertainment), and child-related resources (e.g., child-care, specialised equipment, toys).

Other family resources identified in the literature that were also found here to be directly related to family adaptation were those measured by the FSS. Important family supports included in/formal kinships, immediate family, and specialised and generic professional services. Interestingly, in the current analysis, *social organisations* were not found to be correlated well with other resources, or family adaptation. This was consistent with past research findings that have suggested social support was related negatively to caregiver burden but had no causal relationship with family adaptation (Lavee et al., 1985).

Family system resources, as measured by the FHI were also found to be related to family adaptation in a positive way. The more resources and stress-resistance a family had to cope with caregiving burden, the better family adaptation was likely. Previous research has identified self efficacy (Sanders & Wooley, 2005), family problem solving ability (Katz, 2002), perception of being in control of life (Paczkowski & Baker, 2007), and family belief systems (Hastings & Johnson, 2001; Walsh, 1998; 2003a), as potential resources for families. This analysis concurred that resiliency from the impact of disability is directly related to family adaptation in terms of measures of co-oriented commitment (family dependability and ability to work together), confidence (that problems will be solved with effort and endurance),
challenge (approaching new challenges with enthusiasm), and control (family sense of making own decisions and life not being determined by outside circumstances).

**Family perceptions and coping.** This research has provided a fundamental contribution to the scientific understanding of the relationship between family perceptions and family adaptation. The measurement model in the current analysis revealed positive and significant correlations between the two latent variables when ‘family perceptions’ consisted of an appraisal of positive contributions to family, capacity to reframe problems positively, and inclination to seek religious/spiritual advice. However, SEM demonstrated that in a broad context of family variables causally impacting on family adaptation, parental perceptions of this nature do not significantly contribute causally to how families adapt.

Positive and significant correlations (but not causal relations) in the current analysis were consistent with original and subsequent studies in the area (Behr, 1990; Hastings et al., 2002). Aspects of parental perceptions examined here included those relating to nine subtests of the PCS. These were: learning through experience; happiness and fulfilment; strength of family closeness; understanding of life’s purpose; awareness about future issues; personal growth and maturity; expanded social networks; career/job growth; and pride and cooperation. Behr (1990) found correlations between active approaches to coping and positive changes in all life domains, including perceptions of positive contributions from having a child with a disability. Behr, et al. (1992) found a significant correlation between the PCS and a measure of family satisfaction as part of their construct validation procedure. Families who reported higher levels of perceived positive contribution to family life from their child also reported higher levels of satisfaction with their level of family functioning ($r = 0.3$). Positive contributions (using the PCS) have also been shown to
correlate with parents’ capacity for positive reframing coping strategies, positive affect (Hastings, et al., 2005) and to predict scores on the FHI (Hastings & Taunt, 2002). Coping strategies (measured by the F-COPE), especially cognitive reframing have also been shown to be significant independent predictors of parents’ positive perceptions about the impact of caregiving burden (Hastings, et al., 2002). Hastings and Taunt (2002) have theoretically described positive contributions as a family resource variable.

It seems that if parent perceptions are conceptualised as family system resources (Factor bB), direct causal (Lavee, et al., 1985; 1998) and mediating (Salovitta, et al., 2003) influences on family adaptation can be observed. When Manning et al. (2011) conceptualised coping as a combined (bB) and (cC) variable in the model, using the same measure as here (FCOPE), they also found it could partially predict family adaptation.

Although correlated significantly, the lack of causality of Family Perceptions (cC), as a latent variable in the model, has here been replicated (Benzar, 2009; Bristol, 1987; Orr, 1991). This pinpoints an area for further research since without directionality of the relation between family perceptions and adaptation confirmed, all that can be said is that parent perceptions and family adaptation are correlated. Their uni-, bi-directional, or transactional relation is undetermined and in need of further exploration.

An interesting finding in the current research was that passive appraisals made by parents (such as, “we face problems by... watching tv, waiting for luck, knowing we can’t solve things well, or waiting for it to go away”) made only a small loading on the latent variable of Family Perceptions (cC), as predicted. Hence it was dropped from the measurement model. Yet, McCubbin, Olsen, and Larson (1981)
reported passive appraisal to be directly and significantly related to family adaptation. Avoidant coping strategies (Stuart & McGrew, 2009) and negative appraisals (Salovitta, et al., 2006) have also been reported to be related to caregiver/marital/family burden. Yet in the current inquiry, the variable did not load onto the latent variable of Family Stress & Demands (aA) either. Coping strategies and appraisal-style may be better conceptualised as an aspect of Family Resources & Supports (bB). Indeed there are similar items included in both the FCOPE (used as a Factor cC measure) and the FHI (used as a Factor bB measure). Further research collapsing the (bB) and (cC) variables and exploring the impact of coping- and appraisal-style as a family resource is warranted.

**Applications to family support programs.** In a clinical sense, the current research project also contributes significantly to the field of family support for parents of children with developmental disabilities. Results provide clear indications of appropriate targets to facilitate not just parenting and child behaviour, but family adaptation in a broader context. The Double ABCX model of family adaptation offers policy developers and service providers a way of viewing family needs holistically and individually. The current research contributes a clear understanding of family variables that contribute to family adaptation. The additive conceptualisation of the Double ABCX model, which was supported through the current analysis, suggests that support services should take a direct and additive approach to both (a) decreasing family caregiving burden and, (b) increasing family resources, supports and stress-resistance (family hardiness). Both aspects of family adaptation contribute to positive family outcomes.

Rather than only targeting child needs or child-related caregiving burdens, support services should take a family-centred approach to identifying all sources of
stress or burden within the family system. From the development of the current measurement model, it was established that both child-related caregiving burden, and the burden of piled-up life events, contribute to how families adapt. Of course, not all families will bear the same burdens. Therefore individual needs-assessment is required. The current research has contributed a clear account of the child and family caregiving burdens that should be assessed and targeted directly when needed. Table 28 outlines potential family caregiving burdens, measures used to identify them, and examples of services that directly target them.

The measurement model developed here also points to how a range of family social and system resources and supports are also directly, causally related to healthy family adaptation to disability. The resources that may be required by a family relate not only to the child with a disability, but to broader ecological, social, and family psychology needs, as well. Providing resources to families builds resilience against poor adaptation and equips a family to manage their own family caregiving burden. The current research has contributed a clear account of family resources and supports that impact directly on healthy family adaptation that can be provided through family support programs. Examples are provided in Table 28.

The current research has already contributed to the development of parent resources on family adaptation that are used as part of a brief, targeted, primary-care treatment within the SSTP system of interventions. The SSTP Booklet Series (Sanders, et al., 2009b) includes A Guide to Family Adaptation, which introduces parents to ideas for improving functioning in a range of family variables. One section, Adapting to Having a Child with a Disability, focuses directly on aspects of family adaptation derived from the current research.
Table 28

*Example Family Caregiving Burdens, Measures Used to Identify Them, and Examples of Support Services that Directly Target Them*

<table>
<thead>
<tr>
<th>Family Variable</th>
<th>Measure Used</th>
<th>Example Inventory Item</th>
<th>Example of Targeted Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family caregiving burden – child related</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child behaviour / needs</td>
<td>PHS</td>
<td>My child seeks constant attention.</td>
<td>• Provide skills development in the area of independent play</td>
</tr>
<tr>
<td>Parent needs / characteristics</td>
<td>PHS</td>
<td>I have no time for myself.</td>
<td>• Offer regular respite</td>
</tr>
<tr>
<td>Education/child development</td>
<td>PHS</td>
<td>My child can’t communicate needs, wants or feelings.</td>
<td>• Introduce an alternative or augmentative communication system</td>
</tr>
<tr>
<td><strong>Family caregiving burden – life-event related</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td>LDI</td>
<td>I am distressed in the area of my social life and recreation/leisure.</td>
<td>• Provide information and support to join relevant support or social groups</td>
</tr>
<tr>
<td>Life satisfaction</td>
<td>LDI</td>
<td>I am distressed in the area of expectations for future.</td>
<td>• Provide collaborative problem solving and goal setting</td>
</tr>
<tr>
<td>Finance and employment</td>
<td>LDI</td>
<td>I am distressed in the area of finance and employment.</td>
<td>• Provide financial counselling and links with employment agencies</td>
</tr>
<tr>
<td>Marital distress</td>
<td>LDI</td>
<td>I am distressed in the area of my relationship with my spouse.</td>
<td>• Provide partner support interventions or relationship counselling</td>
</tr>
<tr>
<td><strong>Family resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child-related resources</td>
<td>FRS</td>
<td>I don’t have adequate resources for specialised equipment.</td>
<td>• Explore sources of public funding for disability equipment</td>
</tr>
<tr>
<td>Basic resources</td>
<td>FRS</td>
<td>I don’t have adequate resources for telephone access or furniture.</td>
<td>• Provide financial counselling</td>
</tr>
<tr>
<td>Time resources</td>
<td>FRS</td>
<td>I don’t have adequate time resources to be with my other children.</td>
<td>• Offer regular out-of-home respite</td>
</tr>
<tr>
<td>Money resources</td>
<td>FRS</td>
<td>I don’t have adequate money to buy food and necessities.</td>
<td>• Link to emergency public assistance services</td>
</tr>
</tbody>
</table>
### Table 28
(Continued)

<table>
<thead>
<tr>
<th>Family Variable</th>
<th>Measure Used</th>
<th>Example Inventory Item</th>
<th>Example of Targeted Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family social supports</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal kinship support</td>
<td>FSS</td>
<td><em>My friends are not at all helpful in raising my child.</em></td>
<td>• Brainstorm which friends may be open to helping, and build assertion skills</td>
</tr>
<tr>
<td>Formal kinship support</td>
<td>FSS</td>
<td><em>My relatives are not at all helpful in raising my child.</em></td>
<td>• Brainstorm which relatives may agree to be more involved, and build assertion skills</td>
</tr>
<tr>
<td>Immediate family support</td>
<td>FSS</td>
<td><em>My spouse is not at all helpful in raising my child.</em></td>
<td>• Offer marital counselling or partner support interventions</td>
</tr>
<tr>
<td>Professional support</td>
<td>FSS</td>
<td><em>My child’s intervention program is not helping.</em></td>
<td>• Review program goals and strategies, and match them to family capacity</td>
</tr>
<tr>
<td><strong>Family system resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family co-oriented commitment</td>
<td>FHI</td>
<td><em>We do not believe that things will work out better if we work together as a family.</em></td>
<td>• Offer family therapy to build positive family relationships and expectations</td>
</tr>
<tr>
<td>Family confidence</td>
<td>FHI</td>
<td><em>It is not wise to plan ahead and hope because things do not turn out anyway.</em></td>
<td>• Build self-confidence by setting small goals and achieving them. Use motivational interviewing techniques.</td>
</tr>
<tr>
<td>Family challenge</td>
<td>FHI</td>
<td><em>We tend to do the same things over and over... it’s boring.</em></td>
<td>• Introduce novel ideas and family activities</td>
</tr>
<tr>
<td>Family control</td>
<td>FHI</td>
<td><em>We realise our lives are controlled by accidents and luck.</em></td>
<td>• Build self-empowerment and facilitate reality-based attributions</td>
</tr>
</tbody>
</table>

**Notes:**
Not all families require all direct interventions, resources, or supports that are available. Every family is individual and their needs are unique. Assessing family adaptation using the outcome measures here may provide adequate screening to detect which families require further assessment to identify sources of poor family adaptation. That is, once screened using the FAD-GF and GHQ-12, latent variable measures used in this inquiry would be a fair way to assess more specific needs in the area of both family caregiving burden (child, parent, and family stressors) and family resources and supports (basic, practical, emotional, family, cognitive/behavioural, and stress-resistance).

**Limitations and Recommendations for Future Evaluation**

The current project highlights the need for ongoing high-quality evaluation of (a) behavioural and family intervention for parents of children with disabilities, (b) the Double ABCX model, especially around the latent variable of parental perceptions, and (c) applied family support programs that target adaptation. Further research and recommendations for improved methodology relating to definitive questions for these three areas are discussed below.

**Does behavioural family intervention effect family adaptation?** Study 1 did not find significant group effects of intervention on a range of non-targeted variables related to family adaptation. Although any effects were expected to be relatively small, compared to that for targeted variables, the non-significant group effects may have been due to small sample sizes and/or normative baseline means on family variable measures. It is important to determine whether interventions that target the broad context of family adaptation are needed to produce positive outcomes for families. If intervention targeting parenting and child behaviour can be demonstrated to facilitate family adaptation, then multi-targeted interventions may not
only be not needed, but may not be parsimonious or cost-effective. Therefore, continued high-quality evaluation of behavioural family intervention, using samples with non-normative baseline means on measures of family adaptation, is needed.

**Can mediating or moderating influences in the Double ABCX model be determined?** Further research into the Double ABCX model should take account of limitations aforementioned, including the use of a more normative socio-economic status-stratified sample. Also further research is needed to investigate the viability of mediating or moderating influences of family variables on family adaptation.

Study 2 supported the model in that Factor (aA) and Factor (bB) were shown to have additive and direct causal influences on Factor (xX). Although the current analysis did support Factor (bB), but not Factor (cC), as a partial mediator of the relationship between (aA) and (xX), the statistical model was implausible. The implausibility arose from analysing data from just one point in time. Consequently further evaluation is needed where proposed mediators are identified a priori and repeatedly measured at 2+ time points are taken. Latent variables would be considered mediators of family adaptation if it could be shown longitudinally that they change over time, and also predict change in the endogenous variable (Factor xX). Taking a longitudinal approach to validating the Double ABCX model is recommended. In addition, holding the current measurement model constant in further evaluations would increase comparability between results.

Another limitation of Study 2 was the use of maternal responses to questionnaires only as the unit of analysis. As demonstrated by Pozo (2014), family adaptation modelling yields different results when measures are taken from both maternal and paternal caregivers. Taking a more eco-social transactional family perspective, including observations of family level processes such as family routines
and interactions, would account for potential reporting bias from only one family member. The use of mixed assessment methods that define an ecological unit of analysis integrating (a) child behaviour, (b) parent-child interaction; and family activity settings (routines) and utilises multiple baseline design (Binnendyk, 2009; Lucyshyn, et al., 2014) is recommended.

Study 2 rejected the Double ABCX moderating model. However, the analysis did produce a pathway from the (aA x bB) interaction term to Factor (xX) that was significant at $p < .05$, suggesting some level of moderating effects. It was dismissed since the predictor (Factor aA) and the moderator (Factor bB) were highly correlated and this meant that the apparent interaction may only be a non-linear effect of (aA). Consequently, further evaluation to check for moderating variables is needed. This would need to address the problem of correlating latent variables. One potential way to operationalise such, would be to take independent, blind, observational measures of outcome variables.

Another area in need of further investigation is the conceptualisation of Factor (cC). Operationalised as parental perceptions of positive contributions and family coping styles, the Factor did not have significant causal influences on how families adapt in Study 2. Yet, family stress-resistance as measured by the FHI was found to play an important role in determining family adaptation. It may be that active and problem-focused cognitive appraisals and coping strategies are better conceptualised as a Factor (bB) variable—family resources. Previous research (Saloviita et al., 2006) suggests that passive cognitive appraisals contribute to parents’ experience of burden. Perhaps such cognitive passivity would load more appropriately on a Factor (aA) latent variable. If this was the case, then Factor (cC) of the model could be dispersed and the model would more closely resemble Lazarus and Folkman’s
original model of stress and coping. Such an evaluation would need to redefine the measurement model but should retain the same high quality measures used here.

**Does family support, targeting family adaptation to disability, improve family and child outcomes?** The current research highlights the direct and additive influence of (a) family caregiving burden, and (b) family resources and supports, on family adaptation. As mentioned above, key elements from these findings have been incorporated into SSTP resources. Research is needed to explore acceptability and effectiveness of this specific resource and its associated brief, targeted intervention.

There is some evidence that positive effects of behavioural family intervention may be maintained better, when adjunctive modules of intervention targeting family variables such as parent stress management and partner support, are provided (Plant & Sanders, 2007b). If this is the case, then an adjunctive intervention module specifically targeting indicated aspects of family adaptation is also needed. Related research directions include (a) the development of such a module that aims to decrease family caregiving burden, and increase family resources, supports and hardiness, and (b) evaluating its clinical efficacy, effectiveness, and cost-benefit.

**Summary and Conclusion**

This inquiry addressed questions initially raised in the context of two contrasting families who had responded differently to the experience of raising a child with a developmental disability. The Ross family were burdened by their child’s behaviour problems, education program expectations, maternal mental health issues, and a lack of partner support. They also lacked resources such as coping ability, effective practical/emotional supports, and a lack of family hardiness or stress-resistance. The Black family, on the other hand, were well adapted even though they had a child with complex care needs. They had adequate practical and emotional
resources and supports, a resilient outlook, and clear roles within the family. The questions were: *What aspects of their experience contribute to how they adapt over time?* And *what aspects of family life would be appropriate targets for intervention?*

The inquiry demonstrated that a behavioural family intervention impacted families positively and significantly with regard to targeted variables of child behaviour and parenting style, but did not impact significantly on measures of other family variables including family adaptation. With this as a rationale to further explore family adaptation, *SEM* was used to evaluate the Double ABCX model (McCubbin & Patterson, 1983), which suggests that the level of positive Family Adaptation (xX) is determined by influences from Family Stress & Demands (aA), Family Resources & Supports (bB), and Family Perceptions (cC). Four theoretically-driven interpretations of this model were tested, revealing support for direct, additive, causal effects from Factor (aA) and Factor (bB) on Factor (xX) and no significant influence from Factor (cC) on Factor (xX). Despite methodological limitations that call for longitudinal data and mixed methods to test models further, it can be concluded that support programs for families of children with developmental disabilities should assess and aim to decrease family caregiving burden as well as to increase family supports, resources and hardiness.

For the Ross family, this inquiry suggests that family adaptation over time was likely to be influenced by their present and past family caregiving burden, their lack of emotional and practical supports, and their lack of family hardiness and ability to work together. A support program targeting only child behaviour or parenting skills would be unlikely to make significant improvement in family adaptation overall. A support program that did that, as well as provided assessment, referral and/or intervention for indicated burdens and required resources would be appropriate.
References


Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with


Trivette, & A. Deal (Eds.), *Enabling and empowering families. Principles and

with young children. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.),
*Supporting and strengthening families* (pp. 105-114). Cambridge: Brookline
Books.

Dunst, C. J., & Trivette, C. M. (1994). Aims and principles of family support
programs. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting and

support: Personal, family, and child outcomes. *American Journal of Mental
Deficiency, 90,* 403-417.

families. Principles and guidelines for practice.* Cambridge, MA: Brookline
Books.

intervention practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.),
*Supporting & strengthening families. Methods, strategies and practices* (140 –

families with young children with disabilities. In C. J. Dunst, C. M. Trivette,
& A. G. Deal (Eds.), *Supporting and strengthening families: Methods,


University of New South Wales and Centre for Developmental Psychiatry, Monash University.


disabilities. Paper presented at the 121st Annual Meeting of the American
Association on Mental Retardation, New York.
children with disabilities: associations with daily hassles and problem-focused
course of daily parenting stress in families of young children with intellectual
disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997. doi:
10.1111/j.1365-2788.2009.01220.x
for adjustment for siblings of children with a disability. *Journal of Intellectual
Disability Research, 50*(12), 937-945. doi: 10.1111/j1365-2788.2006.00928.x
Austin, TX: Pro-Ed Inc.
in mothers rearing children with intellectual disabilities. *Journal of
Intellectual Disability Research, 47*(4/5), 250-263.
Glidden, L. M., Billings, F. J., & Jobe, B. M. (2006). Personality, coping style and
well-being of parents rearing children with developmental disabilities.
*Journal of Intellectual Disability Research, 50*(12), 949-962.
doi:10.1111/j.1365-2788.2006.00929.x
Goldberg, D., Gater, R., Sartorious, N., Ustun, T., Piccinelli, M., Gureje, O., & Rutter,
C. (1997). The validity of two versions of the GHQ in the QHO study of
mental illness in general health care. *Psychological Medicine, 27,* 191-197.


Green, S. E. (2007). We’re tired, not sad: benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64* (1), 150-163.


*Psychosomatic Medicine, 55*, 234-247.


doi:10.1177/1066480708317503


Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families, health and illness: perspectives on coping and intervention* (pp. 21-63). St Louis, MO: Mosby.


empowerment: active coping skills and strategies for intervention (pp. 175-201). Baltimore, MD: Paul H. Brookes.


Persons with Severe Disabilities, 29(2), 95-103. doi:
https://dx.doi.org/10.2511/rpsd.29.2.95

Rivero, N., Martinez-Pampliega, A., & Olson, D. O. (2010). Spanish adaptation of the
FACES IV questionnaire: Psychometric characteristics. The Family Journal:
Counseling and Therapy for Couples and Families, 18, 288-296.
doi:10.1177/1066480710372084

family intervention for children with developmental disability and behaviour

children with developmental and medical conditions. Children and Youth


Saloviita, T., Itäläinna, M., & Leinonen, E. (2003). Explaining the parental stress of
fathers and mothers caring for a child with intellectual disability: a Double

validated multilevel parenting and family support strategy for the prevention
of behavior and emotional problems in children. Clinical Child and Family
Psychology Review, 2, 71-90.

Sanders, M. R. (2012). Development, evaluation, and multinational dissemination of
the Triple P – Positive Parenting Program. Annual Review of Clinical


Sanders, M. R., Mazzucchelli, T. G., & Studman, L. J. (2009g). Primary Care Stepping Stones Triple P session presentations [CD]. Brisbane, Australia: Triple P International Pty. Ltd.


predictors of strength of alliance and impact of alliance on outcome. *Brain Injury, 21*(7), 663-672.


Zarit, S. & Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired


Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.
Appendix A

Study 1. Parent Information and Consent Form

STEPPING STONES:
Positive Parenting Program

Parent Information Form

Dear Parent/Guardian,

Stepping Stones is a new program aimed at providing early intervention services to families of young children with developmental disabilities who are displaying behavioural problems. It offers a family focused approach to promoting the development of children with disabilities, and enhancing positive relationships amongst family members. The program provides step by step assistance for changing difficult behaviour in children.

The Stepping Stones program is being trialed by Disability Services Commission in their North Metropolitan Region. The trial involves collaboration between the Disability Services Commission, Curtin University of Technology's School of Psychology and the University of Queensland's Department of Psychology. Two specialist psychologists, Trevor Mazzucchelli and Lisa Studman will work with families using a positive parenting program that is designed to decrease child behaviour problems, increase children's abilities to interact positively with others, and reduce family stress levels.

The program involves twelve weeks of intensive intervention with families working on their individual goals for their children. The intervention sessions will involve home visits, sessions at the Disability Services Commission regional office and phone contact to support parents. As part of an evaluation of the Stepping Stones program parents will be asked to participate in a detailed assessment phase, before and after the intervention. The evaluation will be conducted independently by psychologists from Curtin University of Technology and families will be followed up for two years after the completion of the program, to assess the long term usefulness of the program to families of children with developmental disabilities.

The assessment process will involve parents completing a number of questionnaires relating to their child's behaviour, parenting and family coping. These questionnaires take approximately 90 minutes to complete and can be completed at a time convenient to the family with the assistance of a trained interviewer. Also, in order to target the intervention program at the needs of the individual family, the researchers will observe parents interacting with their children at home for four 20 minute sessions. These observations will be completed before and after the intervention and at two points in the two years following the completion of the program.

Families of children with developmental disabilities aged between 2 and 6 years are eligible for the program, if they are experiencing current difficulties with their child behaviour. Families referred to the program will have a 50% chance of receiving the program immediately, and a 50% chance of being waitlisted to receive the program.
Families who are waitlisted will participate in the assessment procedures and will receive the program approximately 4 months after their referral.

In order to contact families during the follow up period we have asked you to supply your address and phone number on the consent form attached. We have also asked you to supply the names, addresses and contact numbers for two friends or relatives that could be contacted in case you move. This information will be strictly confidential and will be used solely to help find you should you move during the follow up stage of this program. The addresses and phone numbers will not be released without your permission. Assessment results will under no circumstances be released to the friends or relatives that you nominate.

To give your consent to participate in the Stepping Stones research project, please complete and return the attached consent and referral form to Curtin University of Technology in the pre-paid envelope supplied. A staff member from the Stepping Stones research team will contact you on receipt of the consent form and make an appointment to begin the assessment process.

All assessment details will be completely confidential. They will be used only to assist in planning the appropriate intervention to meet your families needs, and to evaluate the effectiveness of the program. Individual answer sheets will be scored separately from the identifying information and no individual results will be released without your permission. You and your family may withdraw from the intervention or research program at any time without affecting your regular early intervention services received from the Disability Services Commission or other agencies. However, we encourage families to stay with us for the follow up phase.

This project has received the approval of the Curtin University Human Ethics Committee. Should you have any questions about the Stepping Stones research project please contact Dr Clare Roberts at the School of Psychology, Curtin University of Technology on (09) 351-7992. If you have any questions about the Stepping Stones intervention please phone Trevor Mazzuchelli or Lisa Studman at Disability Services Commission - North Metropolitan Region, 271-7800.

Dr Clare Roberts  Mr Trevor Mazzuchelli  Ms Lisa Studman
Curtin University of Technology
SCHOOL OF PSYCHOLOGY
STEPPING STONES:
Positive Parenting Program

PARENT/GUARDIAN CONSENT

I / WE ☐

do / do not consent to participate in the Stepping Stones: Positive Parenting Program and associated research project.

• I have received and completed the Stepping Stones Referral Form.

• The nature, purpose, procedures and effects of this program and its associated research project have been explained to me.

• I have been provided with an information sheet.

• I understand that my family can withdraw from the Stepping Stones project at any time without affecting the regular early intervention services that I receive from the Disability Services Commission or other agencies.

Parents(s) Names ___________________________ ___________________________
Parent(s) Signature ___________________________ ___________________________
Date ___________________________ ___________________________
Stepping Stones ___________________________
Staff Signature ___________________________
Date ___________________________
Appendix B

Study 2. Assessment Booklet

Family Adaptation Survey
1. THE FAMILY BACKGROUND QUESTIONNAIRE

This questionnaire collects general information about your child who has a disability and your family. Please complete as much as you can. If you have more than one child between 2 and 12 years old who has a disability please phone 9329 2347 and leave a message for another booklet to be sent to you.

Your child's name: ____________________________

Relationship to child: [ ] Mother [ ] Step mother [ ] Foster mother [ ] Father [ ] Step father [ ] Foster father [ ] Other (specify) [ ]

Address: ___________________________________

Telephone: ______________________

Today's Date: ______________________

Questions about your child who has a disability:

1. Gender: [ ] Male [ ] Female

2. Age: ______ years

3. Date of Birth: __________/________/________

4. Type of Disability(ies); (tick all relevant boxes)
   - Cognitive/Learning
     - Acquired brain injury
     - Specific Learning Disability (inc ADHD)
   - Intellectual
     - Autism / PDD (inc Aspergers)
     - Developmental Delay (0-5 yrs only)
     - Intellectual disability (inc Downs Syndrome)
     - Level of intellectual disability if known [ ] Mild [ ] moderate [ ] Severe/profound
   - Neurological
     - Multiple Sclerosis
     - Other neurological (specify) [ ]
   - Physical
     - Cerebral Palsy
     - Motor Neurone Disease
     - Muscular Dystrophy
     - Para/quadricep (tetra)/hemiplegia
     - Spina Bifida
     - Other physical (specify) [ ]
   - Psychiatric Disability [ ]
   - Sensory
     - Blind/Vision Impairment
     - Deaf/Hearing Impairment
     - Other (specify) [ ]

5. Does your child have any health Problems: [ ] no [ ] yes Please give diagnosis: ________________________________

6. How many brothers and sisters does your child have living at home? [ ]
Questions about your family in general:

1. Which best describes your type of family? (please tick one):
   - Sole parent family
   - Original family (both biological/adoptive parents)
   - Step family (two parents, one being a step-parent)
   - Other: 

2. What is your current marital status:
   - Married
   - Separated
   - De facto
   - Never married/defacto
   - Divorced
   - Widowed

3. What is your highest level of education?
   - Trade / Apprenticeship
   - TAFE / College
   - University
   - Degree(s)
   - Less than yr 10
   - Year 10/11
   - Year 12

4. What is your partner’s highest level of education? (if present)
   - Trade / Apprenticeship
   - TAFE / College
   - University
   - Degree(s)
   - Less than yr 10
   - Year 10/11
   - Year 12

5. Are you (and/or your partner) currently in paid employment?
   - YOU
     - No
     - Part time
     - Full time
   - YOUR PARTNER
     - No
     - Part time
     - Full time

6. In what range is your estimated TOTAL FAMILY INCOME before tax (including Govt Allowances)?
   - Up to $154 per week (up to $8,000 per year)
   - $155 - $385 per week ($8,001 to $20,000 per year)
   - $386 - $673 per week ($20,001 - $35,000 per year)
   - $674 - $961 per week ($35,001 - $50,000 per year)
   - $962 - $1,346 per week ($50,001 - $70,000 per year)
   - $1,346 or more per week (more than $70,000 per year)
   - Don’t know
## 2. Parenting Hassles Scale

Parenting often involves hassles. Hassles are irritants that range from minor annoyances to major pressures, problems or difficulties. They can occur few or many times.

Please circle how each hassle below makes you feel using the scale from 1-5. If it does not occur, circle 1 for No Hassle.

### How Hassled Does This Make You Feel?

<table>
<thead>
<tr>
<th>Hassle</th>
<th>No Hassle</th>
<th>Minor Hassle</th>
<th>Moderate Hassle</th>
<th>Severe Hassle</th>
<th>Major Hassle</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child seeks constant attention</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child wanders away</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child needs constant monitoring, doesn't understand danger</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is a physical threat to others (intentionally or unintentionally)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is destructive, or messes things up</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have to pick up after my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is uncooperative or stubborn</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child doesn't obey me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child throws tantrums or cries</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child fights, hits, or bites others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child hits or bites self</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child gets easily frustrated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is immature, can't get along with other children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child has few playmates</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child has few social skills, like listening, sharing, taking turns</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is very active, can't be still</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child dislikes home therapies, child cries or resists</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is impulsive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child doesn't listen or pay attention for very long</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have problems getting my child to bed or sleep</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child has sleep problems, wakes up often</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child whines or nags</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is very demanding</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Everything with my child takes extra time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child cannot walk, or walk well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child is too dependent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child requires help to move or retrieve things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have to carry my child from place to place</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My child requires additional or special techniques for discipline</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Adaptive/medical equipment is hard to carry or to get into the car</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>It is difficult to find the right adaptive or medical equipment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Some buildings are inaccessible to my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>It is difficult to maintain my child's adaptive or medical equipment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>No Hassle</td>
<td>Minor Hassle</td>
<td>Moderate Hassle</td>
<td>Severe Hassle</td>
<td>Major Hassle</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>--------------</td>
<td>----------------</td>
<td>--------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>34 My child is a picky eater or refuses to eat</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>35 My child is a messy eater</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>36 My child has food allergies</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>37 My child has other feeding or eating problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>38 My child is not toilet trained, wets pants</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>39 My child needs extra help in toilet training</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>40 I have to change my child's nappies</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>41 I have to deal with constipation or other bowel problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>42 I have to deal with catheterization</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>43 I'm not sure how to best discipline my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>44 I have no time for myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>45 It is difficult to take a vacation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>46 I don't have time for my spouse or others in my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>47 I have to deal with my spouse's needs or feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>48 I feel guilty about not having more time to spend with child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>49 I feel sadness about my child's disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>50 I think about what I could have done differently</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>51 I worry about doing something wrong</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>52 I feel responsible for my child's disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>53 I worry about my child's future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>54 I have a hard time managing my responsibilities to my work and to my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>55 I can't seem to get everything done</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>56 I can't get enough sleep</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>57 It is hard to find child care I can trust and afford</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>58 It is difficult to run errands</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>59 I can't find time to do therapy activities at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>60 I don't have time to just play or relax with my children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>61 My child is slow to learn, makes slow progress</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>62 My child can't communicate needs, wants or feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>63 My child can't understand me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>64 I can't communicate with my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>65 My child takes medication</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>66 My child has health issues (ear infections, congestion, oxygen)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>67 My child has a complicated medication schedule</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>68 My children argue or fight with each other</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>69 My other children are jealous of their sibling with a disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>70 I must balance time with my other children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>71 The paperwork is difficult to understand or to organize</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>72 It is hard to find good services for my child (PT, OT, Speech)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>73 I have to schedule and keep up with my child's appointments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>74 I have to take my child to programs and therapies</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>75 I have to find transportation for my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Source: Reprinted with permission from Susanne Gavida-Payne, Royal Melbourne Institute of Technology
3. LIFE DISTRESS INVENTORY

Everyone feels distress about some areas in their life. The following questions will estimate your level of distress. Think about how you currently feel about the following 18 areas of your life.

Circle how distressed you currently feel about each area using the scale from 1-7.

<table>
<thead>
<tr>
<th>HOW DISTRESSED ARE YOU CURRENTLY IN THIS AREA?</th>
<th>Most distressed I've ever felt</th>
<th>Extremely distressed</th>
<th>Very distressed</th>
<th>Moderately distressed</th>
<th>Some-what distressed</th>
<th>Very little distressed</th>
<th>No Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Marriage</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2 Sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3 Relationship to spouse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4 Relationship to children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5 Relationship to relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6 Household management</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7 Financial situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8 Employment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9 Education</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10 Recreation/leisure</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11 Social life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>12 Religion</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>13 Management of time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>14 Physical health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>15 Personal independence</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>16 Role of alcohol in home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>17 Satisfaction with life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>18 Expectations for future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>


How distressed did you get when you first knew about your child's disability |
1 | 2 | 3 | 4 | 5 | 6 | 7 |

How distressed do you get now when you think about your child having a disability |
1 | 2 | 3 | 4 | 5 | 6 | 7 |
4. FAMILY RESOURCES SCALE

This scale is designed to assess whether or not you and your family have adequate resources (time, money, energy, and so on) to meet the needs of the family as a whole as well as the needs of individual family members.

Circle the response that best describes *how well the need is met on a consistent basis* in your family.

<table>
<thead>
<tr>
<th>Resource Description</th>
<th>Does Not Apply</th>
<th>Not at all Adequate</th>
<th>Seldom Adequate</th>
<th>Sometimes Adequate</th>
<th>Usually Adequate</th>
<th>Almost Always Adequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Food for 2 meals a day</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. House or apartment</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Money to buy necessities</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Enough clothes for your family</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Heat for your house or apartment</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Indoor plumbing / water</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Money to pay monthly bills</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Good job for yourself or spouse/partner</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Medical care for your family</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Public assistance (Medicare, Family Payment)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Dependable transportation (own/others car)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Time to get enough sleep / rest</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Furniture for your home or apartment</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Time to be by yourself</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Time for family to be together</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Time to be with your child(ren)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Time to be with spouse or partner</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Time to be with close friend(s)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Telephone or access to a phone</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Babysitting for your child(ren)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. Child care/ day care for you child(ren)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Money to buy special equipment/supplies for child(ren)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. Dental care for your family</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. Someone to talk to</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Time to socialise</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Time to keep in shape and look nice</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. Toys for your child(ren)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. Money to buy things for yourself</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. Money for family entertainment</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. Money to save</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31. Time and money for travel / vacations</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

5. FAMILY SUPPORT SCALE

Listed below are people and groups that often are helpful to members of a family when raising a child who has a disability. The questionnaire asks you how helpful each person or group has been to your family.

Circle the response that best describes **how helpful each one has been to your family in the past 3 – 6 months.** If one or more have not been available to our family during this time, circle the NA (Not Application) response.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Does Not Apply</th>
<th>Not at all Adequate</th>
<th>Seldom Adequate</th>
<th>Sometimes Adequate</th>
<th>Usually Adequate</th>
<th>Almost Always Adequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My parents</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2</td>
<td>My Spouse or partner's parents</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>My relatives / kin</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>My spouse or partner's relative / kin</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>Spouse or partner</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>My friends</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>My spouse or partners friends</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>My own children</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td>Other parents</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>Co-workers</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11</td>
<td>Parent groups</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>Social groups / clubs</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13</td>
<td>Church members / minister</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14</td>
<td>My family or child's physician</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>Early childhood intervention program</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>School / day-care centre</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17</td>
<td>Professional helpers (social worker, therapist, teachers, etc)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18</td>
<td>Professional agencies (public health, social services, mental health, etc)</td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19</td>
<td></td>
<td>N/A</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### 6. FAMILY HARDINESS INDEX

This scale asks questions about how resistant your family is to the stress and demands of everyday life. It looks at your family's sense of control over the outcomes of life events and hardships.

Read each statement below and circle the response that describes *how true you feel each statement below is* for your family.

<table>
<thead>
<tr>
<th>IN OUR FAMILY...</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Trouble results from mistakes we make</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 It is not wise to plan ahead and hope because things do not turn out anyway</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Our work and efforts are not appreciated no matter how hard we try and work</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 In the long run, the bad things that happen to us are balanced by the good things that happen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 We have a sense of being strong even when we face big problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Many times I feel I can trust that even in difficult times things will work out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 While we don’t always agree, we can count on each other to stand by us in times of need</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 We do not feel we can survive if another problem hits us</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 We believe that things will work out for the better if we work together as a family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Life seems dull and meaningless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 We strive together and help each other no matter what</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 When our family plans activities we try new and exciting things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 We listen to each other’s problems, hurts and fears</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 We tend to do the same things over and over...it’s boring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 We seem to encourage each other to try new things and experiences</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 It is better to stay at home than go out and do things with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 Being active and learning new things are encouraged</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 We work together to solve problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 Most of the unhappy things that happen are due to bad luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 We realise our lives are controlled by accidents and luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

# 7. Inventory of Parental Perceptions – Positive Contributions

Many parents with a child who has a disability believe that their child has had a special effect on them and their family. What effect do you believe your child has had on you and other members of your family?

Read the sentences below and think about your child who has a disability. Then circle one response about how much you agree or disagree with each statement.

## MY CHILD IS:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

## I CONSIDER MY CHILD TO BE:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

* Answer items with a star only if your child is 4 years old or more.
### THE PRESENCE OF MY CHILD:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td>Is an inspiration to improve my job skills.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>Helps me understand people who are different.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>*28</td>
<td>Is a source of pride because of his/her athletic achievements.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29</td>
<td>Cheers me up.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30</td>
<td>Confirms my faith in God.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31</td>
<td>Gives a new perspective to my job.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32</td>
<td>Renews my interest in participating in different activities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33</td>
<td>Is very uplifting.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34</td>
<td>Reminds that all children, including those with special needs, need to be loved.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35</td>
<td>Is a reminder that everyone has a purpose in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36</td>
<td>Makes us more in charge of ourselves as a family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37</td>
<td>Helps me take things as they come.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### BECAUSE OF MY CHILD:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>38</td>
<td>My circle of friends has grown larger.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>*39</td>
<td>I have someone who shares responsibility for doing some tasks around the home.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40</td>
<td>My social life has expanded by bringing me into contact with other parents.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>41</td>
<td>I am more compassionate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>42</td>
<td>I learned about intellectual disability.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>43</td>
<td>My family is more understanding about special problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>44</td>
<td>I am grateful for each day.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>45</td>
<td>Our family has become closer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>46</td>
<td>I am more sensitive to family issues.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>47</td>
<td>I have learned to adjust to things I can not change.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>48</td>
<td>My other children have learned to be aware of people's needs and their feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>49</td>
<td>I have many unexpected pleasures.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>50</td>
<td>I am more accepting of things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

* Answer items with a star only if your child is 4 years old or more.
### 8. FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES

This scale asks questions about attitudes to problem-solving and how families behave in response to problems or difficulties.

Circle the response that describes *how much you agree or disagree with each statement below.*

<table>
<thead>
<tr>
<th>WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY...</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Knowing we have the power to solve major problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2 Knowing that we have the strength within our own family to solve our problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3 Facing the problems 'head-on' and trying to get solution right away.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4 WATCHING television.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5 Showing that we are strong.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6 Attending church services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7 Accepting stressful events as a fact of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8 Knowing luck plays a big part in how well we are able to solve family problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9 Accepting that difficulties occur unexpectedly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10 Believing we can handle our own problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11 Participating in church services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12 Defining the family problem in a more positive way so that we do not become too discouraged.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13 Feeling that no matter what we do to prepare, we will have difficulty handling problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14 Seeking advice from a minister.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15 Believing if we wait long enough, the problem will go away.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16 Having faith in God.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

9. GENERAL HEALTH QUESTIONNAIRE

We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by circling the answer which you think most nearly applies to you. Remember that we want to know about the present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

<table>
<thead>
<tr>
<th>HAVE YOU RECENTLY:</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Been able to concentrate on whatever you're doing?</td>
<td>Better than usual</td>
<td>Same as usual</td>
<td>Less than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>2. Lost much sleep over worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>3. Felt that you are playing a useful part in things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less useful than usual</td>
<td>Much less useful</td>
</tr>
<tr>
<td>4. Felt capable of making decisions about things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less useful than usual</td>
<td>Much less capable</td>
</tr>
<tr>
<td>5. Felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>6. Felt you couldn’t overcome your difficulties?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>7. Been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>8. Been able to face up to your problems?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less able than usual</td>
<td>Much less able</td>
</tr>
<tr>
<td>9. Been feeling unhappy and depressed?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>10. Been losing confidence in yourself?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>11. Been thinking of yourself as a worthless person?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>12. Been feeling reasonably happy, all things considered?</td>
<td>More so than usual</td>
<td>About the same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
</tbody>
</table>
10. FAMILY ASSESSMENT DEVICE – GENERAL FUNCTIONING

These items ask you to think carefully about your family as a whole. Read each statement and decide how well it describes your own family. Circle how much you agree or disagree with each statement about your family.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Planning family activities is difficult because we misunderstand each other.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>In times of crisis we can turn to each other for support.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>We cannot talk to each other about the sadness we feel.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Individuals (in the family) are accepted for what they are.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>We avoid discussing our fears and concerns.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>We express our feelings to each other.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>There are lots of bad feelings in our family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>We feel accepted for what we are.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Making decisions is a problem for our family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>We are able to make decisions about how to solve problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>We don't get along well together.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>We confide in each other.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>


WE APPRECIATE HOW MUCH TIME AND EFFORT YOU HAVE TAKEN TO COMPLETE THIS QUESTIONNAIRE. YOUR INFORMATION WILL ASSIST IN OUR UNDERSTANDING OF THE NEEDS OF FAMILIES WITH CHILDREN WHO HAVE A DISABILITY. BY RETURNING THIS COMPLETED BOOKLET YOU ARE CONSENTING TO HAVE YOUR INFORMATION INCLUDED.

THANK YOU.
Appendix C

Study 2. Pilot Test and Outcomes

Family Adaptation Survey
Have your say about it...

Dear

You may have heard that a wide-scale survey of families of children who receive services from the Disability Services Commission will commence in August/September, 2003. Before this happens, we need to find out whether families are likely to complete surveys and how we can make it a 'family-friendly' as possible. We want to ask you to complete the survey and then let us know how it could be improved. It is very important that we conduct the survey so that we can understand better how families adapt to having a child with a disability and how we can help support them.

What's the survey about?
It's about how families adapt to having a child with a disability. Research in other countries has shown that when a child has a disability most families experience a change in their level of stress and demands. They may decide to change things like: who does what; how they communicate feelings; how to get support from professionals; and how they cope as a family. The resources they have and their thoughts about having a child with a disability can influence how they change.

What will the survey information be used for?
Information will be used to find out what helps Western Australian families adapt and what does not help. It will be used to develop a therapeutic support group program to assist families to adapt to having a child with a disability.

Finding out how people will feel about filling in questionnaires.
Before the survey is sent to hundreds of families it is being sent to just a handful so that we can get feedback about it. If you have some spare time (about 1½ hours) and want to help us make the survey as family-friendly as possible, here's what you can do.

1. Read the introductory letters and complete the questionnaire booklet,
2. Mark down anything that is unclear on the booklet, as you go,
3. Complete the questions stapled to this sheet and send it all back to us.

Is this really necessary?
We know family time and energy is precious. There would be no point in sending this out to hundreds of families if it was unlikely they would be interested. That's why we are trying it with just some families first to see what they think. We are dedicated to using family responses to help develop good services and assist as best we can.

Who to talk to about this...
If you would like to chat about this over the phone, please feel free to call:

Lisa Studman
9329 2347

After completing the survey booklet come back to this page and give as much information as you would like about it.
ABOUT THE INTRODUCTORY LETTER AND PARTICIPANT’S INFORMATION SHEET

1. Did you understand why the survey is being done? □ Yes □ No
   What might make it more understandable?

2. Was it clear that some questions were to be about your child, □ Yes □ No
   some about yourself and some about the family?
   What would make it clearer?

3. Did the answers to “Frequently Asked Questions” make sense? □ Yes □ No
   What else would families like to know?

4. Was there enough information to let you know how important □ Yes □ No
   the survey is? If not, what else would help?

ABOUT THE QUESTIONNAIRES

1. How long did it take you to complete the booklet?

2. Did the description of each questionnaire clearly explain what it was about? □ Yes □ No

3. Was it easy to understand how to answer the questions?
   □ Yes □ No

4. How did you feel about answering questions on yourself and your level of stress?

GENERAL

1. What do you think about the level of language used in the questionnaires? We want it to be simple and straight-forward enough to reach a wide-range of people?

2. How could we increase the chances that families will complete and send the survey back?
PILOT RESULTS

15 respondents out of 50
4 completed survey but not pilot questions
1 wrote a letter of personal experiences
6 have requested contact regarding support groups

Summary of responses

<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Did you understand why the survey is being done? What would make it more understandable?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Was it clear that some questions were to be about your child, some about yourself and some about the family? What would make it clearer?</td>
<td>10</td>
<td></td>
<td>• Don’t use the word ‘adequate’&lt;br&gt;• Maybe could be put in two sections with cover pages for each (child) or (parent/family) etc</td>
</tr>
<tr>
<td>3</td>
<td>Did the answers to “Frequently Asked Questions” make sense? What else would families like to know?</td>
<td>10</td>
<td></td>
<td>• About more services&lt;br&gt;• Are there groups for families with ‘…syndrome’&lt;br&gt;•</td>
</tr>
<tr>
<td>4</td>
<td>Was there enough information to let you know how important the survey is? If not, what else would help?</td>
<td>9</td>
<td>1</td>
<td>• Specific information on possible future support groups services etc&lt;br&gt;•</td>
</tr>
<tr>
<td>5</td>
<td>How long did it take you to complete the booklet?</td>
<td></td>
<td></td>
<td>20-30mins: 3&lt;br&gt;31-40mins: 0&lt;br&gt;41-50mins: 2&lt;br&gt;51-60mins: 4&lt;br&gt;61-70mins: 0&lt;br&gt;71-80mins: 0&lt;br&gt;81-90mins: 1&lt;br&gt;90+ mins: 0&lt;br&gt;</td>
</tr>
<tr>
<td>6</td>
<td>Did the description of each questionnaire clearly explain what it was about?</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Was it easy to understand how to answer the questions?</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>How did you feel about answering questions about yourself and your level of stress?</td>
<td></td>
<td></td>
<td>• Nervous&lt;br&gt;• It was a bit difficult as most of the time I try to block out those feelings and just get on with each day, I find that easier than thinking about difficulties etc&lt;br&gt;• I had to face up to my problems&lt;br&gt;• Alright&lt;br&gt;• Hard as it brings feelings to the surface as on a day to day basis you just do what you have to with not much thought to feelings or stress&lt;br&gt;• No problem&lt;br&gt;• Fine. Stress is part of everyday life!!</td>
</tr>
<tr>
<td>9</td>
<td>What did you think about the level of language used? We want it to be simple and straightforward enough to reach a wide-range of people.</td>
<td></td>
<td></td>
<td>• OK x2 / The language was OK&lt;br&gt;• It was easy to understand x2&lt;br&gt;• Simple and straightforward x2&lt;br&gt;• I had to look a few words in the dictionary&lt;br&gt;• Q9 ‘only answer is over 4’ should be bigger and at the top of page as it’s too small to see before you finish the list.&lt;br&gt;• Seems fine to me</td>
</tr>
<tr>
<td>10</td>
<td>How could we increase the chances that families will complete and send the survey back?</td>
<td></td>
<td></td>
<td>• Just offer a reward for our time – not competition&lt;br&gt;• Unsure&lt;br&gt;• Give them a little more time to complete the survey – 1 week was a bit short&lt;br&gt;• Don’t know x2&lt;br&gt;• Send two teabags (only joking) I think it was fine. Maybe there could be a free call number for help with form for long distance families if they are sent form and maybe easier to turn pages its very hard with all staples and will put people off.&lt;br&gt;• Maybe a voucher&lt;br&gt;• Personal contact by DSC/LAC or more incentives</td>
</tr>
</tbody>
</table>
Appendix D

Study 2. Promotional Flyer

Family Adaptation Survey

Family Adaptation is what happens to a family when an unexpected event happens. The family responds with many different feelings. Then they come to an understanding of what changes might be helpful. When a child is diagnosed with a disability, families may react in this way.

Research in other countries has shown that most families experience a change in their level of stress and demands. This can influence how they decide to make changes or adapt. They may decide to change things like: who does what; how they communicate feelings; how to get support from professionals; and how to cope better. How a family adapts may depend on the resources they have and their thoughts about having a child with a disability.

The diagram below shows examples of stress, resources and thoughts that influence positive and negative family adaptation.

![Diagram of Family Adaptation](image)

Some Western Australian metropolitan families will soon be asked how this way of seeing Family Adaptation fits for them. A survey will be sent to families of children with any type of disability who is between the ages of 2-years and 12-years old. The information gathered will be used to design a therapeutic support group program to assist families to adapt to having a child with a disability. Therefore it is important that we gather information about what does work for Western Australian families and what does not work.

Throughout the rest of the year, some families will receive a letter explaining the survey and a booklet of questionnaires to complete if they have time. These families will be chosen randomly from the DSC Database. They will be asked to return the completed booklet within a week in a pre-paid envelope. After a week, reminder letters will be sent. The first 100 families to respond will be entered into a draw for a $50 gift voucher.

Lisa Studman
Developmental Psychologist
Stepping Stones Triple P

[Disability Services Commission logo]
[Government of Western Australia logo]
[University of Technology logo]
Appendix E

Study 2. Introductory Letter and Participant Information Form

Family Adaptation Survey
For parents with a child who has a disability

Dear [Name] Family

I am writing to you about the current survey that some parents of children with disabilities are being asked to complete. If you have already received a copy of this survey, please disregard this one.

Information from this survey will be used to help us understand the needs of families who have a child with a disability. We are interested in looking at how families cope with added stress and demands. This information will help us develop support groups for parents.

The survey is part of a research project being conducted through the Curtin University and Disability Services Commission, WA. The key researcher has worked within the Commission for 10 years and has a broad range of experience with families and children who have a disability.

If you or a partner have some time soon, please take this opportunity to sit, have a cuppa and complete the attached questionnaires. There are no right or wrong answers and it is best to circle the first response that comes to mind. Do not think too much about individual items. Just do it as quickly as you feel comfortable. Altogether the survey will take about 1 hour to complete. A stamped, addressed envelope is provided for you to return the completed forms.

Completed surveys need to be returned within two weeks. Families who participate will go into a draw for a $50 gift voucher!

The enclosed information sheet may answer any questions you have and can be detached for you to keep. Or, please phone and leave a message for me, if you wish. My number is 9329 2347.

Yours sincerely

Lisa Studman, MPsych
Senior Developmental Psychologist

30th June
Family Adaptation Survey
Participant Information Sheet

Having a child with a disability can have an impact on the entire family. Sometimes this is positive and sometimes not. This survey is to gather information about how families in Western Australia adapt to having a child with a disability. We are particularly interested in whether families adapt to stress by thinking in certain ways or having particular beliefs about themselves and their family.

Results from this survey will be used to design a support group program to assist families to adapt to having a child with a disability. Therefore it is important that we gather information about what has worked for families and what does not work. If you decide to participate, here are answers to questions you may have.

<table>
<thead>
<tr>
<th>FREQUENTLY ASKED QUESTION</th>
<th>ANSWER</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did you get my family's name?</td>
<td>It was selected randomly from the Disability Services Commission's database. Curtin University staff does not have direct access to any identifying information about you.</td>
</tr>
<tr>
<td>How long will it take to complete this survey?</td>
<td>About 1hr. If you need help you can call Lisa Studman on 9329 2347. The booklet needs to be returned within two weeks.</td>
</tr>
<tr>
<td>Who will get this information about my family?</td>
<td>Questionnaires are given a code number and only these numbers will ever be used to record results. Data is kept on computer and secured with a password. Survey forms are stored at Curtin University of Technology in locked filing cabinets for approx 5-7 years, and then shredded.</td>
</tr>
<tr>
<td>Do I have to provide my name and other details?</td>
<td>We do need your child’s name so we know who to send reminder letters to. Also if you are interested in participating in a support group with other parents, please sign the consent form at the end of the survey booklet and give details so we can contact you.</td>
</tr>
<tr>
<td>Will my service providers have access to my completed questionnaires?</td>
<td>Your completed questionnaires can be sent to service providers only if you request it and give permission for us to send it to them. In this case you would need to provide us with your details.</td>
</tr>
<tr>
<td>Will participating in the survey affect the services I already get?</td>
<td>No. Not in any way. But you may be interested in coming to a support group to help adapt to having a child with a disability.</td>
</tr>
<tr>
<td>What is covered in the questionnaires?</td>
<td>There are questionnaires about your family and how you all cope with the demands upon you. There are also questionnaires that are not related to your child at all. These ask questions about you individually and other parts of your life. This is so that we can compare stress from your child’s demands with stress from other aspects of life to see how they are related. Details of questionnaires included are on the following page.</td>
</tr>
<tr>
<td>Do I need to sign a consent form?</td>
<td>Only if you are interested in participating in a support group for parents wanting support in adapting to having a child with a disability. If so, give contact details and sign the form at the end of the questionnaire.</td>
</tr>
</tbody>
</table>

If, for what reason, completing this survey makes you feel upset, it can be helpful to talk to a support person or friend about it. Alternatively, you could make contact with your usual service providers, Crisis Care (ph: 9223 1111) or Lisa Studman (ph: 9329 2347).
### Questionnaires Included:

<table>
<thead>
<tr>
<th>Area of Family or Personal Life</th>
<th>Name of Questionnaire</th>
<th>Who is it about?</th>
<th>What's it about?</th>
<th>No. of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress and Demands</td>
<td>Family Background</td>
<td>Your whole family</td>
<td>Age of child, Gender, Number of children, Education, etc.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parent Hassles</td>
<td>Your child</td>
<td>The types of stress and demands on you related to having a child with a disability</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>Life Distress</td>
<td>You</td>
<td>Current distress in other parts of your life.</td>
<td>20</td>
</tr>
<tr>
<td>Resources and Supports</td>
<td>Family Resources</td>
<td>Your whole family</td>
<td>Time, money, energy etc your family needs</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Family Support</td>
<td>You and your child</td>
<td>People who give your family some help</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Family Hardiness</td>
<td>Your whole family</td>
<td>Your family's resistance to stress – how your family deals with it!</td>
<td>20</td>
</tr>
<tr>
<td>Parental Thoughts and Family Problem Solving</td>
<td>Positive Contributions</td>
<td>Your child</td>
<td>Positive effects your child has had on your family</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Family Crisis-Orientation Personal Evaluation Scales</td>
<td>Your whole family</td>
<td>How your family usually responds to difficulties or problems</td>
<td>16</td>
</tr>
<tr>
<td>Family Adaptation and General Health</td>
<td>General Health Questionnaire</td>
<td>You</td>
<td>Your general level of health</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Family Assessment Device – General Functioning</td>
<td>Your whole family</td>
<td>How your family communicates and feels about being together</td>
<td>12</td>
</tr>
</tbody>
</table>
Appendix F

Study 2. Reminder Parent Letter

Dear _______ Family

I am writing to you about the survey you may have received over that last few weeks. The Family Adaptation Survey is part of a research project being conducted from Disability Services Commission and Curtin University of Technology.

About 15% of families who received the survey were able to find time to complete it and send it back. Thank you if you were one of them. I realise that time is precious. If you completed the consent form to be contacted about support groups, your name has been added to the list.

If you were not able to find time to complete the survey, I would just like to remind you that it is not too late. All the information that we can get is helpful when deciding how to develop a new service for families. We are interested not only in aspects of family life that contribute to difficulties. We really would like to know what it is that families do or have that makes them cope well with stress too. This is the information that the survey can provide.

If you, or a partner, have some time soon please complete and return the survey forms. Further copies can be obtained by leaving a message for me at 9329 2347. Families who participate will go into a draw for a $50 gift voucher!

Yours sincerely

[Signature]

Lisa Studman, MPsysch
Senior Developmental Psychologist
Disability Services Commission / Curtin University of Technology

15th July
Appendix G

Study 2. Measurement Model and Hypothesis Testing Syntax

A Confirmatory Factor Analysis of the Measurement Model

Observed variables:
- phs_f1 - phs_f3
- ldi_f1 - ldi_f4
- pc_f1 - pc_f9
- fcope_f1 - fcope_f3
- fhi_f1 - fhi_f4
- frs_f1 - frs_f4
- fss_f1 - fss_f6
- fadtot = FamilyAdaptation
- ghq_f1 - ghq_f3

Correlation Matrix

Latent variables
Sample size = 404

A
B
C
D
E
F
G
H
I
J
K
L
M
N
O
P
Q
R
S
T
U
V
W
X
Y
Z

Appendix G

Sample size = 404

Wide print
End of Problem
Testing the Additive Model

Observed variables:

<table>
<thead>
<tr>
<th>phs_f1</th>
<th>phs_f3</th>
<th>ldi_f1</th>
<th>ldi_f4</th>
<th>pc_f1</th>
<th>pc_f9</th>
<th>fcope_f1</th>
<th>fcope_f2</th>
<th>fhi_f1</th>
<th>fhi_f4</th>
<th>fss_f1</th>
<th>fss_f6</th>
<th>fadtot</th>
<th>gbq_f1</th>
<th>gbq_f3</th>
</tr>
</thead>
</table>

Correlation Matrix

<table>
<thead>
<tr>
<th></th>
<th>1.0</th>
<th>0.694</th>
<th>0.525</th>
<th>0.543</th>
<th>0.509</th>
<th>0.509</th>
<th>0.510</th>
<th>0.410</th>
<th>0.418</th>
<th>0.618</th>
<th>0.661</th>
<th>0.757</th>
<th>0.785</th>
<th>0.866</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.694</td>
<td>0.694</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.525</td>
<td>0.525</td>
<td>0.525</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.543</td>
<td>0.543</td>
<td>0.543</td>
<td>0.543</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>0.509</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.510</td>
<td>0.510</td>
<td>0.510</td>
<td>0.510</td>
<td>0.510</td>
<td>0.510</td>
<td>0.510</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>0.410</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>0.418</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Testing the Additive Model

<p>| | | | | | | | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress&amp;Demands</td>
<td>Perceptions</td>
<td>Resources&amp;Support</td>
<td>FamilyAdaptation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sample size = 404

Latent variables

<table>
<thead>
<tr>
<th>Stress&amp;Demands</th>
<th>Perceptions</th>
<th>Resources&amp;Support</th>
<th>FamilyAdaptation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Relationships:

<table>
<thead>
<tr>
<th></th>
<th>phs_f1</th>
<th>phs_f3</th>
<th>ldi_f1</th>
<th>ldi_f4</th>
<th>pc_f1</th>
<th>pc_f9</th>
<th>fcope_f1</th>
<th>fcope_f2</th>
<th>fhi_f1</th>
<th>fhi_f4</th>
<th>fss_f1</th>
<th>fss_f6</th>
<th>fadtot</th>
<th>gbq_f1</th>
<th>gbq_f3</th>
</tr>
</thead>
</table>

FamilyAdaptation = Resources&Support Perceptions Stress&Demands

set the error covariances between phs_f1 - phs_f3 free

set the error covariances between fss_f1 - fss_f6 free

set the error covariances between fhi_f1 - fhi_f4 free

Path diagram

Number of decimals = 3

Wide print

End of Problem
Testing the Single Mediator Model (Full)

Observed variables:
- $\text{fhs}_f$ - $\text{fhs}_1$
- $\text{fd}_f$ - $\text{f}_d$
- $\text{pc}_f$ - $\text{pc}_f$
- $\text{fc}_{f1}$ - $\text{fc}_{p1}$
- $\text{fhs}_f$ - $\text{fhs}_f$
- $\text{ff}_f$ - $\text{ff}_f$

Correlation Matrix

<table>
<thead>
<tr>
<th></th>
<th>$\text{fhs}_f$</th>
<th>$\text{fd}_f$</th>
<th>$\text{pc}_f$</th>
<th>$\text{fc}_{f1}$</th>
<th>$\text{fhs}_f$</th>
<th>$\text{ff}_f$</th>
<th>$\text{fd}_f$</th>
<th>$\text{pc}_f$</th>
<th>$\text{fc}_{f1}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>$\text{fhs}_f$</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\text{fd}_f$</td>
<td>0.52</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\text{pc}_f$</td>
<td>0.54</td>
<td>0.53</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\text{fc}_{f1}$</td>
<td>0.128</td>
<td>0.181</td>
<td>0.135</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\text{fhs}_f$</td>
<td>0.418</td>
<td>0.577</td>
<td>0.267</td>
<td>0.674</td>
<td>0.548</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\text{ff}_f$</td>
<td>0.032</td>
<td>0.031</td>
<td>0.059</td>
<td>0.065</td>
<td>0.029</td>
<td>0.117</td>
<td>0.320</td>
<td>0.346</td>
<td>0.516</td>
</tr>
<tr>
<td>$\text{fd}_f$</td>
<td>0.024</td>
<td>0.010</td>
<td>0.014</td>
<td>0.025</td>
<td>0.031</td>
<td>0.011</td>
<td>0.117</td>
<td>0.320</td>
<td>0.516</td>
</tr>
<tr>
<td>$\text{pc}_f$</td>
<td>0.135</td>
<td>0.184</td>
<td>0.165</td>
<td>0.157</td>
<td>0.081</td>
<td>0.055</td>
<td>0.244</td>
<td>0.297</td>
<td>0.360</td>
</tr>
<tr>
<td>$\text{fc}_{f1}$</td>
<td>0.019</td>
<td>0.004</td>
<td>0.016</td>
<td>0.026</td>
<td>0.010</td>
<td>0.036</td>
<td>0.020</td>
<td>0.295</td>
<td>0.275</td>
</tr>
<tr>
<td>$\text{fhs}_f$</td>
<td>0.299</td>
<td>0.326</td>
<td>0.292</td>
<td>0.286</td>
<td>0.314</td>
<td>0.318</td>
<td>0.301</td>
<td>0.310</td>
<td>0.309</td>
</tr>
<tr>
<td>$\text{ff}_f$</td>
<td>0.052</td>
<td>0.050</td>
<td>0.059</td>
<td>0.056</td>
<td>0.080</td>
<td>0.029</td>
<td>0.117</td>
<td>0.320</td>
<td>0.516</td>
</tr>
</tbody>
</table>

Testing the Single Mediator Model (F)

End of Problem

Sample size = 404

Latent variables
- Stress&Demands
- Perceptions
- Resources&Support
- FamilyAdaptation

Relationships:
- $\text{fhs}_f$ - $\text{fhs}_1$
- $\text{fd}_f$ - $\text{f}_d$
- $\text{pc}_f$ - $\text{pc}_f$
- $\text{fc}_{f1}$ - $\text{fc}_{p1}$
- $\text{ff}_f$ - $\text{ff}_f$
- $\text{fd}_f$ - $\text{f}_d$

Perceptions = Stress&Demands

Path diagram
- Number of decimals = 3
- End of Problem
Testing the Single Mediator Model (Partial)

Observed variables:
- phs_f1 - phs_f3
- ldi_f1 - ldi_f4
- pc_f1 - pc_f9
- fcope_f1 - fcope_f3
- fhi_f1 - fhi_f4
- frs_f1 - frs_f4
- fss_f1 - fss_f6
- fadot

Latent variables:
- ghq_f1 - ghq_f3

Correlation Matrix

Testing the Single Mediator Model (Partial)
Testing the Two-Mediator Model (Full)

A test of the mediator model

Observed variables:

- phs_f1 - phs_f3
- ldi_f1 - ldi_f4
- pc_f1 - pc_f9
- fcpe_f1 - fcpe_f3
- fhu_f1 - fhu_f4
- frs_f1 - frs_f4
- fss_f1 - fss_f6
- fadot
- ghq_f1 - ghq_f3

Correlation Matrix

|   | .01 | .09 | .13 | .17 | .20 | .23 | .26 | .29 | .32 | .35 | .38 | .41 | .44 | .47 | .50 | .53 | .56 | .59 | .62 | .65 | .68 | .71 | .74 | .77 | .80 | .83 | .86 | .89 | .92 | .95 | .98 | 1.0 |
|   | .01 | .09 | .13 | .17 | .20 | .23 | .26 | .29 | .32 | .35 | .38 | .41 | .44 | .47 | .50 | .53 | .56 | .59 | .62 | .65 | .68 | .71 | .74 | .77 | .80 | .83 | .86 | .89 | .92 | .95 | .98 | 1.0 |
| GHQ | .64 | .65 | .66 | .67 | .68 | .69 | .70 | .71 | .72 | .73 | .74 | .75 | .76 | .77 | .78 | .79 | .80 | .81 | .82 | .83 | .84 | .85 | .86 | .87 | .88 | .89 | .90 | .91 | .92 | .93 | .94 | .95 | .96 | .97 | .98 | .99 | 1.0 |
| FCPE | .60 | .61 | .62 | .63 | .64 | .65 | .66 | .67 | .68 | .69 | .70 | .71 | .72 | .73 | .74 | .75 | .76 | .77 | .78 | .79 | .80 | .81 | .82 | .83 | .84 | .85 | .86 | .87 | .88 | .89 | .90 | .91 | .92 | .93 | .94 | .95 | .96 | .97 | .98 | .99 | 1.0 |
| FSS | .55 | .56 | .57 | .58 | .59 | .60 | .61 | .62 | .63 | .64 | .65 | .66 | .67 | .68 | .69 | .70 | .71 | .72 | .73 | .74 | .75 | .76 | .77 | .78 | .79 | .80 | .81 | .82 | .83 | .84 | .85 | .86 | .87 | .88 | .89 | .90 | .91 | .92 | .93 | .94 | 1.0 |
| FAD | .50 | .51 | .52 | .53 | .54 | .55 | .56 | .57 | .58 | .59 | .60 | .61 | .62 | .63 | .64 | .65 | .66 | .67 | .68 | .69 | .70 | .71 | .72 | .73 | .74 | .75 | .76 | .77 | .78 | .79 | .80 | .81 | .82 | .83 | .84 | .85 | .86 | .87 | .88 | .89 | .90 | 1.0 |

Sample size = 404

Latent variables

- Stress&Demands
- Perceptions
- Resources&Support
- FamAdaptation

Relationships:

- phs_f1 - phs_f3 ldi_f1 - ldi_f4 = Stress&Demands
- pc_f1 - pc_f9 fcpe_f1 - fcpe_f3 = Perceptions
- frs_f1 - frs_f4 fss_f1 = Resources&Support

Path diagram

Number of decimals = 3

Wide print

End of Problem
290
Testing the Two-Mediator Model (Partial)
Observed variables:
phs_f1 - phs_f3
ldi_f1 - ldi_f4
pc_f1 - pc_f9
fcope_f1 - fcope_f3
fhi_f1 - fhi_f4
frs_f1 - frs_f4
fss_f1 - fss_f6
fadtot
ghq_f1 - ghq_f3
Correlation Matrix
1.0
.694 1.0
.525 .560 1.0
.543 .705 .368 1.0
.509 .704 .354 .832 1.0
.410 .530 .248 .626 .679 1.0
.418 .577 .261 .765 .674 .548 1.0
.063 .055 .084 -.033 -.028 -.020 -.027 1.0
-.305 -.315 -.224 -.286 -.258 -.136 -.228 .295 1.0
-.071 -.171 -.050 -.212 -.190 -.044 -.229 .514 .492 1.0
-.060 -.052 -.059 -.065 -.080 -.029 -.117 .320 .346 .516 1.0
.032 -.031 .012 .001 -.031 .052 -.047 .494 .414 .589 .424 1.0
-.024 -.102 -.039 -.157 -.149 -.021 -.152 .468 .361 .599 .411 .565 1.0
-.135 -.184 -.165 -.157 -.179 -.081 -.055 .244 .298 .407 .290 .360 .405 1.0
-.019 .004 -.076 -.026 -.010 .036 .020 .290 .275 .363 .410 .431 .440 .364 1.0
-.299 -.326 -.327 -.204 -.229 -.065 -.144 .108 .371 .301 .180 .311 .309 .416 .324 1.0
-.140 -.216 -.119 -.294 -.299 -.176 -.314 .228 .365 .422 .149 .166 .297 .119 .137 .188 1.0
-.052 -.035 -.066 -.058 -.102 -.094 -.105 .024 .108 .182 .615 .148 .178 .203 .288 .088 -.004 1.0
-.096 -.145 -.060 -.191 -.177 -.137 -.243 .004 .069 .014 -.025 -.105 -.077 -.044 -.042 -.221 .174 -.104 1.0
-.277 -.366 -.175 -.435 -.416 -.237 -.481 .133 .421 .444 .293 .238 .273 .228 .186 .195 .539 .190 .274 1.0
-.326 -.445 -.236 -.506 -.527 -.446 -.448 .080 .256 .168 .065 .008 .076 .185 .056 -.011 .288 .079 .487 .471 1.0
-.296 -.387 -.163 -.467 -.442 -.332 -.436 .062 .300 .269 .191 .111 .159 .225 .090 .179 .308 .080 .299 .514 .467 1.0
-.127 -.192 -.134 -.166 -.200 -.177 -.201 -.036 .075 .000 -.022 -.132 -.069 .045 -.081 -.124 .092 .041 .458 .176 .444 .179 1.0
-.255 -.257 -.146 -.343 -.316 -.402 -.284 .041 .128 .040 .035 -.013 .047 .086 -.005 -.067 .123 .038 .188 .205 .368 .225 .127 1.0
-.427 -.632 -.312 -.636 -.588 -.557 -.513 .045
-.306 -.365 -.192 -.397 -.385 -.496 -.346 .011
.111 .012 -.009 .002 .024 .070 .008 .040 .119 .023 .107 .206 .351 .249 .066 .773 .592 1.0
-.217 -.250 -.099 -.275 -.250 -.246 -.236 .025
.042 .032 .023 .002 .003 .103 .035 .022 .017
.061 .040 .121 .216 .134 .037 .507 .505 .587
1.0
-.195 -.193 -.191 -.217 -.252 -.160 -.167 .053
.143 .153 .187 .124 .120 .295 .144 .150 .057 .257 .070 .199 .188 .253 .136 .155 .287 .218 .207
1.0
.078 .125 .016 .099 .115 .174 .115 .006 -.047 -.015 -.017 .054 -.007 .164 .066 .085 .006 .014 -.026 .014 -.101 -.024 -.051 -.040 -.071 -.029 .087
.303 1.0
-.108 -.140 -.070 -.177 -.153 -.173 -.158 .042 .096 .110 .040 .104 .082 .149 .068 .071 .051 .056 .018 .049 .192 .176 -.003 .225 .304 .306 .331 .303
.169 1.0
-.162 -.191 -.076 -.272 -.277 -.241 -.208 .090 .198 .112 .082 .091 .072 .142 .075 .083 .139 .112 .088 .219 .239 .225 .053 .323 .394 .346 .280 .337
.101 .491 1.0
-.104 -.088 -.046 -.148 -.137 -.104 -.092 .095 .137 .109 .082 .109 .066 .139 .076 .058 .071 .095 .008 .137 .069 .118 -.053 .124 .166 .086 .182 .242
.121 .298 .230 1.0
-.117 -.147 -.054 -.188 -.142 -.175 -.181 .037
.047 .073 -.004 .058 .035 .062 .037 .052 .083 .075 .049 .050 .088 .092 -.025 .134 .212 .155 .172
.292 .196 .261 .217 .436 1.0
-.264 -.359 -.205 -.447 -.425 -.320 -.468 .188 .357 .381 .177 .184 .232 .146 .061 .112 .457 .079 .358 .616 .518 .528 .184 .293 .338 .264 .128 .181 .070 .164 .248 .170 .210 1.0
-.248 -.329 -.128 -.425 -.460 -.313 -.349 .034
.135 .104 .009 -.020 .073 .135 .020 .049 .224 .000 .294 .288 .442 .287 .208 .175 .279 .171 .093
.125 -.059 .106 .186 .042 .104 .344 1.0
-.348 -.462 -.165 -.551 -.580 -.442 -.500 -.030 .180 .130 -.033 -.059 .050 .094 -.030 .073 .225 .009 .297 .316 .486 .375 .247 .228 .411 .249 .175
.135 -.142 .052 .152 .075 .083 .355 .613 1.0
-.288 -.402 -.166 -.471 -.498 -.414 -.432 .004 .131 .121 .003 .018 .081 .076 .003 .128 .180 .028 .240 .228 .400 .310 .133 .187 .423 .236 .170 .185 .047 .120 .192 .179 .163 .340 .546 .698 1.0

Sample size = 404
Latent variables
Stress&Demands
Perceptions
Resources&Support
FamilyAdaptation
Relationships:
phs_f1 - phs_f3 ldi_f1 - ldi_f4 = Stress&Demands
pc_f1 - pc_f9 fcope_f1 - fcope_f2 = Perceptions
frs_f1 - frs_f4 fss_f1 fss_f3 - fss_f6 fhi_f1 - fhi_f4 = Resources&Support
ghq_f1 - ghq_f3 fadtot = FamilyAdaptation
Resources&Support Perceptions FamilyAdaptation
= Stress&Demands
FamilyAdaptation = Resources&Support Perceptions
set the error covariances between phs_f1 - phs_f3 free
set the error covariances between frs_f1 - frs_f4 free
set the error covariances between fss_f1 fss_f3 - fss_f6 free
set the error covariances between fhi_f1 - fhi_f4 free
Path diagram
Number of decimals = 3
Wide print
End of Problem


Testing the Full Factorial Moderator Model

Observed variables:
- pbs\_f1 - pbs\_f3
- ldi\_f1 - ldi\_f4
- pc\_f1 - pc\_f9
- fcpe\_f1 - fcpe\_f3
- fhi\_f1 - fhi\_f4
- frs\_f1 - frs\_f4
- fss\_f1 - fss\_f6
- fadtot
- gbg\_f1 - gbg\_f3

PERsSD SUPsSD PERsSUP PxsXsd

Correlation Matrix

Testing the Full Factorial Moderator M

End of Problem

Number of decimals = 3

Latent variables
- Stress\&Demands
- Perceptions
- Resources\&Support
- FamilyAdaptation

perXsd supXsd perXsup pxsXsd

Relationships:
- pbs\_f1 - pbs\_f3
- ldi\_f1 - ldi\_f4
- pc\_f1 - pc\_f9
- fcpe\_f1 - fcpe\_f3
- fhi\_f1 - fhi\_f4
- frs\_f1 - frs\_f4
- fss\_f1 - fss\_f6
- fadtot
- gbg\_f1 - gbg\_f3

set the error covariances between pbs\_f1 - pbs\_f3
set the error covariances between ldi\_f1 - ldi\_f4
set the error covariances between pc\_f1 - pc\_f9
set the error covariances between fcpe\_f1 - fcpe\_f3
set the error covariances between fhi\_f1 - fhi\_f4
set the error variance of PER\_sSUP to .001
set the error variance of SUPsSUP to .001
set the error variance of PERsSUP to .001
set the error variance of PxsXsd to .001

Path diagram

Number of decimals = 3

End of Problem
Testing the Reduced Moderator Model

**Observed variables:**
- **phs_f1** - **phs_f3**
- **ldl_f1** - **ldl_f4**
- **pc_f1** - **pc_f9**
- **fcope_f1** - **fcope_f3**
- **fhf_f1** - **fhf_f4**
- **frs_f1** - **frs_f4**
- **fss_f1** - **fss_f6**
- **fadtot**
- **gbq_f1** - **gbq_f3**

**PERsSD SupxSD PERsSup PlexSD**

**Correlation Matrix**

<table>
<thead>
<tr>
<th></th>
<th>1.0</th>
<th>.694 1.0</th>
<th>525 560 1.0</th>
<th>543 705 368 1.0</th>
<th>509 704 354 832 1.0</th>
<th>410 530 248 626 679 1.0</th>
<th>418 577 261 675 674 548 1.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>.004</td>
<td>.035</td>
<td>.101</td>
<td>.051</td>
<td>.192  .179  .163  .340  .546  .698  1.0</td>
<td>.248  .170  .210  1.0</td>
<td>.078  .125  .016  .009  .269  .191  .000  .080  299 514 467 1.0</td>
<td></td>
</tr>
<tr>
<td>.009</td>
<td>.035</td>
<td>.101</td>
<td>.051</td>
<td>.192  .179  .163  .340  .546  .698  1.0</td>
<td>.248  .170  .210  1.0</td>
<td>.078  .125  .016  .009  .269  .191  .000  .080  299 514 467 1.0</td>
<td></td>
</tr>
<tr>
<td>.030</td>
<td>.051</td>
<td>.192</td>
<td>.179  .163  .340  .546  .698  1.0</td>
<td>.248  .170  .210  1.0</td>
<td>.078  .125  .016  .009  .269  .191  .000  .080  299 514 467 1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>.003</td>
<td>.016</td>
<td>.009</td>
<td>.099  .212  .190  .044  .229  514 492 1.0</td>
<td>.055  .249  .298  407 290 360 405 1.0</td>
<td>.093  .237  .283  228 186 593 190 274 1.0</td>
<td>.100  .109  .016  .009  .269  .191  .000  .080  299 514 467 1.0</td>
<td></td>
</tr>
<tr>
<td>.001</td>
<td>.003</td>
<td>.002</td>
<td>.032  .127  .163  .044  .059  .166  297 119 137 188 1.0</td>
<td>.019  .076  .010  .016  .290  275 365 410 341 480 548 1.0</td>
<td>.037  .098  .145  .055  .516  1.0</td>
<td>.037  .098  .145  .055  .516  1.0</td>
<td></td>
</tr>
</tbody>
</table>

**Latent variables**
- Stress&Demands
- Perceptions
- Resources&Support
- FamilyAdaptation
- perXsd supXsd

**Relationships**:
- **phs_f1** - **phs_f3**
- **ldl_f1** - **ldl_f4**
- **pc_f1** - **pc_f9**
- **fcope_f1** - **fcope_f3**
- **fhf_f1** - **fhf_f4**
- **frs_f1** - **frs_f4**
- **fss_f1** - **fss_f6**
- **fadtot**
- **gbq_f1** - **gbq_f3**

**Sample size = 404**

Number of decimals = 3

End of Problem