

**VOLUME I**  
**RESEARCH COMPONENT**

THE RELATIONSHIP BETWEEN BEHAVIOURAL  
DIFFICULTIES, COGNITIONS AND STRESS IN PARENTS OF  
INDIVIDUALS WITH INTELLECTUAL DISABILITIES

by

LISA KIM NELSON

A thesis submitted to

The University of Birmingham

in partial fulfillment of the requirements for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY (ClinPsyD)

School of Psychology

The University of Birmingham

June 2013

UNIVERSITY OF  
BIRMINGHAM

**University of Birmingham Research Archive**

**e-theses repository**

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

## Abstract

This thesis comprising both research and clinical volumes is submitted in partial fulfillment of the degree of Doctor of Clinical Psychology (DClinPsy) at the University of Birmingham.

Volume I consists of a literature review, an empirical paper and a public domain briefing paper. The literature review provides a systematic review of the literature on the relationship between behavioural difficulties, cognitions and well-being in parents of individuals with intellectual disabilities from 2005 onwards. A review of studies using correlational analyses and regression analyses allowed for the initial investigation of these relationships. Parental cognitions were then examined as mediators and moderators of the effect of behavioural difficulties on parental well-being. This paper was prepared as if for submission to the *Journal of Applied Research in Intellectual Disabilities*. The empirical paper initially examined the applicability of the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) to mothers of individuals with intellectual disabilities. The CBPQ was employed to examine whether maternal perceptions of challenging behaviour mediated the effect of challenging behaviour on stress in mothers of children and young adults with intellectual disabilities. This paper was prepared as if for submission to the *Journal of Intellectual Disability Research*. Finally, the public domain briefing paper provides an accessible summary of the empirical paper.

Volume II consists of five clinical practice reports relating to clinical work conducted whilst on placement in a Child mental health, Adult mental health, Learning disability and Older adult memory service. The first report provides two formulations from a behavioural and systemic perspective, for a ten year-old boy with obsessive compulsive disorder. The second report is a case study of a fourteen year-old girl with selective mutism.

The report includes information regarding assessment, formulation, intervention and evaluation. The third report is a single-case experimental design, providing an evaluation of the effectiveness of a cognitive-behavioural intervention for a female with trichotillomania. The fourth report is a service evaluation which examined the development of a new model of service delivery to address staff stress and staff well-being in a Learning Disability service. The fifth report is a one-page summary of a clinical presentation. The presentation was a case study of Jane, an older adult with dementia who experienced anxiety and low self-esteem.

## **Dedication**

This thesis is dedicated to my amazing husband Kevin and my beautiful son Caleb who both mean the world to me.

## **Acknowledgements**

Firstly, I would like to thank all the mothers who took part in this research project. Without their time, commitment and willingness to engage in research, this study would not have been possible. Thank you also to Becky Hardiman for her hard work on the project and help with data collection.

I would like to say a big thank you to John Rose, who has put up with me for three years both as my appraisal tutor and my research supervisor! I have really valued his guidance and support with my research project and his dry sense of humour has helped me along the way. Thank you to Neil Phillips who has also supervised me on this project. He has been incredibly helpful and determined in ensuring that I recruited enough participants for my research project. Without him, I don't think I would have ever recruited enough people!

Thank you to all of my placement supervisors over the past three years: Amanda Buchanan, Heather Bennett, Nikki Rose, Deborah Gittins, Clare Rose, Louise Price and Biza Stenfert Kroese. Their knowledge, support and words of encouragement have allowed me to build my confidence with my clinical work. I feel really lucky to have had such exceptional supervisors.

Finally, I would like to say an extra special thank you to my husband, Kevin, whose love and support has meant so much to me on this journey and to my son Caleb who always brightens up my day!

## Table of Contents for Volume I

### **CHAPTER ONE: LITERATURE REVIEW: THE RELATIONSHIP BETWEEN BEHAVIOURAL DIFFICULTIES, COGNITIONS AND STRESS IN PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES: A SYSTEMATIC REVIEW**

Abstract.....	2
Introduction.....	3
Methodology.....	7
Search strategy.....	7
Inclusion and Exclusion Criteria.....	7
Methodology for Reviewing the Quality of the Evidence Base.....	8
Results.....	10
Review of the Literature.....	18
1. Behavioural difficulties in individuals with ID.....	18
2. Parental cognitions.....	18
3. Parental well-being.....	20
4. The association between behavioural difficulties and parental well-being.....	21
5. The relationship between child behavioural difficulties and parental cognitions	22
6. The relationship between parental cognitions and parental well-being.....	24
7. Predictions of parental well-being.....	25
8. Mediation Analysis.....	28
9. Moderation Analysis.....	29
Discussion.....	31
Limitation of the studies reviewed.....	35

Limitations of the review.....	36
Clinical implications.....	37
Future directions.....	37
Conclusions.....	39
References.....	40
Preface to Chapter 2.....	47

**CHAPTER TWO: EMPIRICAL PAPER: THE RELATIONSHIP BETWEEN CHALLENGING BEHAVIOUR, COGNITIONS AND STRESS IN MOTHERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES**

Abstract.....	49
Introduction.....	50
Method.....	60
Participants.....	60
Measures.....	61
Background information.....	61
Child’s level of challenging behaviour.....	61
Maternal Cognitions.....	62
Maternal stress.....	65
Procedure.....	65
Results.....	68
Data Analysis.....	68
1. Psychometric properties of the CBPQ.....	69
Internal Consistency.....	72



Test-retest reliability.....	72
Concurrent validity of the CBPQ.....	72
2. Correlations.....	76
3. Mediation Analysis.....	78
Mediation analysis for aggression/destruction and parental stress.....	80
Mediation analysis for self-injurious behaviour and parental stress.....	81
Discussion.....	83
Psychometric properties of the CBPQ.....	83
The relationship between challenging behaviour, maternal cognitions and maternal stress.....	85
Maternal cognitions as a mediator of challenging behaviour on maternal stress.....	88
Limitations of the study.....	89
Future directions.....	90
Clinical implications.....	91
Conclusion.....	92
References.....	93
Public domain briefing document.....	102

## Appendices for Volume I

### **LITERATURE REVIEW: THE RELATIONSHIP BETWEEN BEHAVIOURAL DIFFICULTIES, COGNITIONS AND STRESS IN PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES: A SYSTEMATIC REVIEW**

Appendix A: Checklist for measuring study quality (Downs & Black, 1998).....104

### **EMPIRICAL PAPER: THE RELATIONSHIP BETWEEN CHALLENGING BEHAVIOUR, COGNITIONS AND STRESS IN MOTHERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES**

Appendix B: Questionnaire pack..... 106

Appendix C: Ethical Approval..... 116

Appendix D: Participant Information sheet..... 119

Appendix E: Counter-balancing the questionnaire pack..... 121

Appendix F: Descriptive information for the questionnaires..... 122

Appendix G: Tests of normality for all measures included in current study..... 123

Appendix H: Exploration of potentially confounding variables..... 124

Appendix I: Bootstrapping analysis for self-injurious behaviour and aggressive/  
destructive behaviour..... 125

**List of Figures for Volume I**

**EMPIRICAL PAPER: THE RELATIONSHIP BETWEEN CHALLENGING  
BEHAVIOUR, COGNITIONS AND STRESS IN MOTHERS OF INDIVIDUALS  
WITH INTELLECTUAL DISABILITIES**

*Figure 1.* Significant correlations between the variables in the proposed model for  
aggression / destruction..... 79

*Figure 2.* Significant correlations between the variables in the proposed mediation model  
for self-injurious behaviour..... 79

## List of Tables for Volume I

### **LITERATURE REVIEW: THE RELATIONSHIP BETWEEN BEHAVIOURAL DIFFICULTIES, COGNITIONS AND STRESS IN PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES: A SYSTEMATIC REVIEW**

Table 1. <i>Search terms employed in the current literature review.....</i>	7
Table 2. <i>A summary of the papers included in the review.....</i>	11

### **EMPIRICAL PAPER: THE RELATIONSHIP BETWEEN CHALLENGING BEHAVIOUR, COGNITIONS AND STRESS IN MOTHERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES**

Table 1. <i>Reliability of the CBPQ at subscale level.....</i>	70
Table 2. <i>Test-rest reliability of the CBPQ at item level.....</i>	71
Table 3. <i>Correlations between the subscales of the CBPQ and the PLOC-SFR subscales, the PSOC Satisfaction subscale and the FoAM.....</i>	73
Table 4. <i>Correlation matrix for study variables.....</i>	76
Table 5. <i>Mediation of the effect of aggression/destruction on maternal stress through maternal perceptions of challenging behaviour.....</i>	80
Table 6. <i>Mediation of the effect of self-injurious behaviour on maternal stress through maternal perceptions of challenging behaviour.....</i>	81

## Table of Contents for Volume II

### CLINICAL PRACTICE REPORT I: PSYCHOLOGICAL MODELS.

#### Formulating the case of a ten-year old boy with obsessive compulsive disorder.

Abstract.....	2
Referral information.....	3
Assessment.....	3
Initial Assessment .....	3
Family Background .....	4
Developmental history.....	7
Educational history .....	7
Interview with Daniel.....	7
Interview with Daniel’s mum .....	10
Interview with Daniel’s nan .....	11
Diary .....	12
Psychometric Measures.....	12
Risk Assessment .....	13
Formulations.....	14
Background to formulations.....	14
Systemic formulation.....	14
Systemic Theory.....	14
Systemic Formulation of Daniel’s Difficulties .....	16
Behavioural Formulation.....	23
Behavioural Theory.....	23
Behavioural Formulation of Daniel’s Difficulties.....	24

Critical appraisal.....	29
Reflections.....	29
Potential Bias.....	30
References.....	33

## **CLINICAL PRACTICE REPORT II: CASE STUDY.**

### **A case study of a fourteen year old girl with selective mutism.**

Abstract.....	37
Background information.....	38
Referral Information.....	38
An overview of selective mutism.....	38
Assessment.....	40
Family Background.....	40
Presentation.....	42
Presenting difficulties.....	42
Interview with Emma’s mum.....	43
Developmental history.....	44
Educational history.....	44
Psychometric Assessments.....	45
Goals.....	47
Potential Sources of Biases/Error.....	47
Formulation.....	48
5 Ps model.....	48
Model based on operant learning theory.....	52

Intervention.....	56
Modelling prompts, Verbal prompts and Fading.....	57
Shaping.....	57
Contingency management.....	57
Graded Exposure.....	58
Tasks outside of sessions.....	58
Social Activities.....	60
Intervention with school.....	61
Maintenance.....	61
Evaluation.....	62
Quantitative Evaluation.....	62
Qualitative Evaluation.....	63
Potential biases in Evaluation.....	64
Reflections.....	65
References.....	67

### **CLINICAL PRACTICE REPORT III: SINGLE-CASE EXPERIMENTAL DESIGN.**

#### **Investigating the effectiveness of a cognitive behavioural intervention for a female with trichotillomania using a single case experimental design.**

Abstract.....	74
Reason for referral.....	75
Assessment.....	75
Assessment tools.....	75
Presenting problems.....	77

History of the condition.....	79
Personal and social history.....	80
Risk Assessment.....	83
Goals for therapy.....	83
Potential Sources of Biases/Error.....	83
Formulation.....	84
Psychological models of trichotillomania.....	84
Behavioural model of trichotillomania.....	84
Cognitive-behavioural model of trichotillomania.....	84
Summary of models.....	85
Sarah's formulation.....	85
Behavioural formulation of the habitual part of Sarah's trichotillomania..	86
Cognitive-behavioural formulation of the habitual part of Sarah's trichotillomania.....	88
Intervention.....	91
Literature on Interventions for Trichotillomania.....	91
Intervention for Sarah.....	92
Psycho-education.....	92
Habit reversal (Azrin & Nunn, 1973).....	92
Problem-solving.....	93
Changing her behavioural pattern of avoidance.....	93
Mindfulness.....	93
Complicating factors.....	94
Liaison with University.....	94



Design.....	94
Results.....	96
Duration of fiddling and pulling hair.....	96
Frequency of episodes of fiddling and pulling hair.....	101
Severity of hair-pulling (i.e. number of hairs pulled).....	103
Changes in scores on psychometric measures.....	106
Discussion.....	107
Reflections on the results of the study.....	107
Reflections on the design of the study.....	108
Personal reflections.....	109
References.....	111

## **CLINICAL PRACTICE REPORT IV: SERVICE EVALUATION.**

### **Developing a new model of service delivery to address staff stress and staff well-being in a Learning Disability service.**

Abstract.....	116
Introduction.....	117
The NHS Constitution.....	117
Government reviews.....	117
Government White Papers.....	119
Government Strategies and Frameworks.....	120
National Institute for Clinical Excellence (NICE) guidance.....	121
Research evidence.....	121
Aims.....	122

Method.....	124
Design.....	124
Participants.....	124
Measures.....	124
Procedure.....	126
Results.....	127
1. Mindfulness skills.....	127
2. Perceived stress levels.....	128
3. Psychological well-being.....	129
Summary of Results.....	129
Discussion.....	130
Interpretation of Findings.....	130
Factors that would facilitate the proposed service development.....	132
Factors that would block the proposed service development.....	133
Strengths of the service evaluation.....	134
Limitations of the service evaluation.....	134
Recommendations.....	136
Personal reflections.....	138
References.....	139

## **CLINICAL PRACTICE REPORT V: CLINICAL PRESENTATION.**

### **A case study of Jane: an older adult with dementia who experienced anxiety and low self-esteem**

Abstract.....	144
---------------	-----

References.....	145
-----------------	-----

## Appendices for Volume II

### **CLINICAL PRACTICE REPORT I: PSYCHOLOGICAL MODELS.**

#### **Formulating the case of a ten-year old boy with obsessive compulsive disorder.**

Appendix A: Exercises used to demonstrate that Daniel understood the concept of thoughts, feelings and behaviour and was able to make the link between these domains...147

### **CLINICAL PRACTICE REPORT II: CASE STUDY.**

#### **A case study of a fourteen year old girl with selective mutism.**

Appendix B: Behavioural terms used ..... 148

### **CLINICAL PRACTICE REPORT III: SINGLE-CASE EXPERIMENTAL DESIGN.**

#### **Investigating the effectiveness of a cognitive behavioural intervention for a female with trichotillomania using a single case experimental design.**

Appendix C: An example of a sheet from Sarah's trichotillomania diary..... 149

Appendix D: The raw data from Sarah's trichotillomania diary..... 150

### **CLINICAL PRACTICE REPORT IV: SERVICE EVALUATION.**

#### **Developing a new model of service delivery to address staff stress and staff well-being in a Learning Disability service.**

Appendix E: Descriptive Statistics..... 152

Appendix F: Tests of Normality..... 154

Appendix G: The output from the Dependent (Paired Samples) T-test..... 155

Appendix H: The output from the non-parametric tests..... 156

## List of Figures for Volume II

### CLINICAL PRACTICE REPORT I: PSYCHOLOGICAL MODELS.

#### Formulating the case of a ten-year old boy with obsessive compulsive disorder.

<i>Figure 1.</i> Genogram of Daniel's family.....	6
<i>Figure 2.</i> A list of Daniel's compulsions at night-time.....	9
<i>Figure 3.</i> Multiple Levels of Context for Daniel's System (Cronen and Pearce, 1985)....	17
<i>Figure 4.</i> Problem-maintaining cycle between Daniel and his mum (adapted from Dallos & Stedman, 2006).....	20
<i>Figure 5.</i> A strange loop of mum's role in Daniel's compulsions (adapted from Pearce and Cronen, 1980).....	22
<i>Figure 6.</i> Process of classical conditioning and subsequent operant conditioning in the development and maintenance of Daniel's behaviour.....	25
<i>Figure 7.</i> Mutual reinforcement of Daniel's behaviour.....	27

### CLINICAL PRACTICE REPORT II: CASE STUDY.

#### A case study of a fourteen year old girl with selective mutism.

<i>Figure 1.</i> Genogram of Emma's family.....	41
<i>Figure 2.</i> Formulation of Emma's difficulties using the 5Ps model.....	49
<i>Figure 3.</i> The mutual reinforcement of Emma's behaviour based on operant learning theory.....	53
<i>Figure 4.</i> Observational evaluation of Emma's verbalisations from baseline (assessment stage) through the intervention.....	62

**CLINICAL PRACTICE REPORT III: SINGLE-CASE EXPERIMENTAL DESIGN.**

**Investigating the effectiveness of a cognitive behavioural intervention for a female with trichotillomania using a single case experimental design.**

*Figure 1.* Genogram of Sarah’s Family..... 82

*Figure 2.* Maintenance cycle based on operant learning for the habitual part of Sarah’s trichotillomania..... 87

*Figure 3.* A hypothetical longitudinal CBT formulation of Sarah’s difficulties..... 89

*Figure 4.* CBT maintenance cycles for the focused part of Sarah’s trichotillomania..... 90

*Figure 5.* (A) The duration of fiddling and pulling hair in the baseline and intervention phases with OLS regression lines fitted and (B) after data transformation.....96

*Figure 6.* An Autocorrelagram of the baseline and intervention phases for the duration of fiddling and pulling hair..... 97

*Figure 7.* Trends per phase in the original units of measurement (A) and after the autoregressive error structure had been removed (B).....99

*Figure 8.* The bootstrap distribution of the regression parameters..... 100

*Figure 9.* An Autocorrelagram of the baseline and intervention phases for the frequency of fiddling and pulling hair..... 101

*Figure 10.* (A) Trends per phase in the original units of measurement and (B) after the autoregressive error structure had been removed..... 102

*Figure 11.* The bootstrap distribution of the regression parameters..... 103

*Figure 12.* An Autocorrelagram of the baseline and intervention phases..... 104

*Figure 13.* The severity of hair-pulling in the baseline and intervention phases with OLS regression lines fitted..... 105

*Figure 14.* The bootstrap distribution of the regression parameters..... 105

## List of Tables for Volume II

### CLINICAL PRACTICE REPORT I: PSYCHOLOGICAL MODELS.

#### Formulating the case of a ten-year old boy with obsessive compulsive disorder.

Table 1. <i>Daniel's Diary of his obsessive-compulsive behaviours during one week.....</i>	12
Table 2. <i>Possible Antecedents and Consequences to Daniel's behaviour.....</i>	24

### CLINICAL PRACTICE REPORT II: CASE STUDY.

#### A case study of a fourteen year old girl with selective mutism.

Table 1. <i>DSM-IV criteria for selective mutism.....</i>	38
Table 2. <i>Information about the observation of Emma's verbalisations.....</i>	46
Table 3. <i>A hierarchy of goals for sessions.....</i>	58
Table 4. <i>A hierarchy of goals outside of sessions.....</i>	59
Table 5. <i>The graded exposure tasks agreed for the corner shop.....</i>	60

### CLINICAL PRACTICE REPORT III: SINGLE-CASE EXPERIMENTAL DESIGN.

#### Investigating the effectiveness of a cognitive behavioural intervention for a female with trichotillomania using a single case experimental design.

Table 1. <i>Sarah's scores on the psychometric measures.....</i>	76
Table 2. <i>The confidence interval for the difference between baseline and intervention intercepts and slopes for the duration of fiddling and pulling hair.....</i>	98
Table 3. <i>Sarah's scores before and after the intervention phase.....</i>	106

**CLINICAL PRACTICE REPORT IV: SERVICE EVALUATION.**

**Developing a new model of service delivery to address staff stress and staff well-being in a Learning Disability service.**

Table 1. *Mean pre and post scores for the staff group on the KIMS.....* 127

Table 2. *Mean pre and post scores for the staff group on the MBI-HSS and the PSS.....* 128



## CHAPTER 1: LITERATURE REVIEW

# THE RELATIONSHIP BETWEEN BEHAVIOURAL DIFFICULTIES, COGNITIONS AND STRESS IN PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES: A SYSTEMATIC REVIEW

## Abstract<sup>1</sup>

*Background* Maternal cognitions may influence the effect of behavioural difficulties on parental well-being via mediation or moderation but no study has reviewed this since 2005. The aims of the review were to assess the relationship between these variables by examining studies using correlational and regression analyses; and to examine whether parental cognitions mediated or moderated the effect of behavioural difficulties on parental well-being.

*Method* Systematic searches of PsycINFO, Embase and Medline were conducted using specific inclusion and exclusion criteria. References of studies identified through this search strategy, were also examined. All articles identified were subject to a review of quality (Downs & Black, 1998).

*Results* 15 articles met the inclusion criteria for this review. The review identified relationships between behavioural difficulties, parental cognitions and parental well-being but findings on the mediating and moderating role of cognitions were inconclusive.

*Conclusion* The literature provides evidence of relationships between behavioural difficulties, parental cognitions and parental well-being. However, further systematic investigations are needed to explore the mediating and moderating role of cognitions.

*Keywords:* *behaviour difficulties, parental cognitions and parental well-being.*

---

<sup>1</sup> The review has been prepared as if for submission to the Journal of Applied Research in Intellectual Disabilities.

## Introduction

Exploring well-being in parents of individuals with intellectual disabilities (ID) has formed an important part of the literature on families (Blacher, Neece, & Paczkowski, 2005; Hassall & Rose, 2005; Hatton & Emerson, 2003). Until recently, the majority of research in this area has focused on maladjustment and the negative consequences of parenting, such as stress and mental health (Hastings, 2002). This may in part be due to a number of findings showing that parents of individuals with ID experience significantly more stress and mental health difficulties than parents of typically developing children (e.g. Dyson, 1993; 1997). Some studies, however, report no difference in well-being between these groups, suggesting that a range of factors are likely to contribute to parental well-being, other than solely presence of ID (e.g. Donenberg & Baker, 1993). More recently, research has also focused on bonadaptation and resilience factors (e.g. optimism) that contribute to well-being in parents, providing a more balanced and comprehensive picture of adaptation in families (e.g. Hastings, Beck, & Hill, 2005; Hastings & Taunt, 2002; Hatton & Emerson, 2003).

Models of parenting stress have been used to explore parental well-being in the field of ID (e.g. Orr, Cameron, & Day, 1991; Saloviita, Itälinna, & Leinonen, 2003). Examples of models include, the Double ABCX model (McCubbin & Patterson, 1983), the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Model of Parent-Child Interactive Stress (Mash & Johnston, 1990). Factors proposed to contribute to parental well-being and adjustment in these models, broadly include child characteristics, parent characteristics and environmental factors (e.g. McCubbin & Patterson, 1983). The specificity of these factors and the way they inter-link, however, differ between models.

In ID research, a range of child characteristics have been examined in relation to parental well-being. One child characteristic found to be most reliably related to parental well-being is behavioural difficulties (Hastings, 2002). Behavioural difficulties have been reported to relate more to parenting stress than other child characteristics, such as severity of ID (Baker, Blacher, Crnic, & Edelbrock, 2002). This relationship is evident even when pertinent family or parent characteristics are controlled for and the relationship also persists over time (Heller, Hsieh, & Rowitz, 1997; Quine & Pahl, 1991; Sloper, Knussen, Turner, & Cunningham, 1991). Behavioural difficulties have also been found to significantly predict parental well-being even when other relevant demographic variables are controlled for (e.g. Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

Models of parenting stress, such as Mash and Johnston (1990), propose that parental appraisals may mediate or moderate the effect of behavioural difficulties on parental well-being. Baron and Kenny (1986) defined both mediation and moderation. Mediation was defined as a variable that "accounts for the relation between the predictor and the criterion. Mediators explain how external physical events take on internal psychological significance" (Baron & Kenny, 1986, p.1176). This suggests that mediators are third variables carrying the effect of an independent variable on a dependent variable (Hastings, 2002). Baron and Kenny (1986) defined a moderator as

a qualitative (e.g., sex, race, class) or quantitative (e.g., level of reward) variable that affects the direction and / or strength of the relation between an independent or predictor variable and a dependent or criterion variable.

Specifically, within a correlational analysis framework, a moderator is a third

variable that affects the zero-order correlation between two other variables.

(p.1174)

This suggests that a moderator changes the relationship between an independent and a dependent variable (Hastings, 2002).

Research is emerging in the family ID literature on the effect of behavioural difficulties on parental well-being via mediation or moderation. For example, Hastings and Brown (2002) examined the effect of self-efficacy on this relationship in mothers and fathers of children with autism. Self-efficacy mediated the relationship between behaviour problems and both anxiety and depression in mothers. The results suggested that children's behavioural problems lowered self-efficacy in mothers leading to increased mental health difficulties. Self-efficacy acted as a moderator of this relationship for fathers, indicating that those with higher levels of self-efficacy were less affected by their child's behavioural difficulties. In another study, coping strategies were found to predominantly mediate the effect of child behavioural difficulties on parental stress (Quine & Pahl, 1991). Similarly, Orr, Cameron, and Day (1991) found that coping partially mediated the effect of child behavioural difficulties on parental distress.

The aims of the current review are to examine the relationship between behavioural difficulties shown by individuals with ID, parental cognitions and parental well-being. Studies employing correlational analyses will be used to explore these relationships initially. The review will then investigate whether behavioural difficulties and parental cognitions predict parental well-being and whether cognitions moderate or mediate the effect of behavioural difficulties on well-being. Before examining these relationships in detail, a preliminary examination of each variable

separately, will be conducted. This will help to determine whether any other factors influence these variables.

The term “parental well-being” will be used to encompass stress, mental health and positive adjustment as these factors have been classified as well-being variables within the literature (e.g. Lloyd & Hastings 2009a; 2009b). *Cognitive appraisal* has been defined as “ a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being and, if so, in what way” (Folkman, Lazarus, Gruen, & DeLongis, 1986, p.572). A range of appraisals have been examined in the ID literature, such as, attributions, parenting satisfaction, coping, optimism and hope (e.g. Hassall, Rose, & McDonald, 2005) and these will all be explored in the current review.

## Methodology

### *Search strategy*

Systematic searches of three databases were conducted. The databases used were PsycINFO, Embase and Medline. The search terms employed to find relevant articles are shown in Table 1. Reference lists of papers identified were also searched.

Table 1

*Search terms employed in the current literature review\**

Search Terms
"Intellectual disab\$" or "learning disab\$" or "mental retard\$" or "developmental disab\$"
AND
"parent\$" or "mother\$" or "maternal" or "father\$" or "paternal"
AND
"cognition\$" or "attribution\$" or "perception\$" or "appraisal\$" or "belief\$" or "efficacy"
AND
"stress\$" or "well-being" or "mental health" or "anxiety" or "depression"

\* "behavioural difficulties" or "challenging behaviour" were not used as search criteria because some articles examined a number of child characteristics, including behavioural difficulties.

### *Inclusion and Exclusion Criteria*

The following inclusion criteria were used to place initial limits on the searches conducted in the databases:

1. English language
2. Human
3. Peer-reviewed journal articles
4. Date: 2005-April 2013

Only articles from 2005 onwards were reviewed as a similar review was published by Hassall and Rose in 2005. Each search produced a number of articles.

These were examined and only included if they were quantitative studies and they included a specific measure of behavioural difficulties / challenging behaviour, parental cognition and parental well-being. In order to assess whether challenging behaviour and / or parental cognitions predicted parental well-being, studies were only incorporated in the current review if they included a regression analysis between at least two of the variables examined.

Exclusion criteria were also employed to finalise the articles included in the current review. Journal articles were excluded from the review if:

1. They were intervention studies.
2. They did not focus on parents of individuals with intellectual disabilities.
3. They did not incorporate a specific measure of behavioural difficulties in individuals with intellectual disabilities, parental cognitions and parental well-being.

#### *Methodology for Reviewing the Quality of the Evidence Base*

A key aspect of a comprehensive systematic review is the assessment of the methodological quality of the primary research (Sanderson, Tatt, & Higgins, 2007). Reviews of quality measures have predominantly concluded that there is no 'gold-standard' tool of quality assessment (Sanderson et al., 2007). For the current review, a measure for assessing the quality of quantitative studies was key. Sanderson et al. (2007) conducted a review of tools developed to measure quality or susceptibility to bias in observational, epidemiological studies. Of the measures reviewed, the Downs and Black (1998) quality criteria seemed most appropriate, as it is a scale and thus produces a summary score with which to compare papers. The questions are also operationally defined making it easier to use and the psychometric properties are also acceptable (Downs & Black, 1998). Only questions applicable to non-intervention



studies were included, resulting in 17 items with which to assess quality (see Appendix A for quality criteria used in the current review). Of these, three items were only applicable to longitudinal studies. Therefore a total possible score of 18 (one item has a possible score of two) was obtainable for longitudinal studies and 15 for cross-sectional studies. Percentages were also calculated for scores to allow for comparisons across all studies.

## Results

The searches in PsycINFO, Embase and Medline produced 74, 119 and 106 articles, respectively. After excluding duplicates and any articles that did not meet the inclusion criteria, 14 articles were identified. One additional article was identified by examining the references of these articles (see Table 2 for the results of the literature search and quality review). In total, 15 articles were identified and these were included in the current review. Any differences in statistical tests referred to in the Results section are statistically significant.

Table 2  
*A summary of the papers included in the review*

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
1. Woodman & Hauser-Cram (2013)	Longitudinal, questionnaire study.	92 mothers in USA (mean age at T1: 43.87 years) of adolescents with ID (mean age at T1: 15.11 years). T1-adolescent was approx. 15 years and T2- adolescent was approx. 18 years.	1. Child Behavior Checklist (Achenbach, 1991)-behavioural difficulties.	1. COPE Inventory (Carver et al., 1989): coping style.	1. Center for Epidemiological Studies-Depression scale (Radloff, 1977)-depression. 2. Family Experiences Questionnaire (Frank et al., 1986)-parenting efficacy. (parenting efficacy is a well-being DV in this study).	Behavioural difficulties and coping style predicted maternal depression. Both active coping/planning and reinterpretation/growth moderated the relationship between behavioural difficulties and maternal depression at T1. Behavioural difficulties predicted change in maternal depressive symptoms from T1 toT2. Behavioural/mental disengagement moderated the relationship between behavioural difficulties and change in depressive symptoms. Behavioural difficulties and coping predicted parenting efficacy. Coping did not moderate the relationship between behavioural difficulties and parenting efficacy.	12/18 (66.7%)
2. MacDonald, Hastings & Fitzsimons (2010)	Cross-sectional, postal,, questionnaire study.	99 fathers (mean age: 47.05 years) of children with mixed aetiology ID (mean age: 11yrs 10 months).	1. Strengths and Difficulties Questionnaire (Goodman, 1997)- behavioural difficulties .	1. Adapted version of Acceptance and Action Questionnaire-II (Bond et al., submitted)- psychological acceptance.	1. Parent and Family Problems subscale from the Questionnaire on Resources and Stress Friedrich-short form (Friedrich et al., 1983)-stress. 2. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)-anxiety and depression. 3. Positive Gain Scale (Pitten Cate, 2003)-positive experiences raising a child with an ID.	Psychological acceptance and the child's Down syndrome diagnosis predicted paternal positive gain. Acceptance and child behavioural problems predicted paternal stress, anxiety and depression. Acceptance partially mediated the impact of child behaviour problems on paternal stress, anxiety and depression.	11/15 (73.3%)

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
3. Norizan & Shamsuddin (2010)*	Cross-sectional, questionnaire study.	147 Malaysian mothers (mean age: 43.1 years) of children with Down syndrome (DS; range: 2-12 years).	1. Paediatric Symptom Checklist (Jellinek et al., 1986): behavioural difficulties	1. COPE Inventory (Carver et al., 1989): coping style.	1. Parental Stress Scale (Berry & Jones, 1995): parental stress. 2. Depression, Anxiety and Stress Scale: depression, anxiety and stress.	Mean parenting stress was significantly higher for mothers of children with behavioural difficulties compared to those without behavioural difficulties. Child behavioural difficulties, maternal acceptance and maternal depression explained 18% of the variance in parenting stress, with acceptance and depression being significant, independent predictors. Depression mediated the relationship between child behavioural difficulties and parenting stress.	8/15 (53.3%)
4. Hill & Rose (2009)	Cross-sectional, questionnaire study (questionnaires administered via interview).	44 mothers (mean age: 68.67 years) of adults with ID (mean age: 40.05 years).	1. Vineland Maladaptive Behavior Domain (Sparrow et al., 1984)- behavioural difficulties .	1. Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978)- Self esteem 2. Parental Locus of Control Scale - short form revised (Campis et al., 1986; Hassall et al., 2005) -locus of control.	1. Parenting stress Index – short form (Abidin, 1990) - parenting stress.	The regression analysis model (adaptive behaviour, behavioural difficulties, social support, parenting satisfaction and locus of control) accounted for 61% of variance in parenting stress. Parenting satisfaction was a significant negative predictor and locus of control was a significant positive predictor of parenting stress. The criteria were not met to explore the cognitive variables as mediators of behavioural difficulties on parenting stress.	8/15 (53.3%)

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
5. Lloyd & Hastings (2009a)	Longitudinal 18-month follow-up, questionnaire study. (questionnaires completed via post and VABS completed via telephone).	Time 1: 91 mothers (mean age: 41.57 years) of children with ID. Time 2: 57 mothers (mean age: 43.96 years) of children with ID.	1. Strengths and Difficulties Questionnaire (Goodman, 1997)- behavioural difficulties.	1. Parental Locus of Control Scale (Campis et al., 1986)- locus of control	1. Parent and Family Problems subscale from the Questionnaire on Resources and Stress Friedrich-short form (Friedrich et al., 1983)-stress. 2. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)-anxiety and depression. 3. Positive Contributions Scale (Behr et al., 1992)- positive perceptions of their child.	Mothers' positive perceptions were predicted by the belief that external factors affect their child's behaviour (fate/chance), the belief in parental control over the child's behaviour, the number of children in the family and maternal employment. Parent control over the child's behaviour predicted maternal anxiety and child control predicted maternal depression and stress. An increase in behaviour problems over time predicted increased maternal stress over time. Mothers whose locus of control became more external over time reported higher stress levels at Time 2. Maternal locus of control did not moderate the effect of behavioural difficulties on maternal distress.	11/18 (61.1%)
6. Lloyd Hastings (2009b)	Cross-sectional, postal questionnaire study.	138 mothers (mean age: 39.56 years) and 58 fathers (mean age: 41.78 years) of children with mixed aetiology ID (mean age: 10.07 years).	1. Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994)- behavioural difficulties/mental health difficulties.	1. Trait Hope Scale (Snyder et al., 1991)- dispositional hope.	1. Parent and Family Problems subscale from the Questionnaire on Resources and Stress Friedrich-short form (Friedrich et al., 1983)-stress. 2. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)-anxiety and depression. 3. Positive Affect Scale (from the PANAS; Watson et al., 1988)-positive affect.	More behavioural difficulties and less hope agency and hope pathways predicted maternal depression. Hope agency and hope pathways interacted significantly in predicting maternal depression. Less behavioural difficulties and more hope agency predicted positive affect in mothers. Behavioural difficulties predicted maternal anxiety and stress. Low hope agency predicted paternal anxiety and paternal depression and high hope agency predicted positive affect in fathers.	8/15 (53.3%)

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
7. Lloyd & Hastings (2008)	Longitudinal 18-month follow-up, questionnaire study. (questionnaires completed via post and VABS completed over the telephone).	Time 1: 91 mothers (mean age: 41.57 years) of children with ID. Time 2: 57 mothers (mean age: 43.96 years) of children with ID.	1. Strengths and Difficulties Questionnaire (Goodman, 1997)-behavioural difficulties.	1. Acceptance and Action Questionnaire (Bond & Bunce, 2000)-psychological acceptance. 2. Mindful Attention Awareness Scale (Brown & Ryan, 2003)-mindfulness. 3. Active Avoidance Coping Scale from an adapted version of Brief Cope (Carver, 1997)-avoidant coping.	1. Parent and Family Problems subscale from the Questionnaire on Resources and Stress Friedrich-short form (Friedrich et al., 1983)-stress. 2. Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)-anxiety and depression. 3. Positive Contributions Scale from the KIPP (Behr et al., 1992)- positive perceptions of their child.	The cross-sectional analysis showed that acceptance predicted anxiety, whilst both acceptance and avoidant coping predicted maternal depression. Child behavioural problems predicted maternal stress. The longitudinal analysis showed that mothers whose acceptance increased from Time 1 to Time 2 reported significantly less anxiety, depression and stress at Time 2.	11/18 (61.1%)
8. Lopez, Clifford, Minnes & Ouellette-Kuntz (2008)	Cross-sectional, telephone interview study (part of larger longitudinal study).	29 parents of children with ID (mean age: 55.65 months) and 17 parents of children without ID (mean age: 49.47 months).	1. Scales of Independent Behavior-Revised (Bruininks et al., 1996)-behavioural difficulties.	1. Ways of Coping Scale-revised (McCull & Skinner, 1995)-coping.	1. Family Stress and Coping Interview (Nachshen et al., 2003)-parenting stress	Behavioural difficulties did not predict stress levels in either group of parents. There was no significant difference between the groups in total coping scores or type of coping used. Parents across the two groups used significantly more problem-focused and perception-focused coping than emotion-focused coping.	7/15 (46.7%)

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
9. Blacher and Baker (2007)	Cross-sectional (study 1) and longitudinal (study 2) questionnaire study.	<i>Study 1:</i> 282 parents (150 Anglo and 132 Latino mothers) in USA of young adults with ID (mean age: 20.3 years). <i>Study 2:</i> 214 families in USA of young children (a) with ID ( $n = 92$ ; mean age: 35.6 months) (b) no ID ( $n = 122$ ; mean age: 34.9 months).	<i>Study 1.</i> Scales of Independent Behavior-Revised (Bruininks et al., 1996)-behavioural difficulties. <i>2.</i> Reiss Screen for Maladaptive Behavior (Reiss, 1994)-mental health difficulties. <i>Study 2.</i> Child Behavior Checklist (Achenbach, 2000)-behavioural difficulties.	<i>Study 1 and 2.</i> The Family Impact Questionnaire (Donenberg & Baker, 1993)-parents' Perceptions of the positive and negative impact of child on the family.	<i>Study 1 and 2.</i> Center for Epidemiological Studies-Depression scale (Radloff, 1977)-depression.	<i>Study 1:</i> Child mental health and positive perceptions significantly predicted negative family perceptions. Positive impact moderated the relationship between child mental health and negative impact. <i>Study 2:</i> Fathers reported higher positive perceptions than mothers. A significant interaction between culture and delay was found for mothers but not fathers. Positive impact significantly moderated the relationship between child behavioural difficulties and negative impact for mothers, at all three time points and this occurred for fathers, at two time points.	11/18 (61.1%)
10. Feldman et al. (2007)	Cross-sectional, questionnaire study. (Questionnaires completed primarily during an interview).	178 primary caregivers (mainly biological mothers) of children with:- (a) ID due to known reasons ( $n = 67$ ). (b) ID due to unknown reasons ( $n = 69$ ). (c) risk of ID due to low birth weight, prematurity or multiple birth ( $n = 58$ ).	1. Child Behavior Checklist (Achenbach, 1992)-behavioural difficulties.	1. Ways of Coping Questionnaire-Revised (Schwarzer & Schwarzer, 1996)-coping. 2. Child Behaviour Management Survey (Feldman & Werner, 2002)-caregiver self-efficacy.	1. Beck Depression Inventory II (Beck et al., 1996).	Child behaviour problems, escape-avoidance coping and social support predicted levels of caregiver depression. Only social support mediated the relationship between child behaviour problems and depression. Social support, escape-avoidance coping and self-efficacy <i>did not</i> moderate the relationship between child behaviour problems and depression.	10/15 (66.7%)

Author	Design of study	Participants	Child behavioural measure(s) (IV)	Parental cognitive measure(s)	Parental well-being measure(s) (DV)	Findings	Quality score
11. Minnes, Woodford & Passey (2007)	Cross-sectional, questionnaire study (questionnaires administered via interview).	80 parents (71 mothers and 9 fathers) over 50 years (mean age: 65.7 years) who were primary carers of adults with ID of mixed aetiology (mean age: 35.7 years).	1. Vineland Maladaptive Behavior Domain (Sparrow et al., 1984)-behavioural difficulties.	1. The Family Stress and Coping Interview (Nachshen et al., 2002)-perceived stress relating to care-giving. 2. Self-perceived adverse age-change: carer (Smith et al., 1995)-adverse perceptions about ageing.	1. Center for Epidemiological Studies-Depression scale (Radloff, 1977)-depression. 2. A question designed by researchers-Quality of life.	Behavioural difficulties predicted parental depression. Perceived stress was a significant mediator of behavioural difficulties on parental stress. Behavioural difficulties were not significantly correlated with perceived adverse ageing or quality of life.	9/15 (60%)
12. Plant & Sanders (2007)	Cross-sectional, questionnaire study.	105 mothers (mean age: 35.24 years) of pre-school (<6 years) children in Australia (mean age: 49.71 months).	1. Rating scale for how often child showed behavioural difficulties during 7 care-giving areas (Plant & Sanders, 2007)-behavioural difficulties during care-giving tasks. 2. Developmental Behaviour Checklist (Einfeld & Tonge, 1995)-behavioural difficulties .	1. Ways of Coping Questionnaire-Revised (Folkman & Lazarus, 1988)-coping. 2. Adaptation of the Revised Ways of Coping Checklist (Vitaliano et al., 1985)-appraisal of care-giving role.	1. Parents rated care-giving tasks they found most stressful in order-stress. 2. Rating scale for level of stress for 8 areas of care-giving-stress.	Behavioural difficulties during care-giving tasks predicted maternal stress levels during care-giving. Mothers' appraisals of care-giving did not mediate the relationship between behavioural difficulties and maternal stress during care-giving tasks. Coping strategies did not moderate the relationship between behavioural difficulties during care-giving and maternal stress during care-giving or between overall behavioural difficulties and maternal stress during care-giving.	10.5/15 (70%)



Author	Design of study	Participants	Child behavioural measure(s) (DV)	Cognitive measure(s)	Parental well-being measure(s) (IV)	Findings	Quality score
13. Kersh et al. (2006)	Cross-sectional, questionnaire study.	67 families (only mothers and fathers who were married since the birth of the child) of children with ID.	1. Child Behavior Checklist (Achenbach, 1991)-behavioural difficulties.	1. Family Experiences Questionnaire (Frank et al., 1986)-parenting efficacy. (n.b. used as a DV in regression analysis).	1. Center for Epidemiological Studies-Depression scale (Radloff, 1977)-depression. 2. Parenting Stress Index (Abidin, 1995)-parenting stress.	Child behaviour problems significantly predicted higher levels of parenting stress and lower efficacy in mothers. Child behaviour problems significantly predicted higher levels of depression and parenting stress and lower levels of efficacy in fathers.	9/15 (60%)
14. Baker, Blacher & Olsson (2005)	Longitudinal, one-year follow-up study.	81 parents in USA of children with ID (mean age: 35.6 months) and 123 parents of children without ID (mean age: 34.9 months)	1. Child Behavior Checklist (Achenbach, 2000)-behavioural difficulties.	1. Life Orientation Test (Scheier et al., 1994)-dispositional optimism.	1. Center for Epidemiological Studies-Depression scale (Radloff, 1977)-depression. 2. The Family Impact Questionnaire (Donenberg & Baker, 1993)- parents' perceptions of the positive and negative impact of child on the family.	Child behaviour problems at T1 accounted for significant additional variance in maternal depression at T2. This effect was not evident for fathers. Optimism had a positive main effect relationship with depression at both time points for mothers and fathers. Optimism moderated the effect of behavioural problems on well-being for mothers.	11/18 (61.1%)
15. Hassall et al. (2005)	Cross-sectional, questionnaire study. (n.b. VABS completed during an interview)	46 mothers (mean age: 38.48 years) of children with ID (mean age: 9.33 years)	1. Vineland Maladaptive Behavior Domain (Sparrow et al., 1984)-behavioural difficulties.	1. Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978)- Self esteem 2. Parental Locus of Control Scale - SFR (Campis et al., 1986) -locus of control.	1. Parenting stress Index (Abidin, 1995) - parenting stress.	Parental locus of control, parenting satisfaction and behaviour difficulties significantly predicted parenting stress and accounted for 59% of its variance. The criteria were not met to investigate whether maternal cognitions mediated the effect of behavioural difficulties on parenting stress.	6/15 (40%)

\* Additional article identified by examining the references of the articles identified via the databases.

## Review of the Literature

### *1. Behavioural difficulties in individuals with ID*

Prevalence rates of behavioural difficulties vary between studies. Woodman and Hauser-Cram (2013) found that 41% of adolescents were reported to be at risk of clinically significant behavioural difficulties, using the Child Behavior Checklist (Achenbach, 1991). Norizan and Shamsuddin (2010) on the other hand, used the Paediatric Symptom Checklist (Jellinek et al., 1986) and found that 22.4% of Malaysian children with Down syndrome (DS) showed behavioural difficulties. These prevalence rates are likely to vary due to differences, such as participants' age, measures employed and the influence of culture.

Two studies compared levels of behavioural difficulties between individuals with and without ID. Both studies reported that significantly more children with ID showed behavioural difficulties compared to those without ID (Baker, Blacher, & Olsson, 2005; Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008). This is consistent with many studies reporting this finding (e.g. Dykens, 2000; Hastings, 2002).

In summary, these findings show that greater behavioural difficulties are evident for individuals with ID compared to those without ID. The prevalence rates of behavioural difficulties for individuals with ID vary between studies, which is likely to be a consequence of methodological differences (see Table 2).

### *2. Parental cognitions*

Studies in this review have examined parental cognitions in relation to parent gender, parent ethnicity and the aetiology of their child's ID. Woodman and Hauser-Cram (2013) examined maternal cognitions in relation to cause of ID and found that maternal self-efficacy and type of coping did not differ between parents of adolescents with three

different causes of ID. Maternal efficacy did not change over a period of approximately three years, indicating some stability in efficacy during adolescence (Woodman & Hauser-Cram, 2013).

Two studies compared cognitions between mothers and fathers (Blacher & Baker, 2007; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Kersh et al. (2006) found in 67 families that mothers reported greater parenting efficacy than fathers of children with ID. Blacher and Baker (2007), however, found that fathers reported more positive perceptions of their child's impact on the family than mothers. In the same study, positive perceptions were examined across two cultures ("Latino" and "Anglo") and a significant interaction between culture and degree of ID was found for mothers (Blacher & Baker, 2007). The results indicated that similar levels of positive perceptions were expressed by mothers of children with no ID but "Latino" mothers of children with ID reported more positive perceptions than "Anglo" mothers. These cultural differences were not significant for fathers, although a similar pattern of results was observed (Blacher & Baker, 2007).

Two studies compared parental cognitions between parents of children with and without ID (Blacher & Baker, 2007; Lopez et al., 2008). Both studies reported no significant difference in positive perceptions, total coping scores or type of coping used, between parents (Blacher & Baker, 2007; Lopez et al., 2008). Lopez et al. (2008) also found that both groups used more problem-focused and perception-focused coping than emotion-focused coping.

Overall these findings suggest that some parental cognitions are affected by parent gender and culture but not presence or cause of ID.

### *3. Parental well-being*

Levels of parental well-being have also been investigated. Feldman et al. (2007) found that 20% of 178 primary caregivers of children with ID scored above the clinical cut-off for further clinical evaluation for depression. Minnes, Woodford and Passey (2007) found that 16% of older caregivers (71 mothers and 9 fathers) of adults with ID scored above the clinical cut-off for depression.

The well-being of mothers and fathers has also been examined separately. One study reported that 23% of mothers of adolescents with ID scored at or above the cut-off for depression and this remained relatively stable over a three-year period (Woodman & Hauser-Cram, 2013). MacDonald, Hastings, and Fitzsimons (2010) found that 10.1% and 7.1% of fathers met the criteria for moderate-severe levels of anxiety and depression, respectively. Kersh et al. (2006) compared mothers and fathers and found that 18% of mothers and 24% of fathers of children with ID met the clinical cut-off for depression. These means did not differ from those for the general population. In the same study, approximately 27% of mothers and 22% of fathers reported stress scores in the high-risk range but again these means did not differ significantly from the normative sample. No difference was found between mothers and fathers in depressive symptoms or stress (Kersh et al., 2006).

The cause of ID has been found to relate to parental well-being. Feldman et al. (2007) found that caregivers of children with ID due to unknown reasons reported more depression than caregivers of children with ID due to known causes. MacDonald et al. (2010) found that fathers of children with autism reported significantly more stress than fathers of children with other ID. Fathers of children with DS reported less stress and more positive gain than fathers of children with other ID (MacDonald et al., 2010).

Two studies comparing well-being between parents of individuals with and without ID have reported contrasting results. Lopez et al. (2008) found that stress levels were higher for parents of children with ID compared to those without ID. However, Baker et al. (2005) found that mothers did not differ in depressive symptoms or marital adjustment at two time points, approximately a year apart. Fathers of children with ID actually reported less depression and greater marital adjustment than fathers of children with no ID, however, these differences were not significant approximately a year later (Baker et al., 2005). The variability in findings between these populations may be due to differences in sample size, measures employed and the age of children and parents. It may also reflect the differences in quality across studies (see Table 2) or the fact that well-being is affected by several factors, leading to different results across studies.

Together these results suggest that cause of ID appears important in affecting parental well-being. Comparisons with parents of children with no ID remain inconclusive at present.

#### *4. The association between behavioural difficulties and parental well-being*

Several studies have examined the relationship between behavioural difficulties and well-being in mothers of children with ID, using correlations. The majority of studies reported that child behavioural difficulties were associated with more maternal stress, anxiety and depression and less maternal positive affect (Baker et al., 2005; Hassall et al., 2005; Lloyd & Hastings, 2009b; Kersh et al., 2006; Plant & Sanders, 2007). Norizan and Shamsuddin (2010) found the same pattern in Malaysian mothers of children with DS. In contrast, one study reported a mixed picture, with child behavioural difficulties being positively associated with maternal stress but no associations were found with positive contributions of their child, anxiety or depression (Lloyd & Hastings, 2008; 2009a). Studies

that have explored this relationship in mothers of adults with ID reported that more behavioural difficulties were associated with greater maternal stress and depression but not with quality of life (Hill & Rose, 2009; Minnes et al., 2007).

Between-group comparisons show that stress was higher for mothers of children with behavioural difficulties compared to those without behavioural difficulties (Norizan & Shamsuddin, 2010). Similarly, Feldman et al. (2007) found that caregivers (mainly biological mothers) who scored above the clinical cut-off for depression reported more child behavioural difficulties than those without depression.

Inconsistent findings have been reported for fathers. Some studies show that greater behavioural difficulties are associated with more paternal anxiety, depression and stress (Baker et al., 2005; Kersh et al., 2006; MacDonald et al., 2010). On the other hand, some have found that more child behavioural difficulties are associated with less paternal stress and were unrelated to anxiety, depression, positive affect and positive gains (Lloyd & Hastings, 2009b; MacDonald et al., 2010).

Consistent with early findings, most research focusing on mothers of children and adults with ID reported relationships between behavioural difficulties and well-being. This relationship was also found in mothers from another culture (Norizan & Shamsuddin, 2010). The findings for fathers were inconsistent with no clear picture emerging at present.

##### *5. The relationship between child behavioural difficulties and parental cognitions*

Various types of parental cognitions have been examined in relation to behavioural difficulties. Three studies have explored the relationship with negative appraisals. All three studies found that greater behavioural difficulties were associated with more negative parental appraisals, including more negative appraisals of care-giving responsibilities, more

negative perceptions and more perceived parental stress (Blacher & Baker, 2007; Minnes et al., 2007; Plant & Sanders, 2007). The latter variable was categorised as a cognitive variable in the study (Minnes et al., 2007).

Some research has focused on parental efficacy, locus of control and satisfaction. A study of mothers of adults with ID found that more behavioural difficulties were associated with less perceived parental control over their child's behaviour but not with parenting satisfaction or efficacy (Hill & Rose, 2009). Child behavioural difficulties were, however, negatively associated with maternal efficacy but this relationship was not significant for fathers (Kersh et al., 2006). Two studies reported that child behavioural difficulties were associated with a more external locus of control (Hassall et al., 2005; Lloyd & Hastings, 2009a).

Some researchers have examined behavioural difficulties and resilience factors. In general, research findings show that greater parental optimism, hope and positive perceptions were associated with fewer behavioural difficulties (Baker et al., 2005; Blacher & Baker, 2007; Lloyd & Hastings, 2009b). Only hope and behavioural difficulties were not associated for fathers (Lloyd & Hastings, 2009b).

The increasing interest in third wave therapies has also affected the cognitions investigated in this field, for example, psychological acceptance and mindfulness. Lloyd and Hastings (2008) found that greater child behavioural difficulties were associated with less psychological acceptance in mothers of children with ID; behavioural difficulties were not related to mindfulness or avoidance coping in mothers.

In summary, these studies indicate that a range of parental cognitions, including negative appraisals, resilience factors, efficacy, locus of control and psychological acceptance, are related to behavioural difficulties. Some cognitions, such as mindfulness,

were unrelated. The results suggest that there may be an effect of child age on this relationship with efficacy being related for mothers of children with ID but unrelated for mothers of adults. There may also be an effect of parent gender on this relationship with some cognitions, such as hope and efficacy being related for mothers but not fathers. The sparsity of research examining these effects means that only tentative conclusions can be drawn.

#### *6. The relationship between parental cognitions and parental well-being*

A range of parental cognitions have been examined in relation to parental well-being. Studies examining attributions, efficacy and satisfaction reported that greater maternal parenting stress was associated with less parenting satisfaction and efficacy and a more external locus of control (Hassall et al., 2005; Hill & Rose, 2009). One study also found that a greater external locus of control in mothers was related to anxiety and depression but not to positive perceptions of their child (Lloyd & Hastings, 2009a).

Studies examining parents' negative appraisals found that more negative appraisals of care-giving responsibilities, more perceived stress (categorised as a cognitive variable) and more negative perceptions of their own ageing were associated with lower levels of well-being (Minnes et al., 2007; Plant & Sanders, 2007).

Studies focusing on resilience factors have reported that more hope, optimism and religious coping were associated with greater levels of well-being in parents (Baker et al., 2005; Lloyd & Hastings, 2009b; Norizan & Shamsuddin, 2010). In each study, not all well-being variables correlated with cognitions, e.g., hope was related to paternal anxiety, depression and positive affect but not paternal stress (Lloyd & Hastings, 2009b).



Studies exploring cognitions related to third wave therapies reported that more psychological acceptance and less avoidant coping was associated with greater well-being in mothers and fathers (Lloyd & Hastings, 2008; MacDonald et al., 2010; Norizan & Shamsuddin, 2010). Psychological acceptance and avoidant coping were not related to positive contributions in mothers, whilst mindfulness was not related to any maternal well-being variables (Lloyd & Hastings, 2008).

The findings show that most cognitions investigated were associated with parental well-being. Cognitions did not always correlate with all well-being variables, so further research is needed to establish the reason for this. Also, some cognitions such as mindfulness did not relate to any well-being variables, perhaps indicating that only certain cognitions are related to well-being. Again, research is needed to explore this further.

### *7. Predictors of parental well-being*

A range of variables have been examined as predictors of parental well-being. Some studies have examined predictors of maternal stress. Plant and Sanders (2007) found that 74% of variance in maternal stress during care-giving was explained by the regression model (difficulty of care-giving tasks, time of care-giving tasks, child behavioural difficulties during care-giving, child disability, total child problem behaviour); and difficult child behaviour during care-giving tasks was one independent predictor of stress. Another study found that child behaviour problems was also an independent predictor in the regression model (poverty, child functioning, child behaviour, social support and marital quality) for maternal stress, explaining 44% of variance (Kersh et al., 2006). Hassall et al. (2005) reported that child behaviour difficulties, parental locus of control and parenting satisfaction all predicted maternal stress, accounting for 59% of variance. Norizan and

Shamsuddin (2010) found that acceptance and depression rather than behavioural problems were independent predictors of maternal stress and the regression model (child behavioural difficulties, maternal acceptance and maternal depression) overall explained 18% of variance in stress. Hill and Rose (2009) also found a significant regression model (adaptive behaviour, behavioural difficulties, social support, parenting satisfaction and locus of control) for mothers of adults with ID, accounting for 61% of variance in parenting stress. Parenting satisfaction and locus of control were the only independent predictors of maternal stress (Hill & Rose, 2009).

Two studies have examined this relationship longitudinally as well as cross-sectionally. Lloyd and Hastings (2008) reported that the regression model (autism diagnosis, family deprivation, behaviour problems, acceptance and avoidance coping) for maternal stress at Time 1 was significant, accounting for 32% of variance in stress. A longitudinal analysis showed that mothers whose acceptance increased over time predicted less maternal stress at Time 2 and this relationship was bi-directional (Lloyd & Hastings, 2008). Lloyd and Hastings (2009a) found that the regression model (presence of autism, family deprivation, child pro-social behaviour, child problem behaviour, parent efficacy, child control and parent control) accounted for 49% of variance in maternal stress and the overall model was significant. A longitudinal analysis showed that an increase in child behaviour problems predicted increased maternal stress over 18 months (Lloyd & Hastings, 2009a). Also, locus of control predicted stress at follow-up and this relationship was bi-directional, indicating that an increase in stress over time also led to a more external locus of control for mothers (Lloyd & Hastings, 2009a).

Some studies have examined predictors of maternal mental health. Lloyd and Hastings (2009a) found that the regression model (child control and parent control)

explained 15% of variance in maternal anxiety and (parent efficacy, child control, parent control and presence of autism) 17% of variance in maternal depression. Parental control was the only independent predictor of maternal anxiety, whilst child control was the only independent predictor of maternal depression. Lloyd and Hastings (2009b) reported that more child behavioural difficulties and less hope predicted maternal depression. Child behavioural problems also predicted maternal anxiety and stress (Lloyd & Hastings, 2009b). Woodman and Hauser-Cram (2013) conducted separate analyses for six types of coping (active coping and planning, suppression of competing activities, positive reinterpretation and growth, focus on venting of emotions, denial and behavioural and mental disengagement) to assess whether they (in combination with adolescent behavioural difficulties, adolescent cognitive skills, adolescent gender and socio-economic status) predicted depression in mothers. Across the six models, the variance in maternal depression explained, ranged from 36% to 54%. Adolescent behavioural difficulties also predicted change in maternal depressive symptoms over a period of approximately three years, whilst coping style did not predict this change (Woodman & Hauser-Cram, 2013). Lloyd and Hastings (2008) found that acceptance was a significant independent predictor of anxiety, whilst both acceptance and avoidant coping were significant independent predictors of depression in mothers. The longitudinal analysis showed that mothers whose acceptance increased over time reported significantly less anxiety and depression at Time 2 and this relationship was bi-directional (Lloyd & Hastings, 2008).

Two studies examined whether maternal perceptions of the positive contributions of their child are predicted by behaviour and cognitions. Lloyd and Hastings (2009a) found that the regression model (maternal employment, number of children in family, belief in fate/chance and parent control) explained 47% of variance in maternal positive perceptions.

In another study mothers' positive perceptions were not associated with acceptance, mindfulness and coping and so were not subject to a regression analysis (Lloyd & Hastings, 2008).

Some studies have focused on predictors of well-being in fathers. One study showed that child behaviour problems significantly predicted higher levels of depression and parenting stress in fathers (Kersh et al., 2006). MacDonald et al. (2010) found that psychological acceptance and the child's Down syndrome diagnosis significantly predicted paternal positive gain. Psychological acceptance and child behavioural problems also predicted paternal stress, anxiety and depression (MacDonald et al., 2010). Less hope has been found to predict paternal anxiety and paternal depression and more hope predicted positive affect in fathers (Lloyd & Hastings, 2009b). Baker et al. (2005) found a different pattern for mothers and fathers. Child behaviour problems at Time 1 accounted for significant additional variance in depression and marital adjustment at Time 2 for mothers but this effect was not evident for fathers.

The findings suggest that various regression models significantly predict parental well-being, although the amount of variance accounted for, differs between models.

#### *8. Mediation Analysis*

Mediation analyses were utilised in a number of studies to examine the effect of behavioural difficulties on parental well-being through appraisals. Two studies showed a mediating role for parental cognitions. MacDonald et al. (2010) found that psychological acceptance partially mediated the impact of child behaviour problems on paternal stress, anxiety and depression. Minnes et al. (2007) investigated perceived stress as a mediating

cognitive variable and found that it mediated the effect of behavioural difficulties on parental depression.

Other studies have found no mediating role for parental cognitions in relation to the effect of behavioural difficulties on parental well-being. Two studies found that parental locus of control and parenting satisfaction did not meet the criteria to examine them as possible mediators of this relationship (Hassall et al., 2005; Hill & Rose, 2009). Plant and Sanders (2007) found that mothers' appraisals of care-giving did not mediate the effect of child behavioural difficulties on maternal stress during care-giving tasks and Feldman et al. (2007) found that social support rather than parental cognitions mediated the effect of child behaviour problems on depression in caregivers. Norizan and Shamsuddin (2010) also reported that depression rather than acceptance, mediated the relationship between child behavioural difficulties and parenting stress.

In summary, the findings are inconsistent, with two studies providing evidence for parental cognitions as mediators but the majority of studies did not provide support for this.

### *9. Moderation Analysis*

Conflicting results were also found for studies employing moderation analysis. Woodman and Hauser-Cram (2013) examined the moderating effect of coping and found that both active coping/planning and reinterpretation/growth moderated the relationship between behavioural difficulties and maternal depression. The results suggested that these coping styles were more effective for mothers whose children showed greater behavioural difficulties. Over time, behavioural/mental disengagement was the only moderator indicating that a higher use of disengagement predicted a larger increase in depressive symptoms over time for mothers of children with more behavioural difficulties (Woodman

& Hauser-Cram, 2013). Focusing on resilience factors, Baker et al. (2005) found that optimism moderated the effect of child behavioural problems on maternal well-being, indicating that mothers of children with more behavioural problems who were less optimistic, experienced lower levels of well-being than more optimistic mothers. Blacher and Baker (2007) described two studies and reported that beliefs about the positive impact of their child on the family moderated the effect of child mental health on the negative impact on parents, such that positive perceptions had a buffering impact when there were more mental health difficulties. In the second study, beliefs about the positive impact of their child moderated the effect of child behavioural difficulties on negative impact for mothers, at three time points and this occurred for fathers at two time points.

In contrast, some studies did not find a moderating effect for cognitions. Lloyd and Hastings (2009a) reported that maternal locus of control was not a moderator of child behavioural difficulties on maternal distress. Also, Feldman et al. (2007) found that escape-avoidance coping and self-efficacy did not moderate the effect of child behaviour problems on caregiver depression. Two other studies also found that coping did not moderate the effect of child behavioural difficulties on maternal stress during care-giving or parenting efficacy (n.b. efficacy was classified as a well-being variable; Plant & Sanders, 2007; Woodman & Hauser-Cram, 2013).

These studies also show that there are inconsistent findings regarding the moderating effect of cognitions.

## Discussion

This review aimed to examine the relationship between behavioural difficulties, cognitions and well-being in parents of individuals with ID. It aimed to investigate whether behavioural difficulties and parental cognitions predicted parental well-being and whether cognitions moderated or mediated the effect of behavioural difficulties on well-being.

The preliminary findings examining behavioural difficulties, cognitions and well-being, separately, showed that, as expected, rates of behavioural difficulties were greater for those with ID than those without ID. Parental cognitions, however, did not appear to differ between these populations. Cognitions appeared to be affected by parent gender and culture. Studies comparing mothers and fathers reported differences in cognitions but these were inconsistent in their findings. Parental well-being seemed to be affected by cause of ID, providing support for previous studies showing an influence of behavioural phenotypes on parental outcomes (Hodapp, Dykens, & Masino, 1997; Hodapp, Fidler, & Smith, 1998). Comparisons of well-being with parents of children without ID were inconclusive. In summary, the examination of each variable separately, suggested that there are specific factors which influence them. The lack of consistent research in this area means that definitive conclusions cannot be drawn about the effects on each variable.

Studies examining the relationship between behavioural difficulties and maternal well-being have predominantly provided more support for this relationship. However, the findings for fathers appear inconsistent with no clear picture emerging. It may be that the lack of studies on this group, reflect the lack of clarity in findings. Perhaps more research will allow for a clearer picture to become evident.

Findings regarding the association between behavioural difficulties and parental cognitions suggest that this relationship may be affected by type of cognition; many

cognitions were related to behavioural difficulties but some were unrelated. Child age and parent gender may also have an effect on this relationship. The sparsity of research examining these effects means that only tentative conclusions can be drawn and further systematic exploration of such effects is needed.

Studies exploring the relationship between parental cognitions and well-being suggested that most cognitions investigated, were associated with parental well-being. As not all cognitions correlated with all parental well-being variables, further exploration of the cause for this is needed. It could be that only specific cognitions are related to certain well-being variables or that significant relationships were not found due to limitations within studies.

Research employing regression analyses suggest that behavioural difficulties and parental cognitions in combination with other variables predict parental well-being. The diversity of variables incorporated into regression models is reflected across the research studies. Findings on behavioural difficulties and cognitions as independent predictors were inconclusive, which again may be due to methodological differences between studies.

The findings for the mediating and moderating role of parental cognitions are to-date inconclusive. Some studies suggested that there was a moderating or mediating role for parental cognitions, whilst others did not. Variability in the specific relationships examined and differences in the methodological quality across studies means that interpretation of these inconsistent findings is more challenging. It may be that only certain appraisals have a mediating or moderating role, thus providing support for this variability in findings. However, it may be that mediating or moderating effects were not detected in some studies due to methodological limitations, such as not examining or controlling for confounding variables and not using the most appropriate statistical analysis.



Overall, it seems that the patterns of investigations in this area of research are changing over time. A similar review by Hassall and Rose (2005) focused on parenting self-esteem, parental attributions and parental locus of control as these were the cognitions reported to be most widely investigated by researchers at the time (Bugental & Johnston, 2000; Grusec & Mammone, 1995). In contrast, the cognitive variables investigated by researchers in more recent years and thus covered in this review, appear to be more wide-ranging. The increased interest in third wave therapies has led to investigations of related cognitions, such as psychological acceptance and mindfulness, in this population (Lloyd & Hastings, 2008; MacDonald et al., 2010). Researchers have also investigated resilience factors, such as hope and optimism, which were not covered in the previous review (Baker et al., 2005; Hassall & Rose, 2005; Lloyd & Hastings 2009b). The increased attention given to resilience factors in recent years may in part reflect the changing emphasis in the literature on family adaptation rather than maladaptation (Hatton & Emerson, 2003).

In contrast to the current review, Hassall and Rose (2005) only reported one study that examined the mediating or moderating role of cognitions in parents of individuals with ID (Hastings & Brown, 2002). This study found that self-efficacy mediated the effect of child behavioural problems on psychological distress in mothers but moderated this relationship in fathers (Hastings & Brown, 2002). Due to the sparsity of research on this topic it was not possible for the authors to draw any conclusions about the mediating or moderating role of cognitions (Hassall & Rose, 2005). The authors of the previous review highlighted that there is a lack of studies examining the mediating and moderating role of cognitions in this population and there is a need for further research in this area (Hassall & Rose, 2005). The current review identified several studies that examined the mediating and/or moderating role of parental cognitions, perhaps reflecting the development of the

literature in this area over recent years. Despite the increased number of studies being conducted on this topic, the research findings to date are inconsistent making any conclusions about meditating and moderating relationships difficult to draw at present.

The review by Hassall and Rose (2005) reported several findings from studies on the relationship between behavioural difficulties, parental cognitions and parental well-being. Studies on locus of control, for example, found that low personal control was associated with more parental stress and psychological distress (e.g. Wiggs & Stores, 2001). The associations reported in the previous review are supported by similar findings reported in the current review (Hassall & Rose, 2005). For example, studies have more recently also shown that a more external locus of control is associated with more parenting stress and more psychological distress (Hassall et al., 2005; Hill & Rose, 2009; Lloyd & Hastings 2009a). The studies reviewed by Hassall and Rose (2005) were all cross-sectional in design, which contrasts to the longitudinal nature of some of the studies examined in this review (e.g. Woodman & Hauser-Cram, 2013). The use of longitudinal studies can provide us with more insight into the nature of the relationship between behavioural difficulties, parental cognitions and parental well-being. However, there is still a need for experimental studies to provide information about the causality of relationships.

As noted in this review, Hassall and Rose (2005) reported that there is an interchangeability of cognitive terms, such as “parenting competence” and “parenting self-esteem” between studies and highlighted the need for greater clarification of these terms. The lack of consistency in the categorisation and use of terms appears to be reflected in both reviews.

Overall, it appears that in general the associations found between behavioural difficulties, parental cognitions and parental well-being in the previous review are supported

by more recent research (Hassall & Rose, 2005). However, comparisons regarding the mediating or moderating role of cognitions are difficult to make given the sparsity of research on this topic prior to this review.

#### *Limitation of the studies reviewed*

Limitations of the studies reviewed must be considered when interpreting the findings. Disparity between studies in the categorisation of variables means that comparisons are more difficult to draw. One study, for example, classified parenting efficacy as a well-being variable, whereas most others categorised it as a cognition (Hassall et al., 2005; Hill & Rose, 2009; Kersh et al., 2006). Another study categorised perceived stress as a cognitive variable, whereas most other studies categorised it as a well-being variable (e.g., Hassall et al., 2005; Minnes, 1997). Consistency is needed in the classification of variables to allow for easier cross-study comparisons.

The cognitive measures employed may also limit the identification of significant findings. The measures employed were general parental cognitive measures rather than specific measures of the perceptions of challenging behaviour. It may be that the lack of significant findings is due to the absence of appropriate measures.

Limitations in the statistical procedures employed may also limit the studies reviewed. Samples were not always large enough for the statistical procedure employed, such as hierarchical regression analysis. Bootstrapping methods are increasingly being used to carry out mediational analysis as it is independent of sample and population distribution and provides robust confidence intervals in smaller samples (Preacher & Hayes, 2008). The bias-corrected bootstrap has been shown to be the most powerful mediation test when compared to other methods, however, no studies reviewed have employed this

analysis (Fritz & MacKinnon, 2007). A move towards the employment of bootstrapping analysis will aid in identifying significant mediation pathways in smaller samples.

The non-experimental nature of the studies reviewed limits the inferences that can be made about causality. The design of these studies means that relationships between variables may be due to other associated variables rather than solely due to the study variables (Barker, Pistrang & Elliott, 2002). Although longitudinal studies can provide better evidence regarding the causality of a relationship, this evidence is still less convincing than that provided by experimental studies. For example, the findings from one longitudinal study showed that an increase in child behaviour problems predicted increased maternal stress over eighteen months (Lloyd & Hastings 2009a). However, increased stress may be related to factors other than solely an increase in child behavioural problems.

#### *Limitations of the review*

The review in itself has a number of limitations. The review focused on a select number of databases and therefore is not an exhaustive search. Additionally, the specific focus on the relationship between behavioural difficulties, parental cognitions and parental well-being is not without its limitations. Many research studies have showed that several inter-linking factors, for example, other child characteristics and environmental characteristics, are important in contributing to parental well-being (e.g. Saloviita et al., 2003). The specificity of this review means that the interaction with other domains has not been explored. On the other hand, examining specific relationships in detail will allow for a more careful analysis of relationships when developing models of parental well-being.

### *Clinical implications*

The advantage of investigating psychological process variables, as suggested by Hastings and Beck (2004), is that they can be targeted in interventions. The current findings can help to inform our thinking about suitable clinical interventions, although the evidence base reviewed is relatively weak. The findings suggest that parental cognitions may be related to behavioural difficulties and parental well-being. It may be that focusing on cognitions during interventions for challenging behaviour, will help to facilitate positive change. The relationship between behavioural difficulties and parental well-being also suggests that systemic interventions may be helpful clinically.

These findings suggest that when working clinically with families who have a child with behaviour that challenges, it may be helpful to incorporate parents/caregivers into formulations. The inclusion of parental cognitions and parental well-being into assessments and formulations may offer a more comprehensive explanation of the client's presenting difficulties.

### *Future directions*

Based on the findings from the current review, it appears that there is a need to improve the design of research studies conducted in this area. Improving the design of both cross-sectional and longitudinal studies would be recommended in the first instance. Studies could use matched comparison groups (e.g. parents of children with no ID or parents from different cultures) to help control for confounding variables. It is also recommended that there should be more consistency across studies in the categorisation of cognitive and well-being variables. This would allow for easier cross-study comparisons.

When examining cognitive variables, researchers could develop and use measures that specifically examine parents' perceptions of challenging behaviour. Such measures, for example, the Challenging Behaviour Attribution Questionnaire (CHABA; Hastings, 1997) and the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) have already been developed and used with staff working in this area. Using such measures may help to provide a more accurate picture of parental perceptions specifically related to challenging behaviour.

When improving the design of future studies, researchers could also employ more appropriate and robust statistical procedures. For example, bootstrapping may be the most appropriate statistic when conducting mediational analysis (Adèr, Mellenbergh & Hand, 2008).

Closer examination of the pathways linking behavioural difficulties, parental cognitions and parental well-being is also recommended. Some research has shown that families report positive and negative outcomes concurrently, indicating that these domains may involve separate cognitive processes (Hastings & Taunt, 2002). Understanding the nature of the pathways leading to various well-being outcomes would allow for a more detailed understanding of these relationships and would thus ultimately help provide more information about which interventions may be most useful.

In a similar vein, it would also be useful to investigate the relationship between topography of challenging behaviour and parental cognitions as research on staff suggests that staff attributions are affected by topography of behaviour (Bailey, Hare, Hatton & Limb, 2006; Stanley & Standen, 2000). Again, a more comprehensive understanding of the nature of these pathways would hopefully ultimately lead to more information regarding the most appropriate interventions for certain challenging behaviours.

In addition to focusing on the relationship between these three variables, future research should also consider the influence of other factors on these variables. For example, some research suggests that social support mediates the relationship between challenging behaviour and parental well-being (Feldman et al., 2007). Systematically investigating other related variables would help to build a more comprehensive picture of the pathways involved in family adaptation.

Finally, a greater use of intervention studies would be recommended in the future as this would help provide more convincing evidence of the relationship between challenging behaviour, parental cognitions and parental well-being. For example, a randomised controlled trial demonstrating that parental well-being improves when certain parental cognitions are targeted would provide better evidence of the relationship between cognitions and well-being than cross-sectional and longitudinal studies (Barker et al., 2002).

### *Conclusions*

The literature review predominantly provides evidence for associations between behavioural difficulties, parental cognitions and parental well-being. Other factors, such as parent gender, cause of ID and culture, may impact upon the nature of these relationships but further research is needed to explore these systematically. The findings from studies investigating the mediating or moderating role of parental cognitions appear inconclusive. This may in part be due to methodological limitations and inconsistency across studies. It also may mean that only certain parental cognitions under specific conditions mediate or moderate this relationship. Further research systematically examining the mediating and moderating effects of parental cognitions is needed to refine current mediation and moderation models.

## References

- Adèr, H. J., Mellenbergh G. J., & Hand, D. J. (2008). *Advising on research methods: A consultant's companion*. Huizen, The Netherlands: Johannes van Kessel Publishing.
- Bailey, B. A., Hare, D. J., Hatton, C., & Limb, K. (2006). The response to challenging behaviour by care staff: emotional responses, attributions of cause and observations of practice. *Journal of Intellectual Disability Research*, *50*, 199–211.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, *107*, 433-444.
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, *49*, 575-590.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*. West Sussex: John Wiley & Sons.
- Baron, R. M. & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.
- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, *112*, 330-348.
- Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry*, *18*, 507-513.
- Bugental, D. B. & Johnston, C. (2000). Parental and child cognitions in the context of the family. *Annual Review of Psychology*, *51*, 315-344.



- Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, *21*, 179–198.
- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, *52*, 377-384.
- Drysdale, E. E., Jahoda, A., & Campbell, E. (2009). Investigating spontaneous attributions in mothers of individuals with intellectual disabilities and self-injurious behaviour. *British Journal of Learning Disabilities*, *37*, 197–206.
- Dykens, E. M. (2000). Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry*, *41*, 407-417.
- Dyson, L. L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. *American Journal on Mental Retardation*, *98*, 207-218.
- Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. *American Journal on Mental Retardation*, *102*, 267-279.
- Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M. L., & Yu, C. T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research*, *51*, 606-619.
- Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology*, *50*, 571-579.

- Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*, 233-239.
- Grusec, J. E. & Mammon, N. (1995). Features and sources of parents' attributions about Themselves and their children. In N. Eisenberg (Ed.), *Review of Personality and Social Psychology* (pp. 49-73). CA; Sage.
- Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: a review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy, 33*, 71-88.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405-418.
- Hastings, R. P. (1997). Measuring staff perceptions of challenging behaviour: the Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research, 41*, 495-501.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27*, 149-160.
- Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*, 1338-1349.
- Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: mothers' and fathers' perceptions. *Journal of Intellectual Disabilities, 9*, 155-165.

- Hastings, R.P., & Brown, A. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation*, *107*, 222-232.
- Hastings, R. P. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, *107*, 116-127.
- Hatton, C., & Emerson, E. (2003). Families with a person with intellectual disabilities: stress and impact. *Current Opinion in Psychiatry*, *16*, 497-501.
- Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal care-giving of persons with mental retardation across the lifespan. *Family Relations*, *46*, 407-415.
- Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, *53*, 969-980.
- Hodapp, R. M., Dykens, E. M., & Masino, L. L. (1997). Families of children with Prader–Willi syndrome: stress-support and relations to child characteristics. *Journal of Autism and Developmental Disorders*, *27*, 11–24.
- Hodapp, R. M., Fidler, D. J., & Smith, A. C. M. (1998). Stress and coping in families of children with Smith–Magenis syndrome. *Journal of Intellectual Disability Research*, *42*, 331–340.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, *50*, 883-893.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

- Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research, 52*, 37-48.
- Lloyd, T., & Hastings, R. P. (2009a). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability, 34*, 104-115.
- Lloyd, T. J., & Hastings, R. (2009b). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*, 957-968.
- Lopez, V., Clifford, T., Minnes, P., & Ouellette-Kuntz, H. (2008). Parental stress and coping in families of children with and without developmental delays. *Journal on Developmental Disabilities, 14*, 99-104.
- MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*, 27-37.
- Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology, 19*, 313-328.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: the double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman & J. M. Patterson (Eds.), *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research*. New York: The Haworth Press.

- Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in ageing family carers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 20*, 539-552.
- Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research, 54*, 992-1003.
- Orr, R. R., Cameron, S. J., & Day, D. M. (1991). Coping with stress in families with children who have mental retardation: an evaluation of the Double ABCX model. *American Journal on Mental Retardation, 95*, 444-450.
- Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*, 109-124.
- Preacher K. J., & Hayes A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods, 40*, 879-891.
- Quine, L. & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' transactional model of coping. *Journal of Community & Applied Social Psychology, 1*, 57-70.
- Sanderson, S., Tatt, I. D., & Higgins, J. P. T. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology, 36*, 666-676.
- Saloviita, T., Itälina, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX Model. *Journal of Intellectual Disability Research, 47*, 300-312.

- Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's Syndrome. *Journal of Child Psychology and Psychiatry*, 32, 655-676.
- Stanley, B., & Standen, P. J. (2000). Carers' attributions for challenging behaviour. *British Journal of Clinical Psychology*, 39, 157-168.
- Wiggs, L., & Stores, G. (2001). Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: effect on mothers and fathers. *British Journal of Health Psychology*, 6, 257-269.
- Williams, R. J., & Rose, J. L. (2007). The development of a questionnaire to assess the perceptions of care staff towards people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, 11, 197-211.
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 57, 513-530.

## PREFACE TO CHAPTER 2

The literature review provides evidence of the relationship between behavioural difficulties, parental cognitions and parental well-being via correlational and regression analyses. The findings on the moderating and mediating effect of cognitions are inconsistent across studies. It may be that only certain appraisals have a mediating or moderating role thus providing support for this variability in findings. However, it may be that mediating or moderating effects were not detected in some studies due to methodological limitations, such as inappropriate statistical analyses or the absence of specific measures of parental perceptions of challenging behaviour.

The empirical paper seeks to further investigate the mediating role of parental cognitions but to improve on the cross-sectional research design by employing a specific measure of parental perceptions' of challenging behaviour and employing bootstrapping analysis to examine mediation.

## CHAPTER 2: EMPIRICAL PAPER

# THE RELATIONSHIP BETWEEN CHALLENGING BEHAVIOUR, COGNITIONS AND STRESS IN MOTHERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES<sup>1</sup>

---

<sup>1</sup> The paper has been prepared as if for submission to the *Journal of Intellectual Disability Research*.



## Abstract

**Background:** Although there has been interest in the influence of maternal cognitions on the relationship between challenging behaviour and maternal well-being, there is an absence of measures to specifically examine mothers' perceptions of challenging behaviour. The psychometric properties of the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) were investigated to assess its applicability to mothers. The study also examined whether maternal cognitions mediated the effect of challenging behaviour on parenting stress.

**Method:** 46 mothers of children and young adults with ID completed questionnaires regarding their child's challenging behaviour, maternal cognitions and stress. A subsample of participants completed the CBPQ approximately two weeks later.

**Results:** Examination of the psychometric properties of the CBPQ resulted in a 24-item measure with six subscales. Co-efficients at subscale level ranged from .70 to .85 for internal reliability and .39 to .93 for test-retest reliability. Evidence of concurrent validity was also found. The overall mediation models for aggression/ destruction and self-injurious behaviour were significant. The CBPQ Consequences client subscale was the only independent significant mediator for both behaviours.

**Conclusions:** The CBPQ is a promising measure of mothers' perceptions of challenging behaviour. Further research is needed to examine the similarities and differences between the mediation models for aggression/ destruction and self-injurious behaviour.

**Keywords:** challenging behaviour, cognition, mothers, stress, intellectual disability

## Introduction

A number of models of parenting stress have been developed and applied to intellectual disability (ID) research (e.g. Jones & Passey, 2005; Quine & Pahl, 1991; Saloviita, Itälänne & Leinonen, 2003). Such models have included the Double ABCX model (McCubbin & Patterson, 1983), the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), the Two-factor Model of Psychological Well-being (Lawton, Moss, Kleban, Glicksman & Rovine, 1991) and the Model of Parent-Child Interactive Stress (Mash & Johnston, 1990). These models propose that a number of specific inter-linking factors contribute to stress in parents and families. Such factors broadly include child characteristics, parental characteristics and environmental characteristics. Within these over-arching themes, the specific factors incorporated into each proposed model and the way they inter-link, have varied. There are however commonalities between the models.

These models emphasise the important role of parental cognitions in influencing parental/ family stress and adjustment. They suggest that parental cognitions may mediate and/ or moderate specific relationships, which impact upon parental stress and well-being (e.g. Mash & Johnston, 1990). This may in part explain why parental stress is not an inevitable result of having a child with an ID (Hastings, 2002; Hastings & Taunt, 2002). Various types of parental cognitions have been examined. These have included attributions (such as locus of control, stability and controllability), self-efficacy, satisfaction, optimism, hope, psychological acceptance, avoidant coping and mindfulness (e.g. Drysdale, Jahoda & Campbell, 2009; Lloyd & Hastings, 2009a).

One pathway proposed to be affected by parental cognitions is that between child characteristics (e.g. degree of disability) and parental stress and well-being. One child characteristic found to be related to parental stress and well-being is challenging behaviour

(Hastings, 2002). Many studies have shown that challenging behaviour is related to levels of parenting stress and well-being, with more challenging behaviour being associated with higher levels of parenting stress and lower levels of well-being (e.g. Baker, Blacher, Crnic & Edelbrock, 2002; Lecavalier, Leone & Wiltz, 2006; Orsmond, Seltzer, Krauss & Hong, 2003). Other studies have also shown that challenging behaviour significantly predicts parental stress and well-being (e.g. Kersh, Hedvat, Hauser-Cram & Warfield, 2006; Woodman & Hauser-Cram, 2012). Although a number of studies have focused on this direct relationship, some research has been published on the influence of parental cognitions via mediation or moderation (e.g. Hassall, Rose & McDonald, 2005; Hastings & Brown, 2002).

Some research has found evidence for the mediation or moderation of parental cognitions on this relationship. For example, Hastings and Brown (2002) assessed the influence of self-efficacy on the relationship between behavioural difficulties and parental well-being in parents of children with autism. Self-efficacy mediated the relationship between behaviour problems and both anxiety and depression in mothers. This suggested that children's behavioural problems lowered self-efficacy in mothers leading to increased mental health difficulties. Self-efficacy acted as a moderator in this relationship for fathers, indicating that those with higher levels of self-efficacy were less affected by their child's behavioural difficulties. MacDonald, Hastings and Fitzsimons (2010) found that psychological acceptance partially mediated the impact of child behavioural problems on paternal stress and well-being. Baker, Blacher and Olsson (2005) found that optimism moderated the relationship between child behavioural problems and maternal well-being. This suggested that mothers of children with more behavioural problems who were less optimistic experienced lower levels of well-being compared to optimistic mothers.

On the other hand some studies have found no evidence for parental cognitions mediating or moderating the relationship between challenging behaviour and parental well-being. Hassall et al. (2005) found that locus of control and parenting satisfaction significantly predicted parenting stress but they did not mediate the relationship between child behavioural difficulties and parenting stress. Hill and Rose (2009) used the same measures with mothers of adults with ID and found that maternal satisfaction and locus of control significantly predicted maternal stress. Again, these cognitions did not mediate this relationship. Feldman et al. (2007) found that social support rather than self-efficacy mediated the relationship between child behaviour problems and depression. Also, Norizan and Shamsuddin (2010) found that depression rather than acceptance mediated the relationship between child behavioural difficulties and parental stress. To date, the research findings appear inconclusive. The variation in results across studies could be due to several reasons, such as differences in parent and child characteristics, examining different cognitions and differences in sample size.

One limitation to this area of research is the lack of discrimination between parents' perceptions of different topographies of challenging behaviour. Within the literature on staff, some studies have compared the attributions of different forms of challenging behaviour (Dagnan, 2012). For example, Stanley and Standen (2000) found that staff working in day services perceived individuals with challenging behaviour to have significantly greater control of aggressive behaviour compared to self-injurious behaviour. However, staff perceived self-injurious behaviour to be significantly more stable than aggressive or destructive behaviour. Bailey, Hare, Hatton and Limb (2006) found that staff perceived other forms of challenging behaviour as significantly more uncontrollable and less stable than self-injurious behaviour. No significant difference was found between the

internal attribution scores for these behaviours. The results to date suggest that staff attributions are affected by topography of behaviour. Comparing parents' perceptions of different topographies of challenging behaviour would therefore be valuable in this population.

Another limitation to this area of research is the absence of measures that specifically examine parents' perceptions of their child's challenging behaviour. Generic measures of parental cognitions, such as the Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978) and the Parental Locus of Control - Short Form Revised (Hassall et al., 2005) have typically been employed due to the lack of specific measures. To our knowledge, no specific measure of parents' perceptions of challenging behaviour exists within the family ID literature.

Measures have however been developed to examine care staff's beliefs about challenging behaviour. These include the Challenging Behaviour Attribution Questionnaire (CHABA; Hastings, 1997) and the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007). Attributional measures developed for other populations have also been used, such as the Attributional Style Questionnaire (ASQ; Peterson et al., 1982) and the Controllability Beliefs Scale (CBS; Dagnan, Grant & McDonnell, 2004; Dagnan, Hull & McDonnell, 2013). These measures are predominantly based on Weiner's (1980; 1985)<sup>2</sup> attributional model of helping behaviour, which has been a dominant model when assessing staff stress and burnout (Dagnan, 2012). Willner and Smith (2008) reviewed the evidence for this model and found it inconclusive. As the CHABA, ASQ and

---

<sup>2</sup> Weiner (1980, 1985) proposes that there are three main aspects to causal attributions. These are controllability-uncontrollable (the extent to which the cause of the person's behaviour is viewed as under their control), stable-unstable (the extent to which the cause of a person's behaviour is viewed as long-lasting) and internal-external (whether the cause of the person's behaviour is viewed as being under their control or due to external factors). He proposed that attributions will lead to certain emotional reactions that consequently affect helping behaviour (Weiner, 1980, 1985).

CBS are based on attribution theory it may be helpful to consider applying other relevant theories to the family domain when exploring parents' perceptions of challenging behaviour.

Leventhal's self-regulatory model may offer an alternative theory with which to expand our knowledge of parents' and staff's attributions (Leventhal & Diefenbach, 1991; Leventhal, Nerenz & Steel, 1984; Williams & Rose, 2007). This theory suggests that in response to an illness threat, cognitive and emotional representations are developed in parallel and these lead to problem-based and emotion-focused coping strategies, respectively. Cognitive illness representations are constructed over five dimensions: identity (ideas about the label, the nature of the illness and the relationship between them), timeline (beliefs about the longevity of the illness), cause (beliefs about the cause of the illness), consequences (perceptions regarding the severity of the illness and the probable impact on functioning) and cure/ controllability (beliefs about the likelihood of cure or controllability of the illness) (Leventhal et al., 1984).

Within the field of Health Psychology, Leventhal's self-regulatory model has been examined in a range of conditions including diabetes, rheumatoid arthritis, coronary artery disease, cancer and Parkinson's disease (Dempster et al., 2011; Leventhal et al., 1984; Stafford, Berk & Jackson, 2009; Weinman, Petrie, Moss-Morris & Horne, 1996). Research has shown that illness perceptions relate to a range of outcomes, such as coping, functional adaptation and psychological well-being (Heijman, 1998; Scharloo, Kaptein, Weinman, Vermeer & Rooijmans, 2000). For example, a study of 62 outpatients with rheumatoid arthritis found that patients who scored above the clinical cut-off for depression on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) viewed the consequences of their illness as being significantly more serious and believed they had significantly less

control over their illness than those who scored below the clinical cut-off (Murphy, Dickens, Creed & Bernstein, 1999). In a study of 193 patients with coronary artery disease (CAD), negative illness beliefs about the consequences of CAD significantly predicted higher levels of symptoms of depression in patients six months later (Stafford, Berk & Jackson, 2009). In a range of cancers, illness perceptions have also been found to explain a significant proportion of the variance in psychological distress (Llewellyn, McGurk & Weinman, 2007; Miller, Purshotham, McLatchie, George & Murray, 2005). The evidence to date suggests that there is a relationship between illness perceptions and psychological well-being across a range of physical health conditions (e.g. Stafford et al., 2009). It would therefore seem appropriate to explore whether cognitions based upon illness perceptions relate to parental well-being in this population.

The Challenging Behaviour Perception Questionnaire (CBPQ) is based upon the self-regulation model of illness behaviour and has been used to explore whether this alternative theory can expand our knowledge of staff attributions (Leventhal et al. 1984; Leventhal, Diefenbach & Leventhal, 1992; Williams & Rose, 2007). The carer's version of the modified Illness Perception Questionnaire (Barrowclough et al., 2001) used with carers of individuals with schizophrenia, was modified to develop the CBPQ. The CBPQ is an informant-based measure specifically designed to examine staff's perceptions of their clients' challenging behaviour (Williams & Rose, 2007). Evidence for the reliability and validity of this measure in staff has also been reported (Williams & Rose, 2007). Utilising a measure such as this within the family domain could be beneficial as it measures specific cognitions related to challenging behaviour.

Assessing the applicability of the CBPQ to parents of individuals with ID is important in the first instance. The reliability and validity of the CBPQ will be examined in

the current study. Reliability will be examined by assessing internal consistency and test-retest reliability. Concurrent validity will be assessed by examining whether the CBPQ subscales are associated with other related cognitive measures. Two studies employing similar research designs used the Parenting Sense of Competence Scale (PSOC, Gibaud-Wallston & Wandersman, 1978) and the Parental Locus of Control - Short Form Revised (PLOC-SFR; Hassall et al., 2005) to assess parental cognitions when investigating the relationship between behavioural difficulties, parental cognitions and parental stress in parents of individuals with intellectual disabilities (Hassall et al., 2005; Hill & Rose, 2009). These measures have been found to relate to both behavioural difficulties and parental stress and predict stress in parents of individuals with ID (Hassall et al., 2005; Hill & Rose, 2009). The Parenting efficacy subscale (PSOC-E) from the PSOC did not correlate significantly with parenting stress or the child and environmental variables examined and there was an overlap in variance between the PSOC-E and the PLOC-SFR so only the Parenting satisfaction subscale (PSOC-S) from this measure will be used to assess concurrent validity (Hassall et al., 2005; Hill & Rose, 2009). These measures have also been chosen to assess concurrent validity as there is some conceptual overlap between these measures and the CBPQ. For example, the CBPQ and the PLOC-SFR contain Child Control and Parental Control subscales, which both assess parental and child control over the child's behaviour. These measures however lack subscales that relate to the CBPQ Emotional representation subscale. A modified version of the Fear of Assault Measure (Rose & Cleary, 2007) has been used in research on staff to examine their fear of assault by clients (Rose, Mills, Silva & Thompson, 2013). Fear of assault has been found to mediate the relationship between challenging behaviour and emotional exhaustion in staff (Rose et al., 2013). This measure is also conceptually similar to the CBPQ Emotional Representation subscale as the CBPQ



examines related emotions, such as feeling afraid, upset and angry. The current study will use these measures to examine the validity of the CBPQ.

The aim of the current study is to examine whether mothers' perceptions of their child's challenging behaviour mediates the effect of challenging behaviour on their stress levels. This study will focus specifically on mothers of children and young adults with ID due to differences reported in cognitions between mothers and fathers (Lloyd & Hastings, 2009b; Saloviita et al., 2003). Self-injurious behaviour (SIB) and aggression/destruction will be examined separately to assess whether differences occur between topography of behaviour. The mediation of cognitions will be focused upon as this has been proposed in several models of parenting stress, such as the Model of Parent-Child Interactive Stress (Mash & Johnston, 1990). The Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) will be employed to specifically measure parents' perceptions of challenging behaviour. As this measure has not been previously used with parents, the psychometric properties will be examined to assess its applicability to this population.

Reliability of the CBPQ will be explored by assessing internal consistency and test-retest reliability. Concurrent validity will be assessed by correlating the CBPQ (Williams & Rose, 2007) with the PLOC-SFR subscales (Hassall et al., 2005), the PSOC Satisfaction subscale (Gibaud-Wallston & Wandersman, 1978) and the FoAM (Rose & Cleary, 2007). Specific hypotheses have been developed regarding the relationship between these measures. The hypotheses are as follows:

1a. The CBPQ Control carer subscale will correlate negatively with the PLOC Parental control subscale, the PLOC Parental responsibility subscale and the PLOC Parental efficacy subscale such that mothers who believe they have greater control over their child's

challenging behaviour also believe they are more in control of their child's behaviour, feel greater responsibility for their child's behaviour and have a higher sense of self-efficacy.

1b. The CBPQ Control client subscale will correlate positively with the PLOC Child control subscale such that mothers who believe their child has greater control over their challenging behaviour will also believe that their child has greater control of their parent's life.

1c. The CBPQ Consequences carer subscale will correlate positively with the PLOC Parental control subscale and the FoAM and negatively with the PSOC Satisfaction subscale such that mothers who believe their child's challenging behaviour has more negative consequences for them will also believe that they are less in control of their child's behaviour, will have a greater fear of assault by their child and will have less parenting satisfaction.

1d. The CBPQ Consequences client subscale will correlate negatively with the PLOC Child control subscale such that mothers who believe the challenging behaviour has more negative consequences for their child will also believe that their child has less control of their parent's life.

1e. The CBPQ Treatment subscale will correlate negatively with the PLOC Parental efficacy subscale such that mothers who believe treatment will be more effective for their child's challenging behaviour will have a greater sense of self-efficacy.

1f. The CBPQ Emotional Representation subscale will correlate positively with the PLOC Parental control subscale and the FoAM and negatively with the PSOC satisfaction subscale such that parents who believe their child's challenging behaviour has a more negative emotional impact on them will also feel less in control of their child's behaviour, will have a greater fear assault by their child and will feel less satisfied as a parent.

Specific hypotheses were not developed for the CBPQ Timeline subscales as this is not assessed by the other cognitive measures and as far as we are aware no other measure of cognition in this area examines timeline.

Hypotheses were also generated regarding the relationship between the study variables. These hypotheses are as follows:

2. Challenging behaviour will be positively correlated with parenting stress.
3. There will be a significant relationship between challenging behaviour and mothers' cognitions.
4. There will be a significant relationship between mothers' cognitions and parenting stress.
5. Mothers' cognitions will mediate the relationship between their child's challenging behaviour (specifically aggression/destruction and self-injurious behaviour) and their stress levels; and cognitions mediating this relationship will differ in accordance with the topography of behaviour.

Directional hypotheses were not made for hypotheses three and four as the CBPQ consists of five dimensions, which, as far as we are aware, have not been investigated previously in this population.

## Method

### *Participants*

Participants were 46 mothers of children and young adults with ID. Mothers' ages ranged from 28 to 59 years ( $M = 44.33$ ;  $SD = 7.89$ ). Of the total sample, 91.3% ( $n = 42$ ) described themselves as White British, 4.3% ( $n = 2$ ) as Black African, 2.2% ( $n = 1$ ) as Pakistani and 2.2% as White Irish ( $n = 1$ ). The majority of participants (95.7% ;  $n = 44$ ) described themselves as the child's biological parent. One participant was an adoptive parent and one was a foster carer. Both reported that they had cared for their child since they were one year old.

The age range of participants' children was 4 to 27 years ( $M = 11.63$ ;  $SD = 6.14$ ) and 63% ( $n = 29$ ) were reported to be male. All mothers reported that their children had received a diagnosis by a professional. Individuals had a mixed aetiology of ID. Diagnoses included Autism/Autism Spectrum disorder/ Asperger syndrome (39.1%;  $n = 18$ ), Cerebral Palsy (4.3%;  $n = 2$ ), Down syndrome (4.3%;  $n = 2$ ), Aicardi syndrome (2.2%;  $n = 1$ ), Alagille syndrome (2.2%;  $n = 1$ ), Fragile X syndrome (2.2%;  $n = 1$ ), Di George syndrome (2.2%;  $n = 1$ ), Shprintzen's syndrome (2.2%;  $n = 1$ ) and Trisomy 9p (2.2%;  $n = 1$ ). This information was based solely on parental reports. Abilities of children were measured using the Wessex Scale (Kushlick, Blunden & Cox, 1973). Vision and hearing were reported to be unimpaired for 69.6% ( $n = 32$ ) and 84.8% ( $n = 39$ ) of individuals, respectively. Of the individuals with ID, 78.3% ( $n = 36$ ) were reported to be fully mobile, 82.6% ( $n = 38$ ) had speech and 63% ( $n = 29$ ) were partly able / fully able in terms of self-help skills (feeding, washing and dressing).

## *Measures*

### *Background information.*

*The Demographic Questionnaire* (see Appendix B for all measures) was designed to obtain background information about participants. The information obtained, included the participant's ethnicity and age; their child's age and gender; whether they are the child's biological parent, adoptive parent or foster carer; whether their child has a diagnosis of a syndrome; and the name of the syndrome they have been diagnosed with, if applicable.

*The Wessex Scale* (Kuschlick, Blunden & Cox, 1973) is an informant-based questionnaire examining social and physical abilities of children and adults with ID. Subscales comprise continence, mobility, self-help skills, speech and literacy. Additional questions regarding vision and hearing are also included. Ratings are based on a three-point likert scale for each question (apart from a question regarding speech comprehensibility). The Wessex scale has good inter-rater reliability at subscale level for both children and adults with ID (Kushlick et al., 1973; Palmer & Jenkins, 1982).

### *Child's level of challenging behaviour.*

*The Behavior Problems Inventory (BPI)* (Rojahn, Matson, Lott, Esbensen & Smalls, 2001) is an informant-based measure examining the frequency and severity of challenging behaviour over the previous two months. It assesses three types of behavioural difficulties: self-injurious behaviour (14 items), stereotyped behaviour (24 items) and aggressive/ destructive behaviour (11 items). Each category also has a residual item for behaviours that are not already specified. Each item is scored on a frequency scale ranging from 'never' to 'hourly' and a severity scale ranging from 'slight' to 'severe'. Frequency and severity

scores are summed for each behaviour, with higher scores indicating a higher frequency or severity of behaviour. Internal consistency ranged from .61 to .82 at subscale level for frequency scores (Rojahn et al., 2001). Test-retest reliability for frequency scales ranged from .64 to .76 at subscale level (Rojahn et al., 2001). Only the self-injurious and aggressive/destructive behaviour subscales were utilised for this study because the aim was to focus on these two categories of behaviours specifically. In order to reduce the number of variables used in the study, the severity and frequency scores were summed for each behaviour, producing a total self-injurious behaviour score and a total aggressive/destructive behaviour score. Furthermore, it was felt that combining frequency and severity scores provided a more complete representation of the behaviours rather than just using one of the subscales.

#### *Maternal Cognitions.*

*The Challenging Behaviour Perception Questionnaire (CBPQ;* Williams & Rose, 2007) was developed to assess the perceptions of staff working with people with ID about episodes of challenging behaviour. The CBPQ consists of 30 statements about the person's challenging behaviour. Staff are asked to rate their response to each statement on a five-point likert scale ranging from 'strongly disagree' to 'strongly agree'. Williams and Rose (2007) examined internal consistency and consequently deleted a number of items and removed three subscales. The resulting 19-item questionnaire had six subscales and Cronbach's alpha ranged from .62 to .79 at subscale level. There was some support for construct validity evidenced by significant correlations with the Attributional Style Questionnaire (ASQ; Peterson et al., 1982; Williams & Rose, 2007). Test-retest reliability was not examined. The original 30-item questionnaire, consisting of nine subscales

(Consequences client, Consequences carer, Control client, Control carer, Treatment, Timeline chronic/acute, Timeline episodic, Timeline cyclical and Emotional representation), was employed in this study because this was the first time the CBPQ had been used with this population and so the psychometric properties needed investigating separately. Higher scores on the Consequences (Client and Carer) subscales are indicative of the belief that challenging behaviour has more serious/negative consequences for the person with ID and the carer. Higher scores on the Control (Client and Carer) subscales are indicative of the belief that challenging behaviour is more under the control of the person with ID and the carer. A higher score on the Treatment subscale indicates that the carer believes that treatment will be more effective in ameliorating the challenging behaviour. Higher scores on the Timeline subscales (chronic/acute, episodic and cyclical) suggest that the carer believes the challenging behaviour will be more chronic, more episodic and more cyclical. A higher score on the Emotional representation subscale is indicative of the belief that challenging behaviour will have more negative emotional consequences for the carer.

*The Parental Locus of Control - Short Form Revised (PLOC-SFR; Hassall et al., 2005)* consists of 24 items rated on a five-point likert scale, ranging from 'strongly agree' to 'strongly disagree'. Higher scores on this measure are indicative of a greater external locus of control. The original questionnaire contained 47 items covering five factors: Parental Efficacy (PE), Parental Responsibility (PR), Child Control of Parents' Life (CC), Fate/Chance and Parental Control of Child's Behaviour (PC; Campis, Lyman & Prentice-Dunn, 1986). The Fate/Chance subscale was removed in the shortened version of the questionnaire due to its lack of discriminant validity and the remaining four subscales were

reduced by choosing items with the highest factor loadings (Hassall et al., 2005). The internal consistency of the subscales ranged from .62 to .86 (Hassall et al., 2005).

*The Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978)* is comprised of 16 items scored on a six-point likert scale, ranging from 'strongly agree' to 'strongly disagree'. The measure consists of two factors: Parenting satisfaction (PSOC-S) and Parenting efficacy (PSOC-E). A higher score on this questionnaire is indicative of greater parenting satisfaction and a higher sense of parenting efficacy (Johnston & Mash, 1989). Johnston and Mash (1989) examined internal consistency using Cronbach's alpha and reported .79 and .76 for the PSOC-S and the PSOC-E, respectively. Test-retest reliability over six weeks was .80 for the PSOC-S and .77 for the PSOC-E (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989). Only the Parenting satisfaction subscale (PSOC-S) was used in the current study.

A modified version of *the Fear of Assault Measure (FoAM; Rose & Cleary, 2007)* consists of two items adapted from the original questionnaire (Leather, Beale, Lawrence & Dickson, 1997) to examine care staff's fear of assault. Staff are asked to rate the following questions on a 5-point likert scale ranging from 'not at all' to 'extremely': "How worried are you by the possibility of violence or assault in your work?" and "How much do you feel personally at risk of violence or assault in your work?". The items are summed to produce a total score and a higher score represents greater fear by staff. As the questionnaire examined fear of assault in a work-related setting, the questions utilised in the current study were modified for parents. The questions used in the current study were as follows: "How



worried are you by the possibility of violence or assault by your child?” and “How much do you feel personally at risk of violence or assault by your child?”.

#### *Maternal stress.*

*The Parental Stress Index-short form (PSI; Abidin, 1995)* is a 36-item questionnaire consisting of three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P/CDI) and Difficult Child (DC). A total score (PSI-TOT) is obtained by summing the subscale scores. Alpha coefficients for internal consistency range from .80 to .91, and test-retest reliability coefficients over a six-month interval range from .68 to .85 at subscale level (Abidin, 1995). Higher scores are indicative of greater parenting stress.

#### *Procedure*

Ethical approval was obtained through the local NHS research ethics committee and approval was also sought through the Research and Development departments within the two NHS Trusts in the West Midlands involved in the research project (see Appendix C for letter of ethical approval). The inclusion criteria for the study were mothers of children and young adults (>30 years) with ID who lived with their child at home. Mothers were recruited through several routes due to the initial low response rate.

Participants were recruited initially through clinicians working in two child Learning Disability services in the West Midlands. Clinicians in these services gave information packs about the project to clients they were working with or have previously worked with. Information packs contained an information sheet about the project, a consent form and a free-post envelope (see Appendix D). Mothers who wished to opt-in to the project were asked to return the consent form in the free-post envelope enclosed in their pack.

Researchers only became aware of mothers' personal details when they returned their consent form. Approximately 85 information packs were distributed via clinicians. Seventeen mothers opted-in to the project, yielding a return rate of approximately 20%. One mother was unable to participate due to personal circumstances and so sixteen mothers participated in total via this method of recruitment.

As a result of low levels of recruitment, information packs were also sent via the Learning Disability register held in one metropolitan district and through schools for children with learning disabilities in the West Midlands region. The Learning Disability register holds information about adults with ID and their families who have been in contact with Social Services. The person maintaining the register agreed to send information packs to mothers who met the above inclusion criteria. Thirty four mothers were identified and each was sent an information pack. Again, researchers were unaware of mothers' contact details unless they returned consent forms to opt-in to the project. Five mothers opted-in to the project, which represents a return rate of 14.71%. One person did not meet the inclusion criteria for the study so four mothers took part in total via this route.

Three schools (two primary schools and a secondary school) in the West Midlands specifically for children with ID were approached to take part in the research project as one of the clinical services had good links with two schools and one of the researchers had good links with another. All three schools agreed to take part in the project. Approximately 322 information packs were sent out to parents of children attending these schools and 32 mothers opted-in. This gave a return rate of approximately 9.94%. However, due to personal reasons four mothers dropped out, one mother could not be contacted and another mother did not return the questionnaire pack sent to her. In total, 26 mothers took part in the study via this route. The overall return rate was approximately 14.88%.

If mothers completed and returned the consent forms, they were contacted to arrange a visit to complete the questionnaires via interview. Some mothers preferred to complete the questionnaire pack themselves and return it through the post ( $n = 11$ ). Questionnaire packs were counter-balanced in three ways and were used in approximately equal proportions (see Appendix E for further information). During the visit, the questionnaire pack was completed with mothers, which took approximately an hour and a half.

Mothers who had taken part in the study via the interview method ( $n = 35$ ) were approached about participating in the test-retest reliability of the CBPQ, approximately two weeks after the initial interview. All participants agreed to this but it was not possible to contact everyone at the time necessary for re-administering the CBPQ so a subsample of 24 mothers took part. This represented 68.5% of the total possible sample. The CBPQ was re-administered via telephone interview approximately two weeks after the initial interviews ( $M = 18.71$ ;  $SD = 7.83$ ).

## Results

### *Data Analysis*

Examination of Q-Q plots and Shapiro-Wilk tests were used to initially assess the distribution of data (see Appendix F for descriptive information about the questionnaires and Appendix G for results of the Shapiro-Wilk tests). Some data from the BPI, CBPQ and FoAM were not normally distributed so non-parametric tests were employed throughout the analysis. Before conducting the main analysis, the following variables were correlated with parental stress (PSI total) to explore whether there were confounding variables: participants' age; children's age; and children's self help, literacy and mobility scores. All correlations were not significant, indicating that these variables did not need to be controlled for in the main analysis (see Appendix H for results).

The results are divided into three sections. Section one addresses the first aim of the study, which is to examine the psychometric properties of the CBPQ. This section includes internal consistency, test-retest reliability and concurrent validity. Cronbach's alpha was used to examine internal consistency for subscales with three or more items, as this is the most widely accepted formulation of reliability (Cortina, 1993). Internal consistency for two-item subscales was measured using the Spearman-Brown co-efficient, as this has been shown to be the most appropriate statistic for two-item scales (Eisinga, Grotenhuis & Pelzer, 2012). Spearman's correlations were used to examine test-retest reliability. Reliability levels between .70 and .80 were considered acceptable and those between .80 and .90 were deemed to be good (Barker, Pistrang & Elliott, 2002; Kline, 1993). Spearman's correlations were also used to examine concurrent validity. Correlations  $\geq .30$  were considered acceptable and levels  $\geq .50$  were considered good (Barker et al., 2002).

Section two addresses hypotheses two to four by examining the relationship between challenging behaviour, maternal cognitions and maternal stress using correlations. Again, Spearman's correlations were used to address these hypotheses.

Section three addresses hypothesis five by examining whether maternal cognitions mediate the effect of challenging behaviour on maternal stress. One of the most commonly used methods of mediation analysis is the Sobel test (1982). However, this test cannot be used in the current analysis as some of the variables were not normally distributed. The bootstrap procedure is more appropriate as it is independent of sample and population distribution and provides robust confidence intervals in small samples (Preacher & Hayes, 2008). Given the relatively small sample size, bootstrapping procedures were used as this has been recommended when there is an inadequate sample size for straightforward statistical inference (Adèr, Mellenbergh & Hand, 2008). The bias-corrected bootstrap was used as it has been shown to be the most powerful mediation test when compared to other methods (Fritz & MacKinnon, 2007). Preacher and Hayes (2004) developed a macro script that can be used in SPSS to analyse full mediation via bootstrapping and this was used in the current study. In order to show significant mediation, zero cannot be within the confidence intervals.

### *1. Psychometric properties of the CBPQ*

Table 1 shows the internal consistency and test-retest reliability of the CBPQ at subscale level and Table 2 shows the test-retest reliability of the CBPQ at item level.

Table 1

*Reliability of the CBPQ at subscale level*

CBPQ subscale	Median score (Inter-quartile range)	Spearman- Brown	Internal Consistency ( $\alpha$ )	Test-retest (Spearman's Rho)
Consequences client	21.00 (15.00-23.00)	(.79) <sup>a</sup>	.85	.84**
Consequences carer	17.00 (15.00-20.00)	(.82)	.80	.82**
Control client	6.00 (4.00-6.00)	.25	----	----
Control carer	7.00 (6.00-8.00)	.67	----	----
Treatment	7.00 (5.75-8.00)	.70	----	.62**
Timeline chronic	10.00 (8.00-12.00)	(.84)	.77	.93**
Timeline episodic	8.00 (8.00-8.00)	.72	----	.39
Timeline cyclical	6.00 (5.00-6.00)	-1.63	----	----
Emotional representation	21.00 (16.75-24.00)	(.83)	.85	.84**

\* $p < .05$ , \*\* $p < .01$

<sup>a</sup>Spearman-Brown co-efficients for the subscales with three or more items are presented for comparison.

Table 2  
*Test-rest reliability of the CBPQ at item level*

CBPQ items		Spearman's correlation
<i>Consequences client subscale</i> <sup>1</sup>		
Q1.	Their challenging behaviour is a serious condition.	.54**
Q2.	Their challenging behaviour has had major consequences on their life.	.81**
Q3r.	Their challenging behaviour has not had much effect on their life.	.60**
Q4.	Their challenging behaviour has strongly affected the way that others see them.	.73**
Q5.	Their challenging behaviour has had serious financial consequences for them.	.41*
Q6.	Their challenging behaviour is disabling for them.	.64**
<i>Consequences carer subscale</i> <sup>2</sup>		
Q7.	Their challenging behaviour has had major consequences on my life.	.78**
Q8r.	Their challenging behaviour has not had much effect on my life.	.73**
Q9.	Their challenging behaviour has strongly affected the way others see me.	.41*
Q10.	Their challenging behaviour has had serious financial consequences for me.	.59**
Q11.	Their challenging behaviour has strongly affected the way I see myself as a person.	.50*
<i>Treatment subscale</i> <sup>3</sup>		
Q14.	Their treatment will be effective in curing their challenging behaviour.	.53**
Q15r.	There is very little that can be done to improve their challenging behaviour.	.50*
<i>Timeline chronic</i> <sup>4</sup>		
Q12r.	Their challenging behaviour will improve in time.	.89**
Q19.	Their challenging behaviour is likely to be permanent rather than temporary.	.86**
Q20.	Their challenging behaviour will last for a long time.	.78**
<i>Timeline episodic subscale</i> <sup>5</sup>		
Q21.	Their challenging behaviour may change from time to time.	.34
Q22.	There will be periods of lots of challenging behaviour and periods of improvement.	.54*
<i>Emotional representation</i> <sup>6</sup>		
Q25.	I get depressed when I think about their challenging behaviour.	.52**
Q26.	Their challenging behaviour makes me feel afraid.	.80**
Q27.	When I think about their challenging behaviour I get upset.	.67**
Q28.	Their challenging behaviour makes me feel angry.	.58**
Q29r.	Their challenging behaviour does not worry me.	.51*
Q30.	Their challenging behaviour makes me feel anxious.	.75**

\* $p < .05$ , \*\* $p < .01$ : <sup>1</sup> A higher score is indicative of the belief that the challenging behaviour has more serious / negative consequences for the client.

<sup>2</sup> A higher score is indicative of the belief that the challenging behaviour has more serious / negative consequences for the carer.

<sup>3</sup> A higher score is indicative of the belief that treatment will be effective in resolving the challenging behaviour.

<sup>4</sup> A higher score is indicative of the belief that the challenging behaviour will be longer lasting.

<sup>5</sup> A higher score is indicative of the belief that the challenging behaviour will be more episodic.

<sup>6</sup> A higher score is indicative of the belief that the challenging behaviour has a more negative emotional impact on the carer.

### *Internal Consistency.*

Table 1 shows that three subscales (Consequences client, Consequences carer and Emotional representation) demonstrated good internal consistency ( $\geq .80$ ) and three subscales (Timeline chronic, Treatment and Timeline episodic) showed acceptable levels of internal consistency ( $\geq .70$ ) (Barker et al., 2002; Kline, 1993). The Control client, Control carer and Timeline cyclical subscales showed poor internal consistency and were subsequently not subject to further analysis (Barker et al., 2002; Kline, 1993).

### *Test-retest reliability.*

Tables 1 and 2 show the test-retest reliability of the CBPQ at subscale and item level, respectively, for the six remaining subscales. Table 1 shows that test-retest reliability at subscale level ranged from .39 to .93. All but one (Timeline episodic) subscale were significantly correlated. The subscales with three or more items (Consequences client, Consequences carer, Timeline chronic and Emotional representation) showed good test-retest reliability ( $\geq .82$ ) (Barker et al., 2002; Kline, 1993). The subscales comprised of two items (Treatment and Timeline episodic) showed poor test-retest reliability.

### *Concurrent validity of the CBPQ.*

The concurrent validity of the CBPQ was examined via correlations with three other measures of parental / carers' cognitions (see Table 3 for correlations).



Table 3

*Correlations between the subscales of the CBPQ and the PLOC-SFR subscales, the PSOC Satisfaction subscale and the FoAM*

	CBPQ Subscales					
	Consequences client	Consequences carer	Treatment	Timeline chronic	Timeline episodic	Emotional representation
PLOC Parental efficacy	.25	.20	<b>-.39**</b>	.17	-.17	.09
PLOC Parental responsibility	.02	-.12	.04	.08	.14	.06
PLOC Child control	<b>.47**</b>	<b>.58**</b>	-.22	.23	.24	<b>.46**</b>
PLOC Parental control	<b>.47**</b>	<b>.55**</b>	-.09	.22	.15	<b>.62**</b>
PSOC Satisfaction	-.03	-.10	-.05	.28	<b>.38*</b>	<b>-.38*</b>
FoAM	<b>.45**</b>	<b>.54**</b>	.08	.18	.06	<b>.59**</b>

\* $p < .05$ , \*\* $p < .01$

(CBPQ: Challenging Behaviour Perception Questionnaire; PLOC-SFR: Parental Locus of Control - Short Form Revised; PSOC: Parenting Sense of Competence Scale; FoAM: Fear of Assault Measure).

Hypotheses 1a and 1b could not be tested as the Control client and Control carer subscales were removed due to poor internal consistency.

*Hypothesis 1c: The CBPQ Consequences carer subscale will correlate positively with the PLOC Parental control subscale and the FoAM and negatively with the PSOC satisfaction subscale.*

As predicted in hypothesis 1c, the CBPQ Consequences carer subscale was significantly positively correlated with the PLOC Parental control subscale and the FoAM. However, it was not correlated with the PSOC Satisfaction subscale. A significant positive correlation was also found between the CBPQ Consequences carer subscale and the PLOC Child control subscale. The strength of the correlations was acceptable (Barker et al., 2002). The significant associations suggest that parents who believe challenging behaviour has more negative consequences for them, feel less in control of their child's behaviour, feel their child has greater control of their life and have a greater fear of assault by their child. These findings provide partial support for hypothesis 1c.

*Hypothesis 1d: The CBPQ Consequences client subscale will correlate negatively with the PLOC Child control subscale.*

Contrary to hypothesis 1d, the Consequences client subscale was significantly positively correlated with the PLOC Child control subscale. The CPBQ Consequences client subscale was also significantly correlated with the PLOC Parental control subscale and the FoAM. The strength of the correlations was good (Barker et al., 2002). The direction of the associations suggests that parents who believe that challenging behaviour has more negative consequences for their child, feel their child has greater control of their life, feel less in control of their child's behaviour and have a greater fear of assault by their child. These findings do not support hypothesis 1d.

*Hypothesis 1e: The CBPQ Treatment subscale will correlate negatively with the PLOC Parental Efficacy subscale.*

As predicted in hypothesis 1e, the CBPQ Treatment subscale was negatively correlated with the PLOC Parental efficacy subscale. The strength of the correlation was acceptable (Barker et al., 2002). This association indicated that the more effective parents believe treatment will be for their child's challenging behaviour, the higher their own sense of self-efficacy. This finding provides support for hypothesis 1e.

*Hypothesis 1f: The CBPQ Emotional Representation subscale will correlate positively with the PLOC Parental Control subscale and the FoAM and negatively with the PSOC Satisfaction subscale.*

As predicted in hypothesis 1f, the Emotional representation subscale was positively correlated with the PLOC Parental control subscale and the FoAM and negatively correlated with the PSOC Satisfaction subscale. The Emotional representation subscale was also significantly correlated with the PLOC Child control subscale. The strength of the correlations was acceptable (Barker et al., 2002). The direction of the relationships suggest that parents who believe challenging behaviour has a more negative emotional impact on them, feel that their child has greater control of their life, feel less in control of their child's behaviour, have a greater fear of assault by their child and feel less parenting satisfaction. The findings predominantly provide support for hypothesis 1f.

Predictions were not made regarding the Timeline subscales as timeline is not assessed by the other measures. Table 3 shows that the Timeline chronic and Timeline

episodic subscales did not correlate with the other measures apart from one significant correlation between the CBPQ Timeline episodic subscale and the PSOC Satisfaction subscale. This suggests that the greater the belief that challenging behaviour is more episodic, the greater the sense of parenting satisfaction.

## 2. Correlations

Correlations were used to address hypotheses two to four by examining the relationship between challenging behaviour, parental cognitions (using the CBPQ) and parental stress (see Table 4 for the correlation matrix).

Table 4

*Correlation matrix for study variables*

	BPI_SIBTotal	CBPQ_Conseqclient	CBPQ_Conseqcarer	CBPQ_Treatment	CBPQ_Timechronic	CBPQ_Timeepisodic	CBPQ_Emotional	PSI_Total
BPI_Aggress/DestructTotal	<b>.41**</b>	<b>.37*</b>	<b>.38**</b>	-.07	.26	.21	<b>.35*</b>	<b>.46**</b>
BPI_SIBTotal		<b>.43**</b>	.28	<b>-.34*</b>	<b>.30*</b>	.16	.23	<b>.51**</b>
CBPQ_Conseqclient			<b>.71**</b>	-.05	<b>.57**</b>	.26	<b>.48**</b>	<b>.63**</b>
CBPQ_Conseqcarer				.06	.25	.27	<b>.66**</b>	<b>.70**</b>
CBPQ_Treatment					<b>-.42**</b>	.23	.14	.06
CBPQ_Timechronic						<b>.30*</b>	.06	<b>.29*</b>
CBPQ_Timeepisodic							.01	.28
CBPQ_Emotional								<b>.65**</b>
PSI_Total								

\* $p < .05$ , \*\* $p < .01$

(BPI: The Behavior Problems Inventory; CBPQ: The Challenging Behaviour Perception Questionnaire; PSI: The Parental Stress Index-short form).

*Hypothesis 2: Challenging behaviour will be positively correlated with parenting stress.*

Table 4 shows that the BPI Aggression/destruction and self-injurious behaviour (SIB) subscales were both significantly positively correlated with the PSI total score. This indicates that more aggression/destruction and SIB were both associated with higher parenting stress levels. This provides support for hypothesis 2.

*Hypothesis 3: There will be a significant relationship between challenging behaviour and mothers' cognitions.*

Table 4 shows that BPI Aggression/destruction and SIB scores were both significantly correlated with three subscales from the CBPQ. The BPI Aggression/destruction score was significantly positively correlated with Consequences client, Consequences carer and Emotional representation subscales. This suggests that more aggression/destruction is associated with the belief that challenging behaviour has more negative consequences for parents and children and there is a more negative emotional impact on parents.

The BPI SIB score was positively correlated with the Consequences client and Timeline chronic subscales and negatively correlated with the Treatment subscale from the CBPQ. This suggests that greater levels of SIB are associated with the belief that challenging behaviour has more negative consequences for the child, that the challenging behaviour will be longer lasting and treatment will not be as effective. These findings partially support hypothesis 3 as only some of the CBPQ subscales correlated significantly with BPI scores.

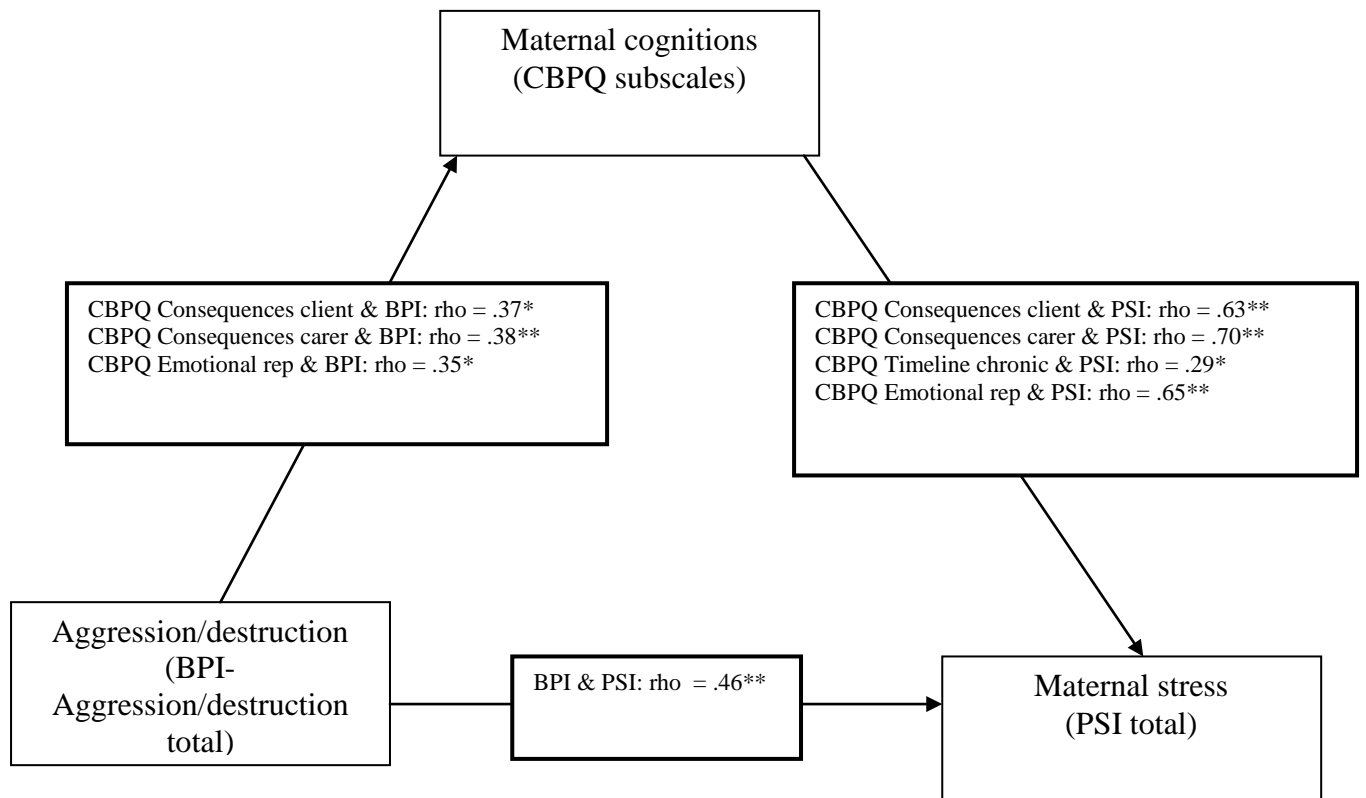
*Hypothesis 4: There will be a significant relationship between mothers' cognitions and parenting stress.*

Table 4 shows that four of the subscales of the CBPQ (Consequences client, Consequences carer, Timeline chronic and Emotional representation) were significantly correlated with the PSI total score. This indicated that higher levels of parenting stress are associated with the belief that challenging behaviour has more negative consequences for the parent and child, the belief that challenging behaviour will be longer-lasting and the belief that challenging behaviour has more negative emotional consequences for the parent. These findings provide partial support for hypothesis 4 as only some of the CBPQ subscales correlated significantly with the PSI total score.

### *3. Mediation Analysis*

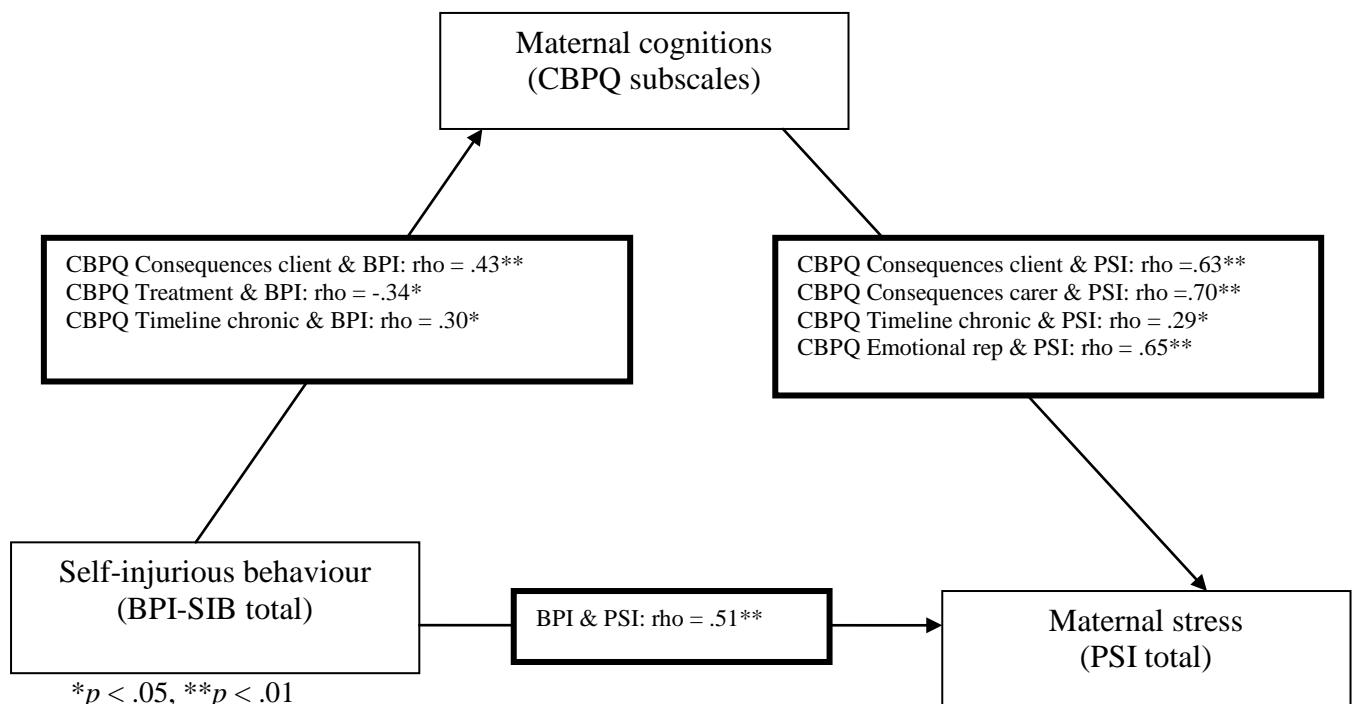
The mediation analysis will address hypothesis 5: *Mothers' cognitions will mediate the relationship between their child's challenging behaviour (specifically aggression/destruction and self-injurious behaviour) and their stress levels; and cognitions mediating this relationship will differ in accordance with the topography of behaviour.*

Significant correlations between the three variables (see Table 4) are shown in the mediation models for aggression/destruction and SIB in Figures 1 and 2.



\* $p < .05$ , \*\* $p < .01$

Figure 1. Significant correlations between the variables in the proposed model for aggression / destruction.



\* $p < .05$ , \*\* $p < .01$

Figure 2. Significant correlations between the variables in the proposed mediation model for self-injurious behaviour.

Figure 1 shows that the cognitive variables that correlated significantly with *both* aggression/destruction and maternal stress were Consequences client, Consequences carer and Emotional representation. Figure 2 shows that the cognitive variables that correlated significantly with *both* SIB and maternal stress were, Consequences client and Timeline chronic.

*Mediation analysis for aggression/destruction and parental stress.*

The CBPQ subscales that significantly correlated with the BPI aggression/destruction score and the PSI total score were included in the mediation analysis. These were Consequences client, Consequences carer and Emotional representation (see Figure 1). Table 5 shows the results of the mediation analysis (see Appendix I for the results of the bootstrapping analysis).

Table 5

*Mediation of the effect of aggression/destruction on maternal stress through maternal perceptions of challenging behaviour*

	Point Estimate	Bootstrap Path Estimate	Bias	Standard Error	Lower BC 95% CI	Upper BC 95% CI
Consequences client	.13	.13	-.00	.08	.02	.35
Consequences carer	.10	.13	.03	.14	-.08	.47
Emotional representation	.16	.14	-.02	.12	-.02	.48
Total	.38	.40	.01	.13	.17	.68

*n* = 46; Bootstrap sample size = 10,000; BC: Bias corrected.



The analysis showed that the overall model was significant ( $R^2 = .59$ ;  $p < .0001$ ) and accounted for 59% of the variance in maternal stress. Table 5 shows that, taken as a whole, Consequences client, Consequences carer and Emotional representation mediated the effect of aggression/destruction on maternal stress. However, the only individual significant mediator of aggression/destruction on maternal stress was Consequences client. Neither Consequences carer nor Emotional representation contributed to the indirect effect, above and beyond, Consequences client.

*Mediation analysis for self-injurious behaviour and parental stress.*

The CBPQ subscales that significantly correlated with the BPI SIB score and the PSI total score were included in the mediation analysis (see Figure 2). These were Consequences client and Timeline chronic. Table 6 shows the results of the mediation analysis.

Table 6

*Mediation of the effect of self-injurious behaviour on maternal stress through maternal perceptions of challenging behaviour*

	Point Estimate	Bootstrap Path Estimate	Bias	Standard Error	Lower BC 95% CI	Upper BC 95% CI
Consequences client	.53	.56	.03	.24	.19	1.11
Timeline chronic	-.09	-.09	-.01	.12	-.37	.10
Total	.45	.47	.02	.21	.12	.93

$n = 46$ ; Bootstrap sample size = 10,000; BC: Bias corrected.

The bootstrapping analysis showed that the overall model was significant ( $R^2 = .43$ ;  $p < .0001$ ) and accounted for 43% of the variance in maternal stress. Table 6 shows that, taken as a set, Consequences client and Timeline chronic mediated the effect of SIB on maternal stress. However, the only individual significant mediator of SIB on maternal stress was Consequences client. Timeline chronic did not contribute to the indirect effect, above and beyond, Consequences client. The findings provide partial support for hypothesis 5; mothers' cognitions were found to mediate the effect of challenging behaviour on maternal stress and the overall mediation models for SIB and aggression/destruction differed, however the same variable (Consequences client) was a significant independent mediator in both models.

## Discussion

The aim of the current study was to examine whether the Challenging Behaviour Perception Questionnaire (CBPQ; Williams & Rose, 2007) is a reliable and valid measure of mothers' perceptions of challenging behaviour. The study also investigated the relationship between challenging behaviour, maternal cognitions and maternal stress and examined whether maternal cognitions mediated the effect of challenging behaviour on parenting stress.

### *Psychometric properties of the CBPQ*

An examination of internal consistency led to the removal of three subscales and resulted in a 24-item measure with six subscales. The co-efficients at subscale level ranged from .70 to .85 with three subscales showing good internal consistency and three showing acceptable internal consistency. This is in contrast to the original study with staff, where the reliability analysis of the CBPQ resulted in a 19-item measure with six subscales and Cronbach's alpha ranged from .58 to .79 at subscale level. Two subscales (Control client and Timeline cyclical) were removed following reliability analysis across both populations, reflecting a lack of reliability in both groups. The Control carer subscale was found to have poor reliability in this population but showed acceptable reliability in the staff population. However, the Treatment subscale was found to show poor internal consistency in the staff population but showed acceptable internal consistency in this population. Internal consistency was higher for all five CBPQ subscales in this population compared to the staff population. This could be a result of the more specific and enduring relationships that parents have with their offspring compared to staff.

An examination of test-retest reliability found that four of the six subscales showed good test-retest reliability whilst two (Treatment and Timeline episodic) showed poor test-retest reliability. The poor reliability of the Timeline episodic subscale could be due to the inherent instability of the concept, meaning that it cannot be reliably measured over time. Test-retest reliability could not be compared to the original study on staff as this was not investigated (Williams & Rose, 2007). In the current study the subscales with poor levels of reliability consisted of two items. The limitation of two-item scales has been reported by researchers who clearly advocate for the inclusion of more items, especially when conducting exploratory research (Emons, Sijtsma & Meijer, 2007; Marsh, Hau, Balla & Grayson, 1998). Further development of the two-item subscales may help to increase the robustness of these subscales and the measure overall.

Concurrent validity of the CBPQ subscales was also investigated and some support for the validity of the CBPQ, was provided. The findings provided support for the validity of the CBPQ Treatment subscale as this was negatively correlated with the PLOC Parental efficacy subscale as predicted. Partial support was provided for the validity of the CBPQ Consequences carer subscale and the Emotional representation subscale with most predicted associations being significant. On the other hand, the direction of the relationship between the CBPQ Consequences client subscale and the PLOC child control subscale was in the opposite direction to that predicted. This association suggested that parents who believe that challenging behaviour has more negative consequences for their child also believe that their child has greater control of their life. It may be that parents who believe that challenging behaviour has had more negative consequences on their child, have provided more time and support to their child in relation to this, which has perhaps made them feel their child has greater control of their life. Predictions were not made for the CBPQ

Timeline chronic and episodic subscales as the other measures do not assess timeline. As expected, these subscales did not correlate with the other cognitive measures, other than one significant correlation between the CBPQ Timeline episodic subscale and the PSOC Satisfaction subscale. The direction of this association indicated that parents who believe that their child's challenging behaviour is more episodic have a greater sense of parenting satisfaction. It may be that parents who believe that challenging behaviour will improve at times, perhaps gives them hope as a parent and makes them feel more satisfied. The lack of association between the CBPQ Timeline subscales and the other measures provides evidence of discriminant validity for these subscales.

Overall, the current findings suggest that the CBPQ subscales with three or more items (Consequences client, Consequences carer, Timeline Chronic and Emotional Representation) predominantly show good internal consistency and good test-retest reliability. However, the two-item subscales (Treatment and Timeline episodic) showed acceptable internal consistency but poor test-retest reliability. Some support was provided for the concurrent validity of the CBPQ Treatment, Consequences carer and Emotional representation subscales. The lack of association between the CBPQ Timeline chronic and episodic subscales and the other cognitive measures provided some evidence for the discriminant validity of these subscales.

#### *The relationship between challenging behaviour, maternal cognitions and maternal stress*

Correlations were used to investigate hypotheses two to four. Support was found for hypothesis two, whilst partial support was found for hypotheses three and four. As predicted in hypothesis two, significant positive relationships were identified between aggression/destruction and maternal stress; and SIB and maternal stress. These findings

provide further support for the body of research demonstrating the relationship between challenging behaviour and parental well-being (e.g. Baker et al., 2002; Lecavalier et al., 2006; Lloyd & Hastings, 2009b; Orsmond et al., 2003). For example, Lloyd and Hastings (2009b) found that child behavioural difficulties were positively correlated with maternal anxiety, depression and stress; and negatively associated with maternal positive affect.

Significant relationships were found between challenging behaviour and maternal cognitions, providing some support for the third hypothesis. Three significant correlations between aggression/destruction and maternal cognitions (Consequences client, Consequences carer and Emotional representation subscales) suggested that more aggression/destruction is associated with the belief that challenging behaviour has more negative consequences for the parents and child and it has a more negative emotional impact on parents. The significant correlations between SIB and maternal cognitions (Consequences client, Timeline chronic and Treatment subscales) indicated that more SIB is associated with the belief that challenging behaviour has more negative consequences for the child, that challenging behaviour will be longer lasting and treatment will not be as effective. Other than Consequences client, the cognitive variables significantly related to the two behaviours, differed.

It may be that cognitions associated with challenging behaviour are related to topography of behaviour. Although this is yet to be closely examined in the family literature, research on staff supports this finding (e.g. Stanley & Standen, 2000). For example, one study found that staff perceived individuals with challenging behaviour to have significantly greater control of aggressive behaviour compared to self-injurious behaviour and perceived self-injurious behaviour to be significantly more stable than aggressive or destructive behaviour (Stanley & Standen, 2000). In the family literature,

research has broadly shown significant relationships between challenging behaviour and a number of parental cognitions, such as locus of control, psychological acceptance and self-efficacy (Feldman et al., 2007; Hill & Rose, 2009; Lloyd & Hastings, 2008). As an example, two studies found that greater child behavioural difficulties were significantly associated with a more external locus of control (Hassall et al., 2005; Lloyd & Hastings, 2009a). These findings further add to the body of literature by providing evidence that the association between challenging behaviour and cognitions may relate to topography of behaviour.

Correlations between maternal cognitions and maternal stress also revealed significant relationships, providing partial support for hypothesis four. Significant correlations were found between four of the CBPQ subscales (Consequences client, Consequences carer, Timeline chronic and Emotional representation) and the PSI total score. The direction of the relationships indicated that higher levels of parenting stress are associated with the belief that challenging behaviour has more negative consequences for the parent and child, the belief that challenging behaviour will be longer-lasting and challenging behaviour will have more negative emotional consequences for the parent. As far as we are aware, no study in the family domain has examined the relationship between specific cognitions of challenging behaviour and parental well-being. Previous research findings have shown associations between more general parental cognitions and parental well-being (e.g. MacDonald et al., 2010). Studies for example, have reported associations between higher levels of maternal stress and lower levels of parenting satisfaction and a more external locus of control (Hassall et al., 2005; Hill & Rose, 2009). Resilience factors, such as hope, have also been associated with maternal well-being (Lloyd & Hastings,

2009b). The current results in addition to previous findings suggest that a broad range of cognitions are associated with maternal well-being.

*Maternal cognitions as a mediator of challenging behaviour on maternal stress*

The findings show that mediation models for both challenging behaviours were significant. The overall model for aggression/destruction accounted for 59% of the variance in parenting stress, whilst the overall model for SIB accounted for 43% of the variance in maternal stress. The overall models differed between the behaviours but the only independent significant mediator for both behaviours was the belief about the impact of challenging behaviour on the child, thus providing only partial support for hypothesis five. For aggression/destruction, the belief about the consequences of challenging behaviour on the child and themselves and the belief about its emotional impact on parents mediated the effect of aggression/destruction on maternal stress. For SIB, the belief about the consequences of challenging behaviour on the child and the belief about the longevity of challenging behaviour mediated the effect of SIB on maternal stress.

These results provide support for previous studies showing a mediating effect of cognitions. Hastings and Brown (2002) found that self-efficacy mediated the relationship between behaviour problems and both anxiety and depression in mothers of children with autism. Also, MacDonald et al. (2010) found that psychological acceptance partially mediated the impact of child behavioural problems on paternal stress and well-being. The current results are in contrast to several studies showing no mediating effect of cognitions on the relationship between challenging behaviour and maternal well-being (Feldman et al., 2007; Hassall et al., 2005; Hill & Rose, 2009). It may be that the employment of general measures of cognition and the examination of all challenging behaviours together have



resulted in the absence of significant findings. Also, it is possible that only certain cognitions mediate the relationship between challenging behaviour and maternal well-being, leading to differences in findings across studies.

The variability in the overall mediation models for each behaviour are similar to research findings on staff attributions, which have shown that attributions differ in accordance with topography of behaviour (e.g. Bailey et al., 2006; Stanley & Standen, 2000). For example, Bailey et al. (2006) found that staff perceived other forms of challenging behaviour as significantly more uncontrollable and less stable than self-injurious behaviour. However, the fact that the same cognition was found to be the only independent significant mediator for both behaviours appears to conflict with the findings in the staff literature. More research is needed in the family domain to explore this further.

#### *Limitations of the study*

One of the most obvious limitations is the low return rate. This in combination with the small sample size represents a threat to external validity and caution must be exercised in generalising the findings. It is difficult to understand the exact cause of the low return-rate but anecdotal reports suggest that it was due to a variety of factors, such as being offered an interview initially rather than a postal questionnaire. In addition, the small sample size limits the conclusions that can be drawn from the bootstrapping analysis. A larger sample is required to reliably interpret the results from the bootstrapping analysis based upon the correlations between the study variables and so caution must be exercised when interpreting these results (Fritz & MacKinnon, 2007).

Diagnoses regarding the presence and cause of ID were also based on parental reports. Of the mothers who participated, 39% reported that their child had an autism

spectrum disorder. Previous research has shown that parental cognitions and parental well-being of children with autism differ when compared to parents of children with other causes of ID (Griffith, Hastings, Nash & Hill, 2010). The high representation of this group within the overall sample could have affected the overall findings and make them less representative of general ID.

Another limitation is the mixed-methodological design used, due to the initial low return rate. Mothers who were interviewed may have been affected by a social desirability bias due to completion of questionnaires face-to-face with the researcher. Also, when conducting the interviews, mothers reported finding some questions across the measures ambiguous. The interview allowed for immediate clarification of such questions, which was not possible via post. The cross-sectional design of the study meant that true causality is difficult to establish. Given the exploratory nature of the study, a cross-sectional design is useful to explore whether relationships exist before examining them over time.

In the current study, all potentially confounding variables were not investigated, such as poverty and parental unemployment (Hatton & Emerson, 2003). This could have caused a bias in the results. The inclusion of only self-report measures is also a limitation. It is likely that mothers' ratings of challenging behaviour were affected by their own stress levels and so this could have biased the results. It was hoped that through the employment of psychometrically sound measures, this issue to some extent would have been circumvented.

#### *Future directions*

The findings from this study could be taken forward in a number of ways. Firstly, further development of the CBPQ two-item subscales and further examination of the

psychometric properties of the questionnaire using larger samples would provide more information about the robustness of the measure. Examination of the psychometric properties of the CBPQ in relation to fathers and parents of older children would examine the applicability of the measure to a broader population.

Research could also focus on further examining the mediation models for various topographies of challenging behaviour. Again further research is needed using larger samples to examine whether the findings in this study are replicated. Perhaps future research could also employ comparison groups of mothers of children showing different topographies of behaviour to assess differences using a between-group approach.

### *Clinical implications*

This study provides some preliminary evidence for the clinical utility of the CBPQ. To our knowledge only general measures of cognition are available to assess perceptions of mothers. More specific measures, such as the CBPQ, may be more sensitive to examining mothers' perceptions of their child's challenging behaviour and could be of real clinical value within Learning Disability services, particularly as referrals for challenging behaviour are common. Cognitive-behavioural therapy is one approach used when working with families so having a psychometrically sound measure of parental cognitions could be a key part of conducting a thorough clinical assessment and allow for a more comprehensive intervention plan.

The findings suggest that maternal perceptions mediate the effect of challenging behaviour on maternal stress. This suggests there is a role for utilising some form of cognitive approach when working with families regarding challenging behaviour. The CBPQ may also be helpful when working with families to help them understand and

manage behaviours that might not seem very amenable to change. For example, if clinicians were to identify that parents believed the timeline of challenging behaviour is chronic, perhaps some psycho-education about the influences on behaviour, such as the environment, would be important.

### *Conclusion*

The findings from the current study show that the Challenging Behaviour Perception Questionnaire could be a promising tool for examining mothers' perceptions of their child's challenging behaviour. Preliminary findings suggest that most CBPQ subscales showed acceptable levels of reliability and concurrent validity. Further development of the measure is required and further examination of the psychometric properties in larger and more varied samples is needed. The current study also showed that maternal cognitions mediated the effect of challenging behaviour on maternal stress. This study examined separate mediation models for aggression/ destruction and SIB but further research is needed to provide greater insight into the similarities and differences between these mediation models using larger samples.

## References

- Abidin, R. R. (1995). *Parenting Stress Index* (3<sup>rd</sup> ed.). Florida: PAR Inc.
- Adèr, H. J., Mellenbergh G. J., & Hand, D. J. (2008). *Advising on research methods: A consultant's companion*. Huizen, The Netherlands: Johannes van Kessel Publishing.
- Bailey, B. A., Hare, D. J., Hatton, C., & Limb, K. (2006). The response to challenging behaviour by care staff: emotional responses, attributions of cause and observations of practice. *Journal of Intellectual Disability Research*, 50, 199–211.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107, 433-444.
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49, 575-590.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*. West Sussex: John Wiley & Sons.
- Barrowclough, C., Lobban, F., Hatton, C., & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology*, 40, 371-385.
- Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The Parental Locus of Control Scale: development and validation. *Journal of Clinical Child Psychology*, 15, 260-267.
- Cortina, J. M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology*, 78, 98-104.

- Dagnan, D. (2012). Carers' responses to challenging behaviour: a comparison of responses to named and unnamed vignettes. *Journal of Applied Research in Intellectual Disabilities, 25*, 88-94.
- Dagnan, D., Grant, F., & McDonnell. (2004). Understanding challenging behaviour in older people; the development of the controllability beliefs scale. *Behavioural and Cognitive Psychotherapy, 32*, 501-506.
- Dagnan, D., Hull, A., & McDonnell, A. (2013). The Controllability Beliefs Scale used with carers of people with intellectual disabilities: psychometric properties. *Journal of Intellectual Disability Research, 57*, 422-428.
- Dempster, M., McCorry, N. K., Brennan, E., Donnelly, M., Murray, L. J., & Johnston, B. T. (2011). Do Changes in Illness Perceptions Predict Changes in Psychological Distress among Oesophageal Cancer Survivors? *Journal of Health Psychology, 16*, 500-509
- Dilworth, J. A., Phillips, N., & Rose, J. (2011). Factors relating to staff attributions of control over challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 24*, 29-38.
- Drysdale, E. E., Jahoda, A., & Campbell, E. (2009). Investigating spontaneous attributions in mothers of individuals with ID and self-injurious behaviour. *British Journal of Learning Disabilities, 37*, 197-206.
- Eisinga, R., Grotenhuis, M., & Pelzer, B. (2012). The reliability of a two-item scale: Pearson, Cronbach, or Spearman-Brown? *International Journal of Public Health, 1*-6.
- Emons, W. H. M., Sijtsma, K., & Meijer, R. R. (2007). On the consistency of individual classification using short scales. *Psychological Methods, 12*, 105-120.

- Feldman, M., McDonald, L., Serbin, L., Stack, D., Secco, M. L., & Yu, C. T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research, 51*, 606-619.
- Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*, 233-239.
- Gibaud-Wallston, J., & Wandersman, L. P. (1978). *Development and utility of the Parenting Sense of Competence Scale*. Paper presented at the meeting of the American Psychological Association, Toronto.
- Griffith, G. M., Hastings, R. P., Nash, S., & Hill, C. (2010). Using matched groups to explore child behavior problems and maternal well-being in children with Down syndrome and Autism. *Journal of Autism and Developmental Disorders, 40*, 610-619.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405-418.
- Hastings, R. P. (1997). Measuring staff perceptions of challenging behaviour: the Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research, 41*, 495-501.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27*, 149-160.

- Hastings, R. P., & Brown, A. (2002). Behavior problems of children with autism, parental self-efficacy and mental health. *American Journal on Mental Retardation*, *107*, 222-232.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, *107*, 116-127.
- Hatton, C., & Emerson, E. (2003). Families with a person with intellectual disabilities: stress and impact. *Current Opinion in Psychiatry*, *16*, 497-501.
- Heijmans, M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *Journal of Psychosomatic Research*, *45*, 39-51.
- Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, *53*, 969-980.
- Hill, C., & Rose, J. (2010). Parenting stress models and their application to parents of adults with intellectual disabilities. *The British Journal of Developmental Disabilities*, *56*, 19-37.
- Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, *18*, 167-175.
- Jones, J., & Passey, J. (2005). Family adaptation, coping and resources: Parents of children with developmental disabilities and behaviour problems. *Journal on Developmental Disabilities*, *11*, 31-46.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, *50*, 883-893.



- Kline, P. (1993). *The Handbook of Psychological Testing*. London: Routledge.
- Kuschlick, A., Blunden, R., & Cox, G. (1973). A method of rating behaviour characteristics for use in large scale surveys of mental handicap. *Psychological Medicine*, 3, 466-478.
- Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two factor model of care-giving appraisal and psychological well-being. *Journal of Gerontology*, 46, 181-189.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer.
- Leather, P., Beale, D., Lawrence, C., & Dickson, R. (1997). Effects of exposure to workplace violence and the mediating impact of fear. *Work and Stress*, 11, 329-340.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183.
- Leventhal, H., Diefenbach, M., & Leventhal, E. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16, 143-163.
- Leventhal, H., Nerenz, D. R., & Steel, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E., Taylor, & J. E. Singer (eds.), *Handbook of Psychology and Health*, vol. 4 (pp. 219-252). Hillsdale, NJ: Erlbaum.
- Llewellyn, C. D., McGurk, M., & Weinman, J. (2007). Illness and Treatment Beliefs in Head and Neck Cancer: Is Leventhal's Common Sense Model a Useful Framework for Determining Changes in Outcome over Time? *Journal of Psychosomatic Research*, 63, 17-26.

- Lloyd, T., & Hastings, R. P. (2009a). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability, 34*, 104-115.
- Lloyd, T. J., & Hastings, R. (2009b). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*, 957-968.
- MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological acceptance mediates the impact of the behaviour problems of children with intellectual disability on fathers' psychological adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*, 27-37.
- Marsh, H.W., Hau, K-T., Balla, J. R., & Grayson, D. (1998). Is more ever too much? The number of indicators per factor in confirmatory factor analysis. *Multivariate Behavioral Research, 33*, 181–220.
- Mash, E. J., & Johnston, C. (1990). Determinants of parenting stress: Illustrations from families of hyperactive children and families of physically abused children. *Journal of Clinical Child Psychology, 19*, 313-328.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: the double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman & J. M. Patterson (Eds.), *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research*. New York: The Haworth Press.
- Miller, K., Purshotham, A. D., McLatchie, E., George, D., & Murray, G. D. (2005). A 1-Year Prospective Study of Individual Variation in Distress and Illness Perceptions after Treatment for Breast Cancer. *Journal of Psychosomatic Research, 58*, 335–342.

- Murphy, H., Dickens, C., Creed, F., & Bernstein, R. (1999). Depression, Illness Perception and Coping in Rheumatoid Arthritis. *Journal of Psychosomatic Research*, *46*, 155-164.
- Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, *54*, 992-1003.
- Orsmond, G. I., Seltzer, M. M., Krauss, M. W., & Hong, J. (2003). Behavior problems in adults with mental retardation and maternal wellbeing: Examination of the direction of effects. *American Journal on Mental Retardation*, *108*, 257-271.
- Palmer, J., & Jenkins, J. (1982). The 'Wessex' behaviour rating system for mentally handicapped people: Reliability study. *British Journal of Mental Subnormality*, *28*, 88-96.
- Peterson, C., Semmel, A., von Baeyer, C., Abramson, L. Y., Metalsky, G. I., & Seligman, M. E. P. (1982). The Attributional Style Questionnaire. *Cognitive Therapy and Research*, *6*, 287-300.
- Preacher K. J., & Hayes A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behaviour Research Methods Instruments & Computers*, *36*, 717-731.
- Preacher K. J., & Hayes A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, *40*, 879-891.
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: a test of Lazarus' transactional model of coping. *Journal of Community & Applied Social Psychology*, *1*, 57-70.

- Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., & Smalls, Y. (2001). The Behavior Problems Inventory: an instrument for the assessment of self-injury, stereotyped behavior, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31*, 577-588.
- Rose, J., & Cleary, A. (2007). Care staff perceptions of challenging behaviour and fear of assault. *Journal of Intellectual and Developmental Disabilities, 32*, 153-161.
- Saloviita, T., Itälina, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX Model. *Journal of Intellectual Disability Research, 47*, 300-312.
- Scharloo, M., Kaptein, A. A., Weinman, J., Vermeer, B. J. and Rooijmans, H. G. M. (2000). Patients' illness perceptions and coping as predictors of functional status in psoriasis: a 1-year follow up. *British Journal of Dermatology, 142*, 899-907.
- Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. *Sociological Methodology, 12*, 290-312.
- Stafford, L., Berk, M., & Jackson, H. J. (2009). Are Illness Perceptions about Coronary Artery Disease Predictive of Depression and Quality of Life Outcomes? *Journal of Psychosomatic Research, 66*, 211-220.
- Stanley, B., & Standen, P. J. (2000). Carers' attributions for challenging behaviour. *British Journal of Clinical Psychology, 39*, 157-168.

- Weiner, B. (1980). A cognitive (attribution) – emotion – action model of helping behaviour: an analysis of judgements of help-giving. *Journal of Personality and Social Psychology*, *39*, 1142-1162.
- Weiner, B. (1985). An attributional theory of achievement, motivation and emotion. *Psychological Review*, *92*, 547–573.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health*, *11*, 431-446.
- Williams, R. J., & Rose, J. L. (2007). The development of a questionnaire to assess the perceptions of care staff towards people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, *11*, 197-211.
- Willner, P., & Smith, M. (2008). Attribution theory applied to helping behaviour towards people with intellectual disabilities who challenge. *Journal of Applied Research in Intellectual Disabilities*, *21*, 150–155.
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, *57*, 513-530.
- Zigmond, A.S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavia*, *67*, 361–370.

## **PUBLIC DOMAIN BRIEFING DOCUMENT**

The relationship between challenging behaviour, cognitions and stress in mothers of individuals with intellectual disabilities

### *Outline*

The research detailed below was conducted by Lisa Nelson, Trainee Clinical Psychologist, University of Birmingham, under the Supervision of Dr John Rose and Dr Neil Phillips. It was submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology.

### *Background*

Research has shown that there are strong relationships between behavioural difficulties shown by individuals with learning disabilities and well-being in parents, such as, stress, anxiety and positive effects. The research so far suggests that parents' perceptions may affect this relationship. However, there is not enough research at present to determine exactly how parental perceptions impact on this relationship. The aim of the current study was to investigate whether the Challenging Behaviour Perception questionnaire (Williams & Rose, 2007) can be used with mothers' of individuals with learning disabilities to assess their perceptions of their child's challenging behaviour. The study also aimed to assess whether parents' perceptions of their child's challenging behaviour influenced the effect of challenging behaviour on mothers' stress levels.

### *Method*

46 mothers of children and young adults with learning disabilities took part in this study. Mothers were predominantly recruited through clinical services and schools. Mothers had to opt-in to the project so that researchers were not aware of their personal details before they agreed to take part. Of the mothers invited to take part, approximately 14% agreed to take part. Mothers who took part, were either interviewed or sent the questionnaires in the post. 24 mothers also completed the Challenging Behaviour Perception questionnaire (Williams & Rose, 2007) approximately two weeks after filling in the questionnaires. This was done to measure how consistent the questionnaire is over time.

### *Results*

The findings suggest that the Challenging Behaviour Perception questionnaire (Williams & Rose, 2007) is a reliable and valid tool for measuring mothers' perceptions of their child's challenging behaviour. The results also suggested that mothers' perceptions influenced the effect of challenging behaviour on mothers' stress levels.

### *Discussion*

The results of this study suggested that mothers' perceptions are important in influencing the effect of children's challenging behaviour on their stress levels. This suggests that certain ways of working with families when they have a child who shows challenging behaviour, may be helpful. For example, the findings show that it is important to support parents, as well as the person with a learning disability. This study has certain limitations, which mean that caution must be exercised when trying to apply the findings to other areas of research. Future research is needed to explore these relationships in more detail.

Appendix B

*Questionnaire pack*

**Demographic Questionnaire**

1. Today's date.....
2. Your name.....
3. Your address.....  
.....
4. Your Ethnicity.....
5. Your age:.....
6. Are you the child's biological parent / adoptive parent / foster carer (please circle one)
7. If you are a foster carer, how many years have you fostered the child for?.....
8. Your child's age:.....
9. Your child's gender:.....
10. Has your child received a diagnosis from a professional? No Yes  
If yes, what diagnosis/ diagnoses have they received.....

**Fear of Assault Measure (Leather et al., 1997)**

1. How worried are you by the possibility of violence or assault by your child? (Please circle).  
1            2            3            4            5  
Not at all    A bit        Moderately    A lot        Extremely
2. How much do you feel personally at risk of violence or assault by your child? (Please circle).  
1            2            3            4            5  
Not at all    A bit        Moderately    A lot        Extremely



**Stress in Mothers of Children with a Learning Disability and Challenging Behaviour**

**Parent Information Sheet**

You are being invited to take part in some research.

***What is the purpose of the study?***

We want to learn more about stress in mothers of children with learning disabilities and challenging behaviour because we know that these parents often have high stress levels. We also want to find out more about how mothers' understanding of their child's challenging behaviour affects their stress levels.

***Do I have to take part?***

No. It is entirely up to you whether you take part in this research. If you *do not* want to take part, simply ignore this letter. Your decision *will not* affect the standard of care that either you, or your child receives from Social Services or the NHS now or in the future.

***What will happen to me if I take part?***

We will call you to arrange a good time to visit you at home to do an interview. The interview will be done with myself or an Undergraduate student who is helping with the project and it will take about 1hr 30 mins. The interview will involve me asking you questions from a number of questionnaires. Two weeks after the interview, the same person will call you to fill in one of the questionnaires again. This will take about *5 minutes* to do.

***What do I have to do?***

If you would like to take part in the study, please sign the enclosed consent form as soon as possible and return it to us in the stamped addressed envelope provided. We will then call you to arrange a time to do the interview.

***What are the possible disadvantages and risks of taking part?***

It is possible that parents may become distressed when asked about their stress levels and their child's level of challenging behaviour. In the unlikely event that this happens, you can contact the Clinical Psychologist (Dr Neil Phillips) at your local Learning Disability team (XXX) to determine what the appropriate course of action should be. In the meantime, you can also

contact Dr John Rose who is a Clinical Psychologist and working on this research project.

***What are the possible benefits of taking part?***

It is hoped that the experience of families such as yourselves can be better understood, and enable services, such as the Local Authority and NHS to provide better support and services for parents and people with learning disabilities. By taking part, you could also win a £50 Boots voucher. One person will be randomly selected to win the voucher.

***What happens when the research study stops?***

At the end of the project, a summary of the results will be sent to parents who have taken part in the research project. We hope to publish the results in a specialist journal for research into learning disabilities. Parents *will not* be identifiable in any report or article.

***Will my taking part in the study be kept confidential?***

Yes. All the questionnaire data will be entirely confidential to the research team unless you tell us that you or someone else may be at risk of harm. In that situation, we would have to let another service know, including your GP. Questionnaire data will be stored in a locked filing cabinet and only the research team will have access to it. The questionnaires will be given a number so that when data is entered onto a computer, your personal details are not with your data. Your personal details will be kept on a separate database which will be password-protected. After the interview you will also be asked whether you are happy for anonymous data from one of the questionnaires to be shared with the person who designed the questionnaire. It is entirely up to you whether you want this data to be shared.

***What if there is a problem?***

If you have any concerns, you can withdraw from the study up until three weeks after taking part. If you withdraw, your data will be destroyed and not used in the research.

***Contact Details:***

Research Supervisor: Dr John Rose XXX / XXX

Thank you for taking the time to read this information.

Lisa Nelson (Trainee Clinical Psychologist)

## Appendix E

### *Counter-balancing the questionnaire pack*

The questionnaires were counter-balanced in the following three ways:

1. Demographic questionnaire, Wessex scale, BPI, CBPQ, Fear of Assault Measure, PLOC, PSOC, PSI.
2. Demographic questionnaire, Wessex scale, BPI, PSI, CBPQ, Fear of Assault Measure, PLOC, PSOC.
3. Demographic questionnaire, Wessex scale, BPI, PSI, PLOC, PSOC, CBPQ, Fear of Assault Measure.

## Appendix F

### *Descriptive information for the questionnaires*

<b>Measure</b>	<b>Median</b>	<b>Inter-quartile range</b>
BPI Aggression/ Destruction total	8.50	0.00-25.38
BPI SIB total	7.50	2.75-13.25
CBPQ Consequences client	21.00	15.00-23.00
CBPQ Consequences carer	17.00	15.00-20.00
CBPQ Control client	6.00	4.00-6.00
CBPQ Control carer	7.00	6.00-8.00
CBPQ Treatment	7.00	5.75-8.00
CBPQ Timeline chronic	10.00	8.00-12.00
CBPQ Timeline episodic	8.00	8.00-8.00
CBPQ Timeline cyclical	6.00	5.00-6.00
CBPQ Emotional representation	21.00	16.75-24.00
PLOC Parental efficacy	14.00	11.75-18.00
PLOC Parental responsibility	20.00	19.00-23.00
PLOC Child control	18.00	16.00-22.00
PLOC Parental control	18.50	17.00-22.00
PLOC total	72.00	66.75-80.25
PSOC Satisfaction	37.00	32.00-38.00
FoAM	2.50	2.00-6.00
PSI total	110.50	96.50-124.25

(BPI: The Behavior Problems Inventory; CBPQ: The Challenging Behaviour Perception Questionnaire; PLOC-SFR: Parental Locus of Control - Short Form Revised; PSOC: Parenting Sense of Competence Scale; FoAM: Fear of Assault Measure; PSI: The Parental Stress Index-short form).

## Appendix G

*Tests of normality for all measures included in current study*

<b>Tests of Normality</b>						
	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
BPI_AggFreqSub + BPI_AggSevSub	.253	35	.000	.857	35	<b>.000</b>
BPI_SIBFreqScore + BPI_SIBSevSub	.188	35	.003	.853	35	<b>.000</b>
CBPQ Consequences Client subscale (1,2,3R,4,5,6)	.129	35	.154	.962	35	.269
CBPQ Consequences Carer subscales (7,8R,9,10,11)	.115	35	.200 <sup>*</sup>	.961	35	.244
CBPQ Control Client (13,16)	.226	35	.000	.927	35	<b>.022</b>
CBPQ Control Carer (17,18)	.219	35	.000	.895	35	<b>.003</b>
CBPQ Treatment (14,15R)	.152	35	.041	.964	35	.310
CBPQ Timeline Chronic (12R,19,20)	.129	35	.151	.962	35	.265
CBPQ Timeline Episodic (21,22)	.331	35	.000	.846	35	<b>.000</b>
CBPQ Timeline Cyclical (23R,24)	.275	35	.000	.875	35	<b>.001</b>
CBPQ Emotional Representation(25,26,27,28 ,29R,30)	.171	35	.011	.936	35	<b>.041</b>
FoAMScore	.296	35	.000	.794	35	<b>.000</b>
PLOC_Total	.079	35	.200 <sup>*</sup>	.984	35	.892
PSOC_SatisfSub	.152	35	.039	.941	35	.059
PSI_Total	.094	35	.200 <sup>*</sup>	.971	35	.461

a. Lilliefors Significance Correction

\*. This is a lower bound of the true significance.

## Appendix H

### *Exploration of potentially confounding variables*

**Correlations**

			PSI Total	Demographic Questionnaire: Parent's age (years)	Demographic Questionnaire: Child's age (years)	Wessex self help score (QG+QH +QI): max score is 9	Wessex Mobility score (QE+QF): min score is 2 and max score is 6	Wessex Literacy score (QM+QN+Q O) Total score = 9.
Spearman's rho	PSI_Total	Correlation	1.000	-.031	.148	-.027	.141	.211
		Coefficient						
		Sig. (2-tailed)	.	.837	.325	.857	.351	.160
		N	46	46	46	46	46	46
Demographic Questionnaire: Parent's age (years)		Correlation	-.031	1.000	.614**	-.022	.029	-.107
		Coefficient						
		Sig. (2-tailed)	.837	.	.000	.886	.846	.481
		N	46	46	46	46	46	46
Demographic Questionnaire: Child's age (years)		Correlation	.148	.614**	1.000	.207	-.047	.115
		Coefficient						
		Sig. (2-tailed)	.325	.000	.	.167	.755	.445
		N	46	46	46	46	46	46
Wessex self help score (QG+QH+QI): max score is 9		Correlation	-.027	-.022	.207	1.000	.564**	.568**
		Coefficient						
		Sig. (2-tailed)	.857	.886	.167	.	.000	.000
		N	46	46	46	46	46	46
Wessex Mobility score (QE+QF): min score is 2 and max score is 6		Correlation	.141	.029	-.047	.564**	1.000	.406**
		Coefficient						
		Sig. (2-tailed)	.351	.846	.755	.000	.	.005
		N	46	46	46	46	46	46
Wessex Literacy score (QM+QN+QO) Total score = 9.		Correlation	.211	-.107	.115	.568**	.406**	1.000
		Coefficient						
		Sig. (2-tailed)	.160	.481	.445	.000	.005	.
		N	46	46	46	46	46	46

\*\* . Correlation is significant at the 0.01 level (2-tailed).

## Appendix I

### *Bootstrapping analysis for self-injurious behaviour*

Run MATRIX procedure:

\*\*\*\*\*

Preacher and Hayes (2008) SPSS Macro for Multiple Mediation

Written by Andrew F. Hayes, The Ohio State University

<http://www.comm.ohio-state.edu/ahayes/>

For details, see Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, 40, 879-891.

\*\*\*\*\*

Dependent, Independent, and Proposed Mediator Variables:

DV = PSI\_Tota

IV = BPI\_SIBT

MEDS = CBPQ\_Con

CBPQ\_Tim

Sample size

46

IV to Mediators (a paths)

	Coeff	se	t	p
CBPQ_Con	.2380	.0771	3.0885	.0035
CBPQ_Tim	.0862	.0401	2.1496	.0371

Direct Effects of Mediators on DV (b paths)

	Coeff	se	t	p
CBPQ_Con	2.2461	.5308	4.2314	.0001
CBPQ_Tim	-.9968	1.0195	-.9777	.3338

Total Effect of IV on DV (c path)

	Coeff	se	t	p
BPI_SIBT	.7713	.2707	2.8489	.0066

Direct Effect of IV on DV (c' path)

	Coeff	se	t	p
BPI_SIBT	.3227	.2514	1.2835	.2064

Model Summary for DV Model

R-sq	Adj R-sq	F	df1	df2	p
.4321	.3916	10.6530	3.0000	42.0000	.0000

\*\*\*\*\*

BOOTSTRAP RESULTS FOR INDIRECT EFFECTS

Indirect Effects of IV on DV through Proposed Mediators (ab paths)				
	Data	Boot	Bias	SE
TOTAL	.4486	.4683	.0197	.2061
CBPQ_Con	.5346	.5631	.0285	.2363
CBPQ_Tim	-.0860	-.0948	-.0088	.1173

Bias Corrected Confidence Intervals		
	Lower	Upper
TOTAL	.1240	.9330
CBPQ_Con	.1897	1.1057
CBPQ_Tim	-.3693	.1023

\*\*\*\*\*

Level of Confidence for Confidence Intervals:  
95

Number of Bootstrap Resamples:  
10000

\*\*\*\*\* NOTES \*\*\*\*\*

----- END MATRIX -----

*Bootstrapping analysis for aggressive/destructive behaviour*

Run MATRIX procedure:

\*\*\*\*\*

Preacher and Hayes (2008) SPSS Macro for Multiple Mediation

Written by Andrew F. Hayes, The Ohio State University

<http://www.comm.ohio-state.edu/ahayes/>

For details, see Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, 40, 879-891.

\*\*\*\*\*

Dependent, Independent, and Proposed Mediator Variables:

DV = PSI\_Tota  
 IV = BPI\_AggT  
 MEDS = CBPQ\_Con  
           CBPQ\_C\_1  
           CBPQ\_Emo

Sample size  
46

IV to Mediators (a paths)				
	Coeff	se	t	p



CBPQ_Con	.1383	.0564	2.4524	.0182
CBPQ_C_1	.1119	.0450	2.4860	.0168
CBPQ_Emo	.1322	.0508	2.6033	.0125

Direct Effects of Mediators on DV (b paths)

	Coeff	se	t	p
CBPQ_Con	.9477	.5035	1.8823	.0669
CBPQ_C_1	.8627	.7861	1.0975	.2788
CBPQ_Emo	1.1850	.5674	2.0887	.0430

Total Effect of IV on DV (c path)

	Coeff	se	t	p
BPI_AggT	.6244	.1859	3.3581	.0016

Direct Effect of IV on DV (c' path)

	Coeff	se	t	p
BPI_AggT	.2401	.1516	1.5836	.1210

Model Summary for DV Model

R-sq	Adj R-sq	F	df1	df2	p
.5905	.5505	14.7780	4.0000	41.0000	.0000

\*\*\*\*\*

BOOTSTRAP RESULTS FOR INDIRECT EFFECTS

Indirect Effects of IV on DV through Proposed Mediators (ab paths)

	Data	Boot	Bias	SE
TOTAL	.3843	.3969	.0126	.1319
CBPQ_Con	.1311	.1299	-.0012	.0789
CBPQ_C_1	.0966	.1265	.0300	.1434
CBPQ_Emo	.1567	.1406	-.0161	.1172
C1	.0345	.0034	-.0312	.1708
C2	-.0256	-.0107	.0149	.1306
C3	-.0601	-.0141	.0461	.2407

Bias Corrected and Accelerated Confidence Intervals

	Lower	Upper
TOTAL	.1633	.6715
CBPQ_Con	.0179	.3401
CBPQ_C_1	-.1321	.3916
CBPQ_Emo	-.0015	.5252
C1	-.2450	.5077
C2	-.3557	.1890
C3	-.6127	.3560

Bias Corrected Confidence Intervals

	Lower	Upper
TOTAL	.1699	.6827
CBPQ_Con	.0218	.3503
CBPQ_C_1	-.0769	.4715
CBPQ_Emo	-.0167	.4773
C1	-.2975	.3874
C2	-.3142	.2114
C3	-.4911	.4471

Percentile Confidence Intervals

	Lower	Upper
TOTAL	.1711	.6845

CBPQ_Con	.0053	.3114
CBPQ_C_1	-.0759	.4754
CBPQ_Emo	-.0647	.4013
C1	-.3702	.3242
C2	-.2769	.2518
C3	-.4440	.5053

\*\*\*\*\*

Level of Confidence for Confidence Intervals:  
95

Number of Bootstrap Resamples:  
10000

----- END MATRIX -----