

**The Factors Predicting Stress, Anxiety and Depression in the Parents of
Children with Autism**

Nicholas Falk, BA (Hons), MA

Submitted in partial fulfilment of the requirements for the Degree of Doctor of
Psychology (Clinical)

University of Tasmania

November 2012

Declaration of Originality

I declare that this thesis is my own work and that, to the best of my knowledge and belief, it does not contain material from published sources without proper acknowledgement, nor does it contain material which has been accepted for the award of any other higher degree or graduate diploma at any university, nor does it contain any material that infringes copyright.

Date _____

Nick Falk

June, 2012

Statement of Authority of Access

This thesis may be made available for loan and limited copying in accordance with the *Copyright Act 1968*.

Date _____

Nick Falk

June, 2012

Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation and the guidelines by the Australian Government's Office of the National Health and Medical Research Council *National Statement on Ethical Conduct in Human Research (2007)*. Approval was granted by the Human Research Ethics Committee (Tasmania) Network.

Date _____

Nick Falk

June, 2012

Acknowledgements

With thanks to the ongoing support and patience of my supervisor, Dr. Kimberley Norris and to Prof. Rapson Gomez for his timely advice on Structural Equation Modelling. Thanks also to Dr. Raimondo Bruno of the University of Tasmania and Dr. Cheryl Dissayanake of the Olga Tennison Autism Research Centre at LaTrobe University.

This project could not have been completed without the invaluable support of the following organisations:

Autism Tasmania

Autism Victoria

The Olga Tennison Autism Research Centre

The National Autistic Society, UK

The National Autism Association, USA

The Autism File Magazine

Carers UK

Siblings Australia

Autisable.com

Parenting Autism.com

Positively Autism.com

Thanks also to the study participants, without whom this research could not have been undertaken.

Abstract

The parents of children with autism have been demonstrated to report significantly higher levels of stress, anxiety and depression than the parents of developmentally normal children. However, the factors predicting stress, anxiety and depression in this parental group remains poorly understood. The present study examined the variables predicting stress, anxiety and depression in the mothers and fathers of children with autism, and tested the validity of a path model describing the relationship between these variables. Three separate studies were carried out, the first focused on mothers of children with autism, the second focused on fathers of children with autism, and the third assessing model fit.

Mothers (N=250) and fathers (N=229) of children with autism aged 4 to 17 years 11 months completed an on-line questionnaire measuring social and economic support, psychological distress, perceived parent-child attachment, parental locus of control, autism symptom severity and child externalizing behaviours. Stepwise regression analysis was used to examine the relationship between independent and dependent variables. The results of Study one, which focused on the mothers of children with autism, suggested a different pattern of predictive variables for stress, anxiety and depression in this maternal group. Aggressive Behaviour, Social Support and Parental Locus of Control significantly predicted maternal depression; whereas Mother's Age, Autism Symptom Severity and Perceived Limit Setting Ability significantly predicted maternal anxiety. The predictive model for maternal stress was a combination of the predictive models for maternal anxiety and depression. In contrast, the predictive model for fathers of children with autism, as investigated in Study two, was consistent across dependent variables. Social Support and Perceived Limit Setting Ability were the primary predictors for paternal stress, anxiety and

depression. Conduct Problems, a variable identified in the existing literature as predictive of stress, anxiety and depression in the parents of children with autism, was not a significant predictor in any of the six stepwise regression models. The results indicated that the relationship between ‘child-centric variables’ (i.e. externalizing behaviours and autism symptom severity) and parental mental health problems may be mediated by other variables.

The results of the stepwise regression analyses formed the rationale for a pathway model describing the relationship between the variables, which was assessed for statistical fit with the observed data in Study three. The model positioned parental cognitions and socio-economic support as a mediator of the relationship between ‘child-centric variables’ and parental distress. Confirmatory Factor Analysis was used to assess the fit of the model with the observed data. The model was shown to be a good fit with the data for both mothers and fathers. Invariance testing, using the Satorra-Bentler chi-square difference test, demonstrated support for metric invariance for the model across gender.

The results of the study were used to propose changes to the existing support services offered to parents of children with autism, and the consideration of a more holistic approach, combining psychotherapeutic support for the parent with behavioural management programs related to the child.

Table of Contents

| | |
|--|----|
| Declaration of Originality..... | 2 |
| Statement of Ethical Conduct..... | 4 |
| Acknowledgements | 5 |
| Abstract..... | 6 |
| Table of Contents..... | 8 |
| List of Tables..... | 11 |
| List of Figures..... | 13 |
| Study Overview | 14 |
| Chapter 1 – Defining the Problem..... | 16 |
| Chapter 2 - Genetic and Environmental Factors Predicting Mental Health Problems in the Parents of Children with Autism | 22 |
| Chapter 3 - Guiding Clinical Interventions | 30 |
| The Different Experience of Mothers and Fathers | 31 |
| Chapter 4 – Aims and Rationale for the Current Study..... | 35 |
| Chapter 5 - Study One – The Factors Predicting Stress, Anxiety and Depression in the Mothers of Children with Autism..... | 38 |
| Section 5.1 – Study One – Method..... | 41 |
| Participants | 41 |
| Materials | 42 |
| Procedure..... | 52 |
| Section 5.2 – Study One – Results | 53 |
| Analysis..... | 54 |
| Correlations..... | 56 |
| Initial Models for Depression | 57 |
| Initial Models for Anxiety..... | 58 |
| Initial Models for Stress | 60 |
| Stepwise Models for Depression..... | 61 |

| | |
|---|-----|
| Stepwise Models for Anxiety | 63 |
| Stepwise Models for Stress..... | 64 |
| Section 5.3 – Study One – Discussion..... | 66 |
| Chapter 6 - Study Two – The Factors Predicting Stress, Anxiety and Depression in the Fathers of Children with Autism | 73 |
| Section 6.1 – Study Two – Method | 76 |
| Participants | 76 |
| Materials..... | 77 |
| Procedure..... | 79 |
| Section 6.2 – Study Two – Results..... | 80 |
| Analysis | 81 |
| Correlations..... | 83 |
| Initial Models for Depression | 84 |
| Initial Models for Anxiety..... | 86 |
| Initial Models for Stress | 88 |
| Stepwise Models for Depression..... | 89 |
| Stepwise Models for Anxiety | 91 |
| Stepwise Models for Stress..... | 92 |
| Section 6.3 – Study Two - Discussion..... | 94 |
| Chapter 7 - Study Three – Towards A Predictive Model of Psychological Distress in the Parents of Children of Autism | 99 |
| Section 7.1 – Study Three – Method | 106 |
| Section 7.2 – Study Three – Results..... | 107 |
| Model Fit Indices..... | 107 |
| Factor Loadings | 109 |
| Measurement and Structural Invariance Across Gender | 112 |
| Section 7.3 – Study Three – Discussion | 113 |
| Chapter 8 - Thesis Conclusions - Defining the Problem..... | 116 |
| Section 8.1 – Thesis Conclusions - The Study Population..... | 118 |
| Section 8.2 – Thesis Conclusions - Study One Results..... | 121 |

| | |
|--|-----|
| Section 8.3 – Thesis Conclusions - Study Two Results | 124 |
| Section 8.4 – Thesis Conclusions - Study Three Results | 129 |
| Section 8.5 - Final Conclusions | 132 |
| References | 134 |
| Appendix A – Study One Questionnaire | 146 |
| Appendix B – Study Two Questionnaire..... | 162 |
| Appendix C..... | 178 |
| Correlation Statistics..... | 178 |

List of Tables

Table 1. *Descriptive statistics for Excluded Variables (Mothers)*

Table 2. *Descriptive Statistics for Variables Included in Regression Analyses (Mothers)*

Table 3. *Pearson Correlation Coefficients for Variables Included in Regression Analyses (Mothers)*

Table 4. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Depression.*

Table 5. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Anxiety.*

Table 6. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Stress.*

Table 7. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Maternal Depression.*

Table 8. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Maternal Anxiety.*

Table 9. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Stress.*

Table 10. *Descriptive Statistics for Excluded Variables (Fathers).*

Table 11. *Descriptive Statistics for Variables Included in Regression Analyses (Fathers).*

Table 12. *Pearson Correlation Statistics For Variables Included in Regression Analyses (Fathers).*

Table 13. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Depression.*

Table 14. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Anxiety.*

Table 15. *Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Stress.*

Table 16. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Depression.*

Table 17. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Anxiety.*

Table 18. *Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Stress.*

Table 19. *Factor Statistics by Gender for the Social and Communication Questionnaire (SCQ).*

Table 20. *Model Fit Indices for Model A for Mothers and Fathers of Children with Autism.*

Table 21. *Factor Loading and Factor Prediction Estimates for Model A for Mothers of Children with Autism.*

Table 22. *Factor Loading and Factor Prediction Estimates for Model A for Fathers of Children with Autism.*

Table 23. *Measurement and Structural Invariance Tests for Model A across Gender (Mothers and Fathers)*

List of Figures

Figure 1. Proposed Path Diagram Representing the Variables Significantly Predicting Stress, Anxiety and Depression in the Mothers of Children with Autism.

Figure 2. Proposed Path Diagram Representing the Variables Significantly Predicting Stress, Anxiety and Depression in the Fathers of Children with Autism.

Figure 3. Model ('Model A') Describing the Relationship Between Parental Distress and Predictive Variables in the Parents of Children with Autism.

Study Overview

In 2008 Woodgate, Ateah and Secco published a qualitative study describing the personal experiences of parents with a child with autism. 'Living in a world of our own,' was a primary theme expressed by the 16 Canadian families participating in the study. The study concluded, based on the interviews conducted, that although much is known about the fundamental importance of providing structured support to parents of children with autism, there is minimal knowledge reported in the literature about the actual experience of parenting a child with autism. If effective supportive interventions are to be developed for this parental group, a clearer understanding of the experience of parenting a child or children with autism is required.

The existing literature demonstrates that the parents of children with autism experience more mental health problems - primarily stress, anxiety and depression - than the parents of both developmentally normal children and the parents of children with intellectual disability, Down Syndrome and severe physical health problems (Benjak, 2009; Fiske, 2009; Lee, 2009; Sanders & Morgan, 1997; Weiss, 2002). However, what are not clearly understood are the predictive factors associated with mental health problems such as stress, anxiety and depression, and the degree to which the predictive model for each of these variables differs from parents of developmentally normal children. The aim of this study is to investigate the factors that correlate with stress, anxiety and depression in the parents of children with autism, generate a clearer understanding of what factors may be predictive of each of these three variables, and suggest how this information can be used to structure effective support programs for this parental group. Three separate studies were undertaken in the pursuit of this aim. The first study focused on mothers of children

with autism, and assessed the factors predictive of stress, anxiety and depression within this parental group. The second study focused on the factors predicting stress, anxiety and depression in the fathers of children with autism. It used the same structure as Study One and the same set of variables. The final study used the data collected in studies one and two to propose and then test a model describing the relationship between the variables identified as significant predictors in each parental group. It also explored the statistical similarity between the predictive models for mothers and fathers.

The introductory chapters to this study can be summarised as follows: Chapter 1 assesses the prevalence of mental health problems in the parents of children with autism, and the comparative disparity, in terms of mental health problems, between the parents of children with autism and the parents of developmentally normal children. Chapter 2 discusses the genetic and environmental factors that have been shown to be predictive of this disparity, and the limitations in the current literature exploring these predictive factors. Chapter 3 focuses on the clinical interventions used with parents of children with autism experiencing mental health problems, and highlights the need for a more rigorous understanding of the presenting problems. Chapter 4, taking all this information into account, then provides a summary of the aims and rationale for the current study.

Chapter 1 – Defining the Problem

Autism Disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revision (DSM-IV-TR, American Psychiatric Association, 2000), is a pervasive developmental disability characterised by impairments in communication, impairments in social interaction and repetitive or restricted behaviours (the ‘triad of symptoms’). Symptoms of the disorder are usually observed by parents before the child is two years old. The emergence of symptoms is usually gradual, although some children with autism exhibit normal development for their first few years and then appear to regress (Stefanatos, 2008). Most commonly this regression occurs at age two or three (Tuchman & Rapin, 1997.) There is no known cure for autism, although early behavioural or cognitive interventions can help children develop self-care, social and communication skills (Myers & Johnson, 2007). However, regardless of intervention, only a small proportion of children with autism live independently after reaching adulthood (Howlin et al., 2004). Twin studies in autism have demonstrated that the disorder has a strong genetic basis, and it has been historically theorised that there may be a common genetic basis for autism’s characteristic triad of symptoms (Happé, 2008). However, current research indicates that autism is a complex disorder, the core aspects of which may be associated with a range of independent genetic loci that often co-occur (Happé, 2006).

Parents of children with autism face unique challenges not faced by other parental groups. Children with autism can be difficult to understand, due to their atypical interpersonal responsiveness (e.g. reluctance to engage, verbally or physically, with caregivers) and patterns of communication (e.g. repetitive or illogical phrasing) (Busch, 2009). Children with autism can also seem ‘impossible to reach’, a

term used by Busch (2009) to describe the perception parents express of being unable to form a productive two-way relationship with their child(ren) with autism. Post-diagnosis, parents express feeling unsupported and stigmatized by both medical professionals and members of the community (Lamminen, 2008; Wright & Williams, 2007), and report being uncertain about the future impact of the diagnosis upon both themselves and the functioning of their family unit (Woodgate et al., 2008). Parents can also report deterioration in marital satisfaction (Rogers, 2008) and a feeling of loss regarding the impact the diagnosis will have on their personal future life opportunities (Myers, 2009).

Parents of children with autism also report difficulties adhering to behavioural treatment recommendations for their child (Moore, 2009). Moore (2009) undertook a survey of the parents of 220 children with autism spectrum disorders, assessing the implementation of both medical and behavioural treatment recommendations focused on managing the problem behaviour of children living at home. Moore found that adherence to medical treatment recommendations was significantly greater than adherence to behavioural treatment recommendations, due in part to the practical difficulty and emotional challenge inherent in adhering to the latter. It was observed that this disparity was significantly associated with marital status (adherence was significantly higher in married individuals), and the support the parent receives from a partner in implementing behavioural treatment recommendations. Support from a partner constitutes an important resource, both emotionally and practically, in implementing and maintaining a behavioural treatment plan.

A number of authors have postulated that lack of adherence to behavioural treatment programs may be due to a higher prevalence of mental health problems in the parents of children with autism, as compared to the parents of developmentally

normal children (Schieve et al., 2007; Fiske, 2009). While the evidence to support this theory is inconclusive (there are no studies showing a statistically significant correlation between parental mental health problems and adherence to behavioural treatment programs), it has been demonstrated in a number of studies that the parents of children with autism do report more mental health problems than the parents of children in other clinical and/or non-clinical groups (Benjak, 2009; Bitsika & Sharpley, 2004; Singer, 2006).

Benjak (2009) conducted a study comparing 178 parents of children with autism spectrum disorders (ASD) and 172 parents of developmentally normal children matched by age, education and place of living. The study found that parents of children with ASD reported significantly more self-perceived health problems than the control parents, as assessed by the Health Status Questionnaire (SF-36). However, the largest disparity was in reported psychological disorders. Eleven percent of parents in the ASD group reported psychological disorders, compared to 4.3% of parents in the control group. Stress, anxiety and depression were the primary psychological disorders reported in both groups (accounting for over 80% of reported psychological disorders).

A number of studies have focused more specifically on depression and anxiety in parents of children with autism. Lee (2009) found that the parents of children with high functioning ASD demonstrated significantly more depression and anxiety than the parents of children without disabilities. However, the sample size was relatively small (48 parents in the ASD group and 26 in the control group), and the focus on high functioning ASD highly specific. The results of this study, therefore, are not necessarily reflective of parents of low or average functioning ASD children, who may present significantly different parenting challenges.

Bitsika and Sharpley (2004) conducted a study of the parents of 107 children with autism in Australia, and found that approximately 50% of participants were severely anxious and nearly two thirds clinically depressed. These figures are above prevalence figures in the standard Australian population (14.4% for anxiety disorders, and 5-6% for mood disorders, based on data from the Australian National Survey on Mental Health and Wellbeing, 2007), but the lack of a control group makes it difficult to draw a clear conclusion from the study regarding the difference in reported mental health problems between the parents of children with autism and the parents of developmentally normal children. Micali, Chakrabarti and Fombonne (2004), undertook a more comprehensive control-comparison study, showing both depression and anxiety were significantly more prevalent in 79 mothers of children with Pervasive Developmental Disorders (of which autism was the dominant diagnostic group) compared to 61 mothers of normally developing children. A meta-analysis of 18 studies looking at depression in mothers of children with or without pervasive developmental disorders reached a similar conclusion, with mothers in the former group shown to be at significantly elevated risk for depression (Singer, 2006).

Other studies have focused specifically on stress in this parental group. Davis and Carter (2008) conducted a study with mothers and fathers of 54 toddlers with ASD (mean age 26.9 months), and found that these parents, on average, displayed elevated levels of stress compared to population norms. However, the study did not include a control group, limiting the validity of the results. Schieve et al. (2007) undertook a more definitive study, using data from the US 2003 National Survey of Children's Health, which included 459 parents of children reported to have autism. Using a rating scale of stress based on aggravation, parents of children with autism were significantly more likely to score in the high aggravation range (55% of parents)

than parents with children with developmental problems other than autism (44% of parents) and parents with children without special health care needs (11% of parents). However, it was also found that high aggravation correlated with recent requirements for special services support (in relation to child behaviour management). Stress levels in parents with children with autism who had not recently requested special services support were not as significantly elevated, potentially indicating a link between stress and perceived parenting problems, as opposed to elevated levels of stress associated with parenting a child reported to have autism.

Two further studies on stress in the parents of children with autism compared this parental group against two other comparison groups. The first study, conducted by Sanders and Morgan (1997), compared parents of children with autism with parents of both developmentally normal children and children with Down Syndrome. The study found that parents of children with autism reported significantly more stress than the parents of children with Down Syndrome, who in turn reported significantly more stress than the parents of developmentally normal children (Sanders & Morgan, 1997). A similar study conducted by Weiss (2002) compared 40 mothers with children with autism against 40 mothers of children with mental retardation and 40 mothers of typically developing children. The study focused on depression, anxiety and somatic complaints. Parents of children with autism reported significantly higher levels of all three measures than parents in both the other groups.

Although the studies above indicate that parents of children with autism report more stress than parents of children without autism, it is possible that this difference is longitudinally inconsistent. One possibility is that elevated stress levels in parents of children with autism may only occur at periods of developmental transition, such as from pre-school to school-age, child to adolescent and adolescent to adult. It is

particularly at these transitional stages that children with autism demonstrate behavioural changes (such as limited acquisition of group socialization skills) that differ from their typically developing peers (Lounds et al., 2007). However, Fiske (2009) found that parenting stress in mothers of children with autism was independent of transitioning phases, and relatively consistent across child age.

One issue in comparing data between the studies described above is the inconsistent definitions of depression, anxiety and stress used across studies. For depression and anxiety, some studies have required a diagnosis of the disorder from a registered clinician, some have used standardised measures of depression and anxiety, like the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and some have used self-report measures in other more general health questionnaires. In assessing stress, studies are equally differentiated, with some assessing parenting stress, others daily stress and others levels of aggravation. With this in mind, the current study uses the same measure, the short-form Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995), to assess all three mental health variables.

The problem this study hopes to address is therefore as follows – parents of children with autism face unique challenges not faced by other parental groups, and experience higher rates of mental health problems, such as stress, anxiety and depression, than parents of developmentally normal children. However, without a clear understanding of the factors predicting these elevated mental health problems, the support offered to this parental group may prove ineffective. The present study therefore aims to provide a clearer understanding of the factors predicting stress, anxiety and depression in the mothers and fathers of children with autism.

Chapter 2 - Genetic and Environmental Factors Predicting Mental Health

Problems in the Parents of Children with Autism

As described in the previous chapter, it has been repeatedly demonstrated, across multiple independent studies, that the parents of children with autism report higher levels of stress, anxiety and depression than the parents of developmentally normal children. The current study, therefore, does not set out to replicate this finding.

However, what is not clearly understood is why this is the case. Some research has focused on the heritability of autism, and that mental health conditions in parents may be independent of, rather than resultant from, having a child with autism.

Yirmiya and Shaked (2005) found that parents of children with autism demonstrated more psychiatric difficulties than a heterogeneous control group (consisting of parents of typically developing children and parents of children with diagnoses other than autism). The study identified a particularly clear difference between parents of children with autism and parents of children with disorders not genetically associated with the parent (such as Down Syndrome). The study postulated this was due to genetic rather than environmental factors. However, making interpretations based on the results of this study is complicated by an inconsistency in the measures used to assess psychiatric difficulties across category and across parental group. Some conditions were scored based on self-report measures and some on clinical measures or prior diagnosis, clouding the ability of the researchers to draw conclusions from the data, and highlighting the requirement for a consistent measure of mental health variables, as used in the current study.

Micali, Chakrabarti and Fombonne (2004) found arguably more reliable evidence of a genetic association between autism and parental mental health problems, finding a correlation between autism in the child and anxiety, depression and obsessive-compulsive disorder not only in parents but also in non-caregiver relatives. Ingersoll and Hambrick (2011) found a correlation between autism symptom severity in the child and both anxiety and depression and Broad Autism Phenotype in the parent, also concluding that parental anxiety and depression were associated primarily with genetic rather than environmental factors.

However, other studies have postulated that environmental causes contribute equally towards elevated levels of mental health problems in the parents of children with autism, as compared to parents of developmentally normal children. Sawyer et al. (2009), in a study of 216 mothers of children with autism, found that maternal mental health problems were significantly associated with the time pressures of caring for a child with autism (once the data was adjusted for child age, social support and child maladaptive behaviour), and argued that environmental factors, such as the additional support required by a child with autism, compared to developmentally normal children, played as significant a contributory role as genetic predisposition in predicting mental health problems in the parents.

There is, however, only a small body of research focused on whether the elevated levels of mental health problems reported by parents of children with autism are genetic or environmental in basis. The issue remains unresolved. The current study is focused primarily on the environmental factors that are predictive of mental health problems in this parental group, as it is an understanding of environmental rather than genetic factors that can best be used to develop parental support services

(as environmental factors, unlike genetic factors, are potentially malleable). In this area a considerable body of research does already exist.

A number of researchers, in trying to identify why parents of children with autism demonstrate higher levels of mental health problems than parents of developmentally normal children, have argued that autism symptom severity in the child is the primary predictor of these mental health problems.

Duarte et al. (2005) compared the mothers of 31 children with autism recruited from mental health clinics with the mothers of 31 children without mental health problems, recruited either from primary schools or a primary care unit. The study results showed that, although a younger child age and older maternal age were contributory factors, the primary variable correlating with higher levels of stress was autism symptom severity. In a study of 141 parents conducting home-based behavioural interventions, Hastings and Johnson (2001) also found a significant correlation between autism symptom severity and parental stress. However in both these studies the researchers recruited parents requesting specialized support services for their child with autism. The sample groups in these studies are thus not necessarily reflective of the general population of parents with children with autism, many of whom may not present to mental health services and request assistance. Studies recruiting directly from the community (and thus including parents who have requested additional support from mental health services and those who have not) have found that autism symptom severity is not as predictive of maternal stress as factors such as child behaviour problems (Hastings et al., 2005). Davis and Carter (2008) found that although delays in social relatedness (one of the three core areas of autism symptoms) were associated with parental stress, communication deficits and repetitive or restricted behaviours (the two other core symptom sets) were not,

indicating that autism symptoms may not be the primary predictors of stress in this parental group.

Aside from autism symptoms, a number of other factors have been shown to correlate with parental mental health problems. Farrugia (2009) found a correlation between perceived and actual stigmatization and parental stress and anxiety. The study identified that receiving an actual diagnosis of ASD was critical for parents to reduce levels of perceived stigmatization. However, the study did not evaluate whether post confirmation of a diagnosis parents showed a corresponding drop in stress and anxiety. Bitsika and Sharpley (2004) identified that perceived physical wellbeing, among parents of children with autism reporting some symptoms of anxiety and/or depression, was significantly associated with higher reported levels of both mental health variables. However, individual studies such as these aside, the majority of authors in this area identify two main factors as being predictive of parental mental health problems - child behaviour problems and social and economic support.

Child Behaviour Problems - A study conducted by Gray (2003)

demonstrated that parents of children with autism displaying aggressive behaviour were more likely to experience parental stress than parents of children with autism who did not display aggressive behaviour. Gray theorized that the relationship between aggressive behaviour in the child and parental stress was mediated by the higher level of real (as opposed to perceived) stigmatization experienced by parents of children displaying aggressive behavior. Although the role of stigma as a mediator has not been demonstrated in other studies, a number of subsequent studies have replicated the correlation between child maladaptive behaviour and parental stress. A study conducted by Lecavalier, Leone and Wiltz (2005) of the parents of 293 children

with ASD found a strong positive correlation between child behaviour problems and stress, although there was little agreement among participants on the definition or extent of behaviour problems exhibited by this group of children, making it difficult to generalize from the results. Civick (2008) asked parents to provide a rating of their child's externalizing behaviours (using a standardized scale), and concluded that externalizing behaviours positively predicted parental stress ratings for both mothers and fathers of children with autism. A further study, conducted by Fiske (2009), produced a similar result in a study of 67 mothers and 39 fathers of children with autism. Although focused on mothers with children diagnosed by an independent practitioner with a pervasive developmental disorder (as opposed to solely autism), Tomanik, Harris and Hawkins' 2004 study of 60 mothers also found that child maladaptive behaviour accounted for a significant proportion of the variance in maternal stress.

Social and Economic Support - In a study of 172 parents of children with autism, Gray and Holden (1992) found that both fathers and mothers who received more social support (in terms of availability of social support, as opposed to satisfaction with social support) had lower scores of depression, anxiety and anger. Lamminen (2008) also reported that social support has a significant negative relationship with perceived parental stress in the parents of children with autism. In a mail survey study of 219 Australian parents with children with autism, Sharpley, Bitsika and Efremidis (1997) concluded that, although social support was associated with lower levels of parenting stress, it was mediated by the perceived expertise of the family member or friend providing respite care for the parents. Two other international studies concluded that lower family income and less access to financial

support were predictive of lower mental-health related quality of life measures in parents of children with autism (Hu, 2009; Lee, 2009).

Although these papers indicate that child behaviour problems and social and economic support play an important role in predicting parental mental health problems, there is a lack of conformity in the definition and choice of variables across studies. While most studies focus on stress, there is little data assessing the predictive role of these factors in parental anxiety and depression. Stress is also defined differently across the different studies, with some papers (Fiske, 2009; Lamminen, 2008; Sharpley et al., 1997) focusing on stress directly related to parenting, whereas others use a more global definition of stress (Lecavalier et al., 2005), similar to the approach being taken by this study. Using a global definition of stress allows an assessment of stress-related factors affecting the parent's functioning as a whole, and not just the parent's functioning in relation to their child with autism. In guiding the development of support services for parents presenting with mental health problems, this ensures the results are applicable to all parents presenting with stress, and not just those presenting with parenting stress.

There are also other potentially predictive factors that have not been included in studies investigating mental health problems in the parents of children with autism. A study undertaken in the parents of children with an intellectual disability found that, in combination with child behaviour problems, parental cognitions, primarily satisfaction with parenting and parental locus of control, accounted for most of the variance in parenting stress (Hassall, Rose, & McDonald, 2005). The study found that parental locus of control mediated the relationship between social (family) support and parenting stress, and concluded that this had implications (in terms of a focus on cognitive therapy) for clinical interventions for parents with intellectually disabled

children. Parental locus of control and parenting satisfaction have, as far as the researcher of this study is aware, not been properly assessed in terms of their role in predicting stress (or anxiety and depression) in the parents of children with autism. However, if these factors have a similarly significant role, it would also have implications for interventions targeting this group of parents.

Another related factor that is yet to be properly assessed in this context is perceived parent-child attachment. A meta-analysis of 16 studies on attachment in children with autism and 10 studies on observed attachment security found that, despite the impairments in social interaction characteristic of autism, a majority of studies showed evidence of attachment behaviours in autistic children (Rutgers et al., 2004). However, despite the presence of attachment behaviours, the meta-analysis found that children with autism were significantly less securely attached to their parents than developmentally normal children (or children in other clinical groups), and that the attachment behaviours displayed by these children were less likely to be recognized by the parent. Hoppes and Harris (1990) found that a lack of interpersonal responsiveness on the part of the child was associated with significantly higher levels of parental stress in 17 mothers of children with autism compared to 21 mothers of children with Down Syndrome. However, this study used parent report as a source of data, and lack of interpersonal responsiveness on the part of the child, as defined by the study, may result from the parent misreading or misunderstanding idiosyncratic or unusual attachment behaviours displayed by the child. If this is the case, then it would suggest a place for attachment behaviour specific psychoeducation in intervention programs structured to support these parents. In assessing parental cognitions relating to parenthood, the current study includes a measure of the perceived parent-child relationship (rather than parental perception of child attachment behaviours), which

may play a significant role in predicting stress, anxiety and/or depression in the parent.

Chapter 3 - Guiding Clinical Interventions

As discussed, there is clear evidence in the literature that the parents of children with autism experience higher levels of stress, anxiety and depression than the parents of developmentally normal children. There is also evidence that parents in this group report more mental health problems than the parents of children with other developmental problems, such as intellectual disability and Down Syndrome. It has also been theorized that parental mental health problems negatively affect adherence to behavioural treatment recommendations for the child with autism (Schieve et al., 2007; Fiske, 2009).

A number of studies have proposed interventions that focus specifically on treating mental health problems in this parental group in order to improve parental functioning and quality of life. Keen (2010) compared parents assigned to a self-directed video based intervention and parents provided a workshop based parent-support intervention post-diagnosis. The workshop focused on educating the parent on the symptoms of autism, and helping the parent implement behavioural management programs for the child. The study concluded that the workshop-based approach was more effective in reducing parenting stress and increased parenting self-efficacy. However, scoring of parental stress occurred directly pre and post intervention, and assumed stress was directly related to the child's diagnosis of autism. It did not take into account other factors, such as social support or parental locus of control that, in the longer term, may also be causal or predictive of stress. Without a measure of longer term parental mental health outcomes, it cannot be assumed that stress levels remained comparatively lower. Also the intervention proposed (a group workshop and ten follow-up home visits) may not be feasible in all cases, especially where home-

based intervention resources are limited. Tonge et al. (2006) used a 20 week parent education and skills training program at the point of child diagnosis, and similarly found that the program provided significant improvements in parent mental health and adjustment, especially for parents with pre-existing mental health problems. Again, there is no longer-term measure of parental mental health, and the intervention itself is labour and cost-intensive, and would arguably be impractical as a suggestion for all parents with children with autism. What is needed is a longer-term supportive approach directed specifically at the issues faced by parents, which may or may not require an autism-centric focus. In order to structure such a program, a clear understanding is needed not only of the extent of mental health problems in this parental group, but the factors that predict these mental health problems. As Busch noted in a 2009 study investigating the efficacy of Acceptance and Commitment Therapy for parents of children with autism, there is little structured support offered to this group of parents, and those programs that do exist focus first and foremost on treating the child.

The Different Experience of Mothers and Fathers

Another core factor that requires consideration, especially with a view to developing effective support programs, is gender difference. In general, research has shown that stressful life events cause more psychological distress in women than they do in men, especially when these events affect family and friends (Aneshensel, 1992; Thoits, 1995). In situations where a child is affected by illness or a disability, mothers are also more likely to blame themselves for their child's problems and feel that their identities are threatened by their child's illness and disability (Anderson & Elfert, 1989). In understanding the experience of parenting a child with autism, and in particular the factors that predict stress, anxiety and depression in this parental group,

it is thus important to consider the difference in experience between fathers and mothers.

Existing research indicates that mothers of children with autism experience higher levels of stress, anxiety and depression than fathers of children with autism. In a study of 172 parents of children with autism, Gray and Holden (1992) demonstrated that fathers of children with autism reported significantly less anxiety and depression than mothers. Hastings et al. (2005), in a study of 41 mother-father pairs, replicated this difference in reported depression. A study conducted by Sharpley et al. (1997) demonstrated that mothers were more depressed and anxious than fathers, and also reported a nonsignificantly higher daily level of parenting stress in mothers.

What factors, however, underlie this difference between the mothers and fathers of children with autism? Are stress, anxiety and depression predicted by similar factors in both (but just to a lesser degree in males) or are the factors predictive of mental health problems different across gender?

Current research indicates that there is a difference in the parental experience between the mothers and fathers of children with autism. In a qualitative study of 32 mothers and 21 fathers of children with autism, fathers, although noting the severe difficulties that their child's autism presented for their families, claimed that their child's condition did not have a significant effect on them personally. Mothers, in contrast to fathers, reported an impact on both personal and family factors (Gray, 2003). The study also noted that having a child with autism tends to reduce families to traditional gender roles, with the mothers taking on a significantly greater proportion of the burden of care. Johnson, Frenn, Feetham and Simpson (2011) corroborated this finding, and concluded, using measures taken from the Feetham Family Functioning

Survey (Roberts & Feetham, 1982), that mothers' family functioning discrepancy scores between 'what is' and 'should be' family functioning were significantly wider than fathers. Milshtein (2010) also reported that parenting a child with autism had a greater emotional impact on the mother than the father, finding that resolution with the child's diagnosis with autism was associated with a perceived negative impact on family life in mothers, but not in fathers.

Rogers (2008) summarized the different experience of mothers and fathers with a child (or children) with autism by concluding that fathers tend to be comparatively unaffected by their child's symptoms and behaviours and affected primarily by their spouse's disposition and level of stress. Davis and Carter (2008), however, contradicted this finding, reporting that paternal stress was significantly affected by their child with autism (specifically by externalizing behaviours exhibited by that child), whereas maternal stress was associated with practical and time management problems. Fiske (2009) again reported a different finding, concluding that child externalizing behaviours equally affected the perceived stress of both mothers and fathers, but that reminders of their child's long term diagnosis increased general and parenting stress for fathers, but not for mothers. Other studies have found that fathers of children with autism perceive there to be less support from family and friends than their partners (Altieri & von Kluge, 2009) and demonstrate fewer adaptive coping skills than mothers (Lee, 2009).

The existing research therefore does not provide a consistent picture as to the different experience of mothers and fathers with a child with autism. However, the existing studies do indicate that such a difference does exist. Fiske (2009) concluded that, whilst mothers and fathers are differentially affected by their experiences with their child with autism, and whilst parent support services may be more effective if

tailored to the specific stressors experienced by each gender, further research is needed to support the development of such tailored interventions. As marital satisfaction is significantly lower in parents of children with autism than parents of both Down Syndrome children and developmentally normal children (Sanders & Morgan, 1997), and as divorce rates are significantly higher in parents of children with autism compared to parents of developmentally normal children (Hartley et al., 2010), supporting the development of such tailored interventions would have clear practical benefit.

Chapter 4 – Aims and Rationale for the Current Study

As stated by Keen (2010), preserving parents' good health and well-being is a precondition for the optimal care of children with autism. However, if supportive interventions are to be effective, it is essential that the factors predicting stress, anxiety and depression, the three major mental health problems identified as elevated in this parental group, are clearly understood. Existing research identifies that social and economic support, child maladaptive behaviour and autism symptom severity correlate with mental health problems in this parental group. However, no existing study has included all of these factors together and assessed the comparative contribution of each. The current literature has also not investigated the role played by perceived parent-child attachment, a factor, based on the existing research into attachment behaviours in autistic children, which may also play a role in predicting parental mental health problems. Additionally, parental locus of control and parenting satisfaction, variables shown to be highly predictive of stress in the parents of children with intellectual disability, have not been included in similar studies in autism. The present study includes all these variables, allowing an assessment of the comparative contribution of each in predicting parental mental health problems. Furthermore, although stress, anxiety and depression have all been demonstrated to be elevated in this parental group compared to controls (either parents of developmentally normal children or parents of children with other developmental disorders), there is a lack of clarity as to the comparative contribution of variables across these three mental health problems. It may be that the factors predicting each will be similar. However if not this too has implications for the structure of

interventions, which may be more effective if differentiated dependent on the specific mental health problems identified in the presenting parent.

Finally, for any interventions targeted at parents with mental health problems to be effective, an understanding of the different pattern of predictive factors across gender is needed. Although existing research has indicated there is a difference between the experience of mothering and fathering a child with autism, no existing studies have looked in detail at the different factors predicting mental health problems across the maternal and paternal groups.

The primary aims of this study are thus twofold – firstly to evaluate the factors predictive of anxiety, stress and depression in separate samples of mothers and fathers with one or more children with a diagnosis of autism or ASD, and secondly to use this information to propose and analyse a model describing the relationship between these predictive factors. It is not an aim of this study to confirm that parents of children with autism experience more stress, anxiety and depression than the parents of developmentally normal children. The existing literature has already demonstrated this to be the case. The purpose of this study is to try and understand what predicts these three mental health problems in this parental group, so as to provide a basis of information to develop targeted, effective support programs. The study includes parents of children with autism aged 4 years 0 months -17 years 11 months. The selected age range parallels that used across the range of other studies described in this introduction, but omits children in the pre-kindergarten category, because of the different factors inherent in parenting school/pre-school age and pre-kindergarten age children. Parents of children with autism under the age of four are more likely to receive minimal support, in terms of both home-based support and childcare relief, from schools, daycare services or professional services (Davis & Carter, 2008), and

within this group the factors predicting mental health problems may be different to that for parents with autistic children within the school or pre-school system. To ensure data clarity, this study thus only includes parents with autistic children of school or pre-school age (4 years and above).

Chapter 5 - Study One – The Factors Predicting Stress, Anxiety and Depression in the Mothers of Children with Autism

The current study aims to investigate the factors predicting stress, anxiety and depression in the mothers of children with autism. The existing literature clearly demonstrates that mothers of children with autism experience higher levels of stress, anxiety and depression than mothers of developmentally normal children. Micali et al. (2004) demonstrated that both depression and anxiety were significantly more prevalent in mothers of children with Pervasive Developmental Disorders (including ASD), compared to mothers of developmentally normal children. A meta-analysis conducted by Singer (2006), assessing 18 studies looking at depression in the parents of children with or without developmental disorders, also indicated mothers in the former group to be at significantly elevated risk. Stress has also been found to be elevated in this parental group. Sanders and Morgan (1997), in a study comparing parents of children with autism with parents of children with Down Syndrome and parents of developmentally normal children, found significantly higher levels of stress in the autism group compared to both of the other groups. Studies focused solely on anxiety have indicated a similar difference. A study conducted by Weiss (2002), comparing levels of anxiety in parents of children with autism, mental retardation, and normal development, found that maternal anxiety levels were significantly higher in the autism group.

A number of factors have been implicated as possibly predictive of this difference in measures of stress, anxiety and depression. Duarte et al. (2005) and Hastings and Johnson (2001), in studies recruiting parents involved in parent support and intervention programs, found that autism symptom severity was the primary

predictor of parental stress. However, both of these studies recruited from specific clinical populations, and thus the results may not be reflective of the general population. A more recent study by Davis and Carter (2008) appeared to contradict these results, finding that communication deficits and repetitive or restricted behaviours in the child with autism (two of the three core symptom sets of autism) were not predictive of parental stress.

Conduct Problems in the child with autism has also been implicated as predictive of parental mental health problems. Fiske (2009) found that higher parental ratings of child externalizing behaviours were a significant contributor to stress in mothers and fathers of children with autism. Lecavalier et al. (2005) also found a significant correlation between child behaviour problems and parental stress, and Tomanik et al. (2004) found that child maladaptive behaviour accounted for a significant proportion of the variance in a measure of maternal stress.

Another factor implicated as predictive of stress, anxiety and depression in this parental group is social support. Gray and Holden (1992) found that both mothers and fathers of children with autism who received more social support had lower scores of both anxiety and depression. Lamminen (2008) found that social support is also a significant negative predictor of stress in this parental group.

However, a problem with the existing data is a lack of uniformity in both independent and dependent variables across studies. Some studies have looked solely at stress, whereas others have included anxiety and/or depression. However, there are no existing studies comparing predictive factors across these three variables. As mothers may present with varying levels of stress, anxiety or depression, it is important to understand the similarities and differences in contributory factors.

Additionally, the majority of studies focus on a small number of predictive factors (for example, studies focused on the relationship between social support and parental mental health problems may not have included autism symptom severity or child conduct problems as additional measures). It is therefore not clearly understood whether social support, as an example, would still be a significant predictor of maternal mental health problems in the presence of these additional variables. Knowledge of such predictive factors could be used to formulate a theoretical framework for effective support services for mothers of children with autism experiencing one or more of these mental health problems.

Study One aims to investigate and compare the predictors of stress, anxiety and depression in the mothers of children with autism. The study includes all the variables identified in the literature as predictive of either maternal (or parental) stress, anxiety or depression (including factors identified as secondary contributors, such as child age, child developmental age, child hyperactive behaviour, maternal age and maternal marital status). The study also includes measures of parental locus of control, demonstrated to be predictive of parental stress in the parents of children with an intellectual disability (Hassall et al., 2005), and parent-child attachment. A meta-analysis conducted by Rutgers et al. (2004) demonstrated that attachment behaviours exhibited by children with autism were less likely to be recognized by parents than attachment behaviours exhibited by developmentally normal children. It is thus hypothesised that the perceived mother-child relationship may be a significant predictor of stress, anxiety and/or depression in mothers of children with autism.

Section 5.1 – Study One – Method

Participants

Eligible participants were mothers with one or more children aged between 4 years 0 months and 17 years 11 months reported to have received a diagnosis of autism or ASD (maternal report). In total there were 392 respondents to the questionnaire. One hundred and twenty respondents were discounted as they did not complete the full questionnaire. A further 22 were discounted for reporting on children with autism outside of the specified age range. The sample incorporated with the present study therefore comprised 250 mothers. The mean age of participants was 39.86 years (range 24-58 years; SD=6.33 years). The mean age of the children with autism reported on by the participants was 8.50 (range 4-17 years; SD=3.99 years). Each participant was requested to complete an online questionnaire.

Recruitment was undertaken with the support of a range of National and Regional Autism Advocacy or Support Organisations, such as Autism Tasmania (www.autismtas.org.au); Autism Victoria (www.autismvictoria.org.au); the Olga Tennison Autism Research Centre at La Trobe University, Melbourne (<http://www.latrobe.edu.au/otarc/centre.html>); the National Autistic Society, UK (www.autism.org.uk); the National Autism Association, US (www.nationalautismassociation.org); the Autism File magazine (www.autismfile.com) and Carers UK (www.carersuk.org). Recruitment was primarily undertaken via the Internet, with these organisations either posting Weblinks to the online questionnaire on their respective Websites, or hosting links to

a 'Facebook' page providing information on the study. The 'Facebook' page provided details on the study, provided a link to the online questionnaire, and offered participants an opportunity to provide qualitative feedback.

The online questionnaire consisted of the questions from the Measures outlined below. When answering questions related to a child with autism, participants were instructed to only respond based on one child with autism (if the participant reported having more than one child with the diagnosis), and to report on the same child for all relevant sections of the questionnaire, ensuring consistency across measures (i.e. that individual maternal scores across each measure related to the same child with autism).

Materials

The full study questionnaire is included in Appendix A.

Demographics. A series of demographic questions was developed by the investigator of the current study. The questions requested the following information from participants – year of birth; highest level of education achieved; the total number of people (including themselves) living in their household; the number of children under the age of 18 living in their household; marital status ('Married/Partner'; 'Separated/Divorced'; 'Widowed'; 'Single.');

current employment status ('Part-time'; 'Full-time'; 'Not employed'); annual personal income; annual household income, the number of their children diagnosed, now or in the past, with autism or ASD; the number of their children, now or in the past, diagnosed with other mental health disorders (from a pre-

defined list, including an 'Other' option); whether or not the participant is receiving treatment for a current medical condition (yes/no) and if yes what medical conditions the participant is receiving treatment for. These questions were included to provide descriptive statistics regarding the recruited participants.

Social and economic support. A brief 12 item questionnaire, developed by the investigator of the current study, was used to assess participant perception of social and economic support. Questions took the form of statements, focused on family support (e.g. *'You get the emotional help and support you need from your family, '*); extra-familial support (e.g. *'You can count on your friends when things go wrong. '*), economic support (e.g. *'You have some friends or family who are willing and able to help you financially'*) and support related specifically to their child with autism (*'You have some family or friends who help you care for your child(ren) with autism. '*) Participants responded to each statement by indicating the extent of their agreement along a 5-point Likert scale, ranging from 1 *"Strongly Disagree"* to 5 *"Strongly Agree"*. 10 of the questions in the questionnaire related to 'Social Support'. A final score for 'Social Support' was calculated by adding the individual scores for each of these ten questions. The other two questions were totaled to provide a score for 'Economic Support.' Possible scores for Social Support ranged from 0 to 50, with higher scores indicating a higher perceived level of received social support. The Cronbach's alpha score for internal consistency for the 10 'Social Support' items was .90. Possible scores for Economic Support ranged from 0 to 10, with higher scores indicating a higher perceived level of received economic support. The Cronbach's alpha of internal consistency for the two questions providing a measure of 'Economic Support' was .84.

Stress, anxiety and depression. To provide consistency across measures and allow inter-measure comparison, this study uses the same clinical measure for all three mental health variables, the short-form Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995). The definitions used by the scale, for depression and anxiety, are closely aligned with DSM-IV-TR, although it requires report of symptoms only over the past week, and is dimensional rather than categorical in its approach. An elevated score on the scale does not therefore indicate a diagnosis of any condition, but only the presence of symptoms that are closely aligned with the symptoms listed in DSM-IV-TR. Thus anxiety, for the purpose of this study, is defined as a persistent feeling of worry, apprehension and/or panic associated with physical symptoms such as shakiness, dry mouth, rapid heart rate and breathing difficulties (Lovibond & Lovibond, 1995). Depression, for the purpose of this study, is defined as a feeling of sadness characterized by self-disparaging thoughts, a feeling that life has no value, pessimism about the future, anhedonia, a lack of interest in activities and a lack of motivation (Lovibond & Lovibond, 1995). Stress, as defined by the DASS, and thus as defined by this study, is not specific to parenting or daily events, but rather defined as a general feeling of tension or over-arousal characterized by an inability to relax, irritability, being touchy, nervy and easily startled, and a marked intolerance of interruption or delay. For all three, symptoms are to have been present over the past week (i.e. in the seven days prior to the participant completing the questionnaire). The DASS is a standardized tool for the assessment of depression, anxiety and stress. It's dimensional approach also lends itself well to the structure of this study, which seeks to measure stress, anxiety and depression as continuums of severity, and not categorical absolutes.

The DASS-21 comprises three self-report subscales, each containing 7 items. One scale relates to depression, one relates to stress and one to anxiety. Each item is presented in the form of a statement. Participants respond to the statements by indicating the extent of their agreement across a 4 point scale, ranging from 0 “*did not apply to me at all*” to 3 “*applied to me very much, or most of the time*”. Participants are requested to consider to what extent each statement applies to themselves over the past week. Possible scores for each scale (stress, anxiety, depression) range from 0 to 21, with higher scores indicating increased severity of symptoms. Although the DASS-21 is based on a dimensional rather than a categorical conception of psychological disorders, recommended cut-off scores for severity levels are provided by the authors, for each of stress, anxiety and depression (categories provided by the cut-off scores are “*normal*”; “*mild*”, “*moderate*”, “*severe*” and “*extremely severe*”). Participants were not categorised based on these cut-off scores. Symptom severity for stress, anxiety and depression was instead assessed as a continuum. Internal reliability for the DASS-21 using Cronbach’s alpha is reported to be .88 for the Depression scale, .82 for the Anxiety scale, .90 for the Stress scale and .93 for the Total scale (Henry & Crawford, 2005).

Individual scores for Anxiety, Stress and Depression were calculated in this study by adding the scores for relevant questions in each group, as outlined by the scale authors (Lovibond & Lovibond, 1995). The Cronbach’s alpha of internal consistency for the DASS-21 for this study was .91.

Child demographic questions. A short series of demographic questions, developed by the investigator of the current study, focused specifically on the child with autism (as opposed to the mother completing the questionnaire). The questions focused on the age and sex of the child, whether the child was an oldest, middle,

youngest or only child, whether the study participant is the primary carer for the child ('yes/no' response), whether the participant is the biological, step or foster mother of the child, and whether the child has received any other mental health diagnoses in addition to autism or ASD. These questions were included to provide descriptive statistics regarding the population of children with autism described by study participants.

Autism symptom severity. Autism symptom severity was assessed using the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The SCQ is a 40-item parent report screening measure that investigates the symptomatology associated with ASD. The items are administered in a *yes/no* response format. The SCQ was originally known as the Autism Screening Questionnaire (Berument et al., 1999), and was developed as a companion screening measure for the Autism Diagnostic Interview-Revised (ADI-R, Lord, Rutter, & LeCouteur, 1994). The SCQ has been demonstrated to correlate closely with the ADI-R in indicating the possibility of an ASD diagnosis (Berument et al., 1999). The authors recommend a clinical cut-off score of 15 to indicate a possible diagnosis of ASD. Factor analysis of the SCQ has demonstrated four symptom domains associated with specific sets of items on the questionnaire, namely *Social Interaction*, *Communication*, *Abnormal Language* and *Stereotyped Behaviour* (Berument et al. 1999).

A total score for Autism Symptom Severity was calculated by adding the scores for questions 2-40 (for children with phrase speech i.e. able to verbalise a short sentence or phrase), or items 8-40 (for children without phrase speech i.e. unable to verbalise a short sentence or phrase), as recommended by the scale authors (Rutter et al., 2003). Possible scores for the SCQ range from 0-34 for children without phrase speech or 0-39 for children with phrase speech. Higher scores indicate comparatively

higher Autism Symptom Severity. In studies assessing reliability across age groups, the SCQ has demonstrated a Cronbach's Alpha index of internal consistency ranging from .84 to .93. In studies assessing reliability across diagnostic categories, the Cronbach's Alpha index of internal consistency (by group) ranges from .81 to .92 (Rutter et al., 2003). The Cronbach's alpha of internal consistency for the SCQ for this study was .80.

The SCQ is designed as a screening tool to identify children who would benefit from a full autism diagnostic review (Rutter et al, 2003). It is not a diagnostic tool in itself, and the authors acknowledge that the SCQ can deliver both false positives and false negatives, and that the measure should not be used as a substitute for a formal diagnostic assessment. Therefore children not meeting the recommended cutoff score for possible autism of 15 on the SCQ (Rutter et al., 2003) were not excluded from the study. Participants were instead asked, as part of the demographic questionnaire, whether or not their child had received a formal diagnosis of autism from a medical professional. If the participant answered 'yes' to this question, it was assumed that the child being reported on had received a diagnosis of autism.

Developmental age. Three questions devised by the study author were used to indicate the developmental age of the child. The items were administered in a *yes/no* format, and scored cumulatively (providing a maximum score of '3' if an answer of 'yes' was provided to all three questions.) The questions were as follows: "*Is she/he able to dress independently, or without considerable assistance from someone else? (Note: needing help to tie shoelaces would not be considered 'considerable assistance')*"; "*Is she/he able to go to the toilet independently, or without considerable assistance from someone else? (Note: needing to be reminded to wash hands or flush the toilet would not be considered 'considerable assistance')*"; and "*Is*

she/he able to bath/shower independently, or without considerable assistance from someone else? (Note: needing help turning on the shower or running the bath would not be considered 'considerable assistance')." A cumulative of score of '0' or '1' across these 3 questions was interpreted in the current study to indicate a comparatively low developmental age. There are a number of existing scales that measure Developmental Age in children with Pervasive Development Disorders, including the Bayley Scales of Infant and Toddler Development (Bayley, 2006) and the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984). However, both these scales require direct observation of the child. No short-form parent-completed questionnaire was identified that provides a measure of developmental age, and could be completed for children ranging in age from four to seventeen. Thus the decision was made to develop the assessment tool described above. The Cronbach's Alpha index for internal consistency for the Developmental Age measure was .79.

Maladaptive behaviour. Child maladaptive problem behaviours ('Conduct Problems') were assessed using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 2007.) The SDQ is a brief behavioural screening questionnaire that asks about 25 child attributes, some positive and others negative. The 25 items are divided between 5 scales of 5 items each, generating scores for conduct problems, hyperactivity, emotional symptoms, peer problems, and prosocial behaviour; all but the last are summed to generate a total difficulties score. Each item requires an answer "*Not True*", "*Somewhat True*" or "*Certainly True*" to be selected. Three versions of the SDQ exist: the self-report for ages 11-17; the parent or teacher form for ages 4-10; and the parent or teacher form for ages 11-17. Wording for the items used from the SDQ in this study is identical between both parent forms (4-10 and 11-17).

Items and the subscales of the SDQ are in line with the current psychology and psychiatry concept of childhood psychopathology (Malmberg, Rydell, & Smedje, 2003). The reliability and validity of the SDQ have been found to be satisfactory in studies of different communities across the world (Goodman, 1997; Goodman, 1999; Goodman and Scott, 1999; Goodman, 2001). The SDQ was designed to be brief, applicable for children age of 4 to 17 with all 25 statements developed to tap into both children's strengths (10 items) and difficulties (Goodman, 1997).

Ten questions from the SDQ were incorporated into the questionnaire for the current study. These 10 questions corresponded to the subscales for conduct problems and hyperactivity. Wording for these 10 questions is identical between the parent report forms for 4-10 year olds and the parent report forms for 11-17 year olds. One question from the 'Conduct Problems' scale of the SDQ was altered from '*Steals from home, school or elsewhere*' to '*Takes things without permission from home, school, or elsewhere.*' As it has been postulated that an impairment in 'Theory of Mind' in children with autism may result in children with autism being unable to relate to the concept of ownership (Baron-Cohen, 2009), the question was changed to include circumstances where the child may be unaware that taking things without permission would be considered stealing.

Separate scores for 'Hyperactive Behaviour' and 'Conduct Problems' were calculated from the raw data, by combining the scores for the five respective questions in each domain, as recommended by factor analysis of the SDQ (Goodman, 2007). Possible scores for both Hyperactive Behaviour and Conduct Problems ranged from 0-10, with higher scores indicating a greater degree of perceived behaviour problems. Alpha scores of internal consistency in this study were .65 for 'Hyperactive Behaviour' and .66 for 'Conduct Problems.'

An additional statement, ‘*Often aggressive or violent towards adults*’ was included, separate to the questions from the SDQ, to assess violent behaviour towards adults displayed by the child. For this item parents were again asked to select one of “*Not True*”, “*Somewhat True*” and “*Certainly True*.” Answers to this question were assigned a value from ‘0’ to ‘2’ and scored separately to the SDQ. A score between ‘0’ and ‘2’ was calculated for each child, based on the answer to this question, and scored as ‘Aggressive Behaviour.’

Parent-child attachment. Maternal perception of parent-child attachment was assessed using the Parent-Child Relationship Inventory (PCRI; Gerard, 1994). The PCRI is a 78-item self-report measure rated on a four-point Likert scale that measures parents’ perceptions about their relationships with their children. Three of the seven PCRI subscales focus on parent-child interaction and perception of parenting, and were considered relevant to the objectives of this study. These subscales were *Satisfaction with Parenting, Involvement* (parent perception of involvement and ‘closeness’ to child – ‘Perceived Maternal Involvement’), and *Limit Setting* (parental perception of their ability to set limits for their child - ‘Perceived Limit Setting Ability’). All questions for these three subscales were included in the questionnaire for the current study, a total of 36 questions. The three subscales were scored separately for the purpose of analysis. Scores for ‘Satisfaction with Parenting’ ranged from 0 to 30, with higher scores indicating greater satisfaction. Scores for ‘Perceived Maternal Involvement’ ranged from 0 to 42, with higher scores indicating higher perceived involvement. Scores for ‘Perceived Limit Setting Ability’ ranged from 0 to 36, with higher scores indicating higher perceived ability to set limits.

Reports of the PCRI’s psychometric characteristics (Gerard, 1994; Heinze & Grisso, 1996) have demonstrated adequate psychometric properties. Tests of internal

consistency of all subscales have yielded Cronbach's alphas above .70 with a median value of .82 (Gerard, 1994). The Cronbach's alpha of internal consistency of the PCRI for this study was .84.

Maternal locus of control. Parental locus of control, a variable indicated as predictive of mental health problems in the parents of children with intellectual disability (Hassall et al., 2005) was assessed using the Parental Locus of Control Scale (PLOC; Campis, Lyman, & Prentice-Dunn, 1986), a 46 item questionnaire consisting of statements assessing self-perception of locus of control across five item factors, *Parental Efficacy*, *Parental Responsibility*, *Child Control of Parent's Life*, *Parental Belief in Fate/Chance* and *Parental Control of Child's Behaviour*. For each statement the parent is requested to select a response across a 5-point Likert scale from '*Strongly Disagree*' to '*Strongly Agree*.' Possible scores, for the full questionnaire, range from 0 to 184, with higher scores indicating a more externalized parental locus of control and lower scores indicating a more internalized parental locus of control.

The PLOC has been demonstrated a valid tool able to discriminate between theoretically different parental groups (those who did not report experiencing any difficulties in the parenting role; and those requesting support for parenting problems) (Campis et al., 1986). Tests of internal consistency provided Cronbach alpha reliability coefficient's for each factor of .75 (Parental Efficacy), .77 (Parental Responsibility), .67 (Child Control of Parent's Life), .75 (Parental Belief in Fate/Chance) and .65 (Parental Control of Child's Behaviour), and a total scale reliability coefficient of .92 (Campis et al., 1986). The Cronbach's alpha of internal consistency for the PLOC for this study was .90.

A single total score for Parental Locus of Control was calculated from the raw data, by combining scores for all 46 questions. A higher score demonstrates a more externalized locus of control, a lower score a more internalized locus of control (Campis et al., 1986).

Procedure

Prior to commencement of the questionnaire, all participants were provided, either by e-mail or via the Internet, an Information Sheet detailing the study objectives, the information being requested, the voluntary nature of participation, the nature of data confidentiality inherent in the study, and providing contact details for relevant support services should participants experience any distress whilst completing the questionnaire. Hard copy versions of the Information Sheet were available on request. Consent was implied through online submission of the completed questionnaire. Participants completed an online questionnaire package containing the measures outlined above. Demographic questions pertinent to the mother completing the questionnaire were always presented first. Participants were prompted to complete all questions before being provided an option to submit the completed questionnaire. On submission, participants were provided with a message thanking them for their participation, and providing contact details of the researcher should they have any further questions.

Qualitative information provided voluntarily by participants on the Study 'Facebook' Website was also collected. Qualitative information was provided unprompted by participants, and not in response to any specific questions.

Section 5.2 – Study One – Results

Based on the number of participants (N= 250), not all the variables included in the questionnaire could be used in a multiple regression analysis. Therefore initial regression analyses were used to identify those variables with comparatively greater predictive relationships with the dependent variables (stress, anxiety and depression). Based on these initial analyses, the following variables were demonstrated to have no significant predictive relationship with the dependent variables - Sex of Child, Marital Status, Employment Status, Number of People in Household, Number of Children with Autism, Participant Medical Condition, Participant Mental Health Diagnosis, Older/Middle/Youngest/Only Child, Relationship with Child, Primary Carer for Child, and Other Mental Health Diagnoses (Child). These variables were therefore excluded from further analysis. Results to questions regarding Household Income and Personal Annual Income were discounted. Respondents to the questionnaire were international and, as the question was asked in Dollars (\$), answers were difficult to interpret (as respondents may or may not have applied a currency exchange calculation), a limitation not considered prior to the commencement of data collection.

Descriptive Statistics for the excluded variables are shown in Table 1 below.

Table 1
Descriptive Statistics for Excluded Variables.

| Variable | SD | Mean | Descriptive |
|--|------|------|---|
| <u>Categorical Variables</u> | | | |
| Sex of Child | | | Female – 49 (21%); Male – 201 (79%) |
| Marital Status | | | Married/Partner – 185 (74%); Single/Widowed/Divorced – 65 (26%) |
| Employment Status | | | Unemployed – 140 (56%); Part-Time – 69 (28%); Full-Time – 41 (16%) |
| Participant Mental Health | | | Yes – 165 (66%); No – 85 (34%) |
| Diagnosis | | | Yes – 80 (32%); No – 170 (68%) |
| Participant Medical Condition | | | |
| Older/Middle/Youngest/Only Child | | | Oldest – 99 (40%); Middle – 37 (15%); Youngest – 71 (28%); Only – 43 (17%); |
| Relationship with Child | | | Biological Mother – 248 (99%); Other – 2 (1%) |
| Primary Carer for Child? | | | Yes – 248 (99%); No – 2 (1%) |
| Child Has Other Mental Health Diagnoses? | | | Yes – 72 (29%); No – 178 (71%) |
| <u>Continuous Variables</u> | | | |
| People in Household | 2.64 | 4.31 | |
| Children with Autism | .55 | 1.23 | |

Analysis

Data was analysed using multiple regression in SPSS. Means and standard deviations for the 13 remaining variables (those included in the main analysis) are as shown in Table 2 below.

Table 2
Descriptive Statistics for Variables Included in Regression Analyses.

| Variable | SD | Mean |
|---------------------------------|-------|-------|
| Stress | 10.11 | 24.08 |
| Anxiety | 10.50 | 13.41 |
| Depression | 12.01 | 18.71 |
| Age of Mother | 6.33 | 39.86 |
| Age of Child | 3.99 | 8.50 |
| Social Support | 8.55 | 20.71 |
| Economic Support | 2.52 | 3.59 |
| Hyperactive Behaviour | 2.19 | 7.31 |
| Conduct Problems | 2.20 | 3.86 |
| Aggressive Behaviour | 0.74 | 0.60 |
| Autism Symptom Severity | 6.44 | 21.20 |
| Developmental Age | 1.22 | 1.81 |
| Perceived Limit Setting Ability | 5.22 | 16.65 |
| Satisfaction with Parenting | 5.58 | 21.49 |
| Perceived Maternal Involvement | 5.39 | 30.99 |
| Parental Locus of Control | 16.50 | 89.12 |

Note: SD = standard deviation

The means for stress, anxiety and depression in mothers of children with autism were noticeably higher than scores in a general community sample (Crawford & Henry, 2003). In the community sample (Crawford & Henry, 2003), the mean for depression was 5.55, the mean for anxiety was 3.56 and the mean for stress was 9.27. The means for all three variables for mothers of children with autism were significantly higher (t-test, one-tailed, $p < 0.05$). It is notable that the means for mothers of children with autism were also higher than the DASS means for a clinical sample (Brown, Chorpita, Kortotisch, & Barlow, 1997). Brown et al. (1997) assessed 437 patients presenting for assessment and treatment at a Phobia and Anxiety Disorders Clinic. Means for depression, anxiety and stress in this clinical sample were 10.65, 10.90 and 21.10 respectively. The mean depression score for mothers of children with autism, 18.71, was markedly more elevated than the comparable score in this clinical sample. In fact, this score is also higher than means scores for depression in clinical cohorts of individuals diagnosed with Panic Disorder, Generalized Anxiety Disorder, Social Phobia and Obsessive-Compulsive Disorder

assessed in the same study (Brown et al., 1997). The mean score for depression in mothers of children with autism is, however, lower than the comparative score in a clinical sample of individuals with a diagnosed mood disorder, for which the mean score was 25.31 (Brown et al., 1997).

Seventeen of the 250 children for whom Social and Communication Questionnaire (SCQ; Rutter et al., 2003) scores were collected as part of this study had total SCQ scores below the recommended cut-off score of 15 (indicative of possible Autism Disorder) (Rutter et al., 2003). However, as all parents confirmed that the child they reported on had received a formal diagnosis of Autism Disorder from a medical professional, the mothers of these 17 children were not excluded from the study. As discussed in the methodology section of this study, the SCQ is not designed as a definitive diagnostic tool for Autism (Rutter et al., 2003), and was used in this study as a measure of Autism Symptom Severity, not as a screening tool for excluding study participants.

Correlations

Correlation coefficients above .60 existed between stress, anxiety and depression (Appendix C). Based on the expected factor correlations for the DASS, the high level of correlations between these variables was expected. Correlation coefficients above .60 were also found between Conduct Problems and Aggressive Behaviour (correlation coefficient .61); and Maternal Involvement and Satisfaction with Parenting (correlation coefficient .61). Overall, however, the correlation data indicates a low probably of variable colinearity (Appendix C).

Initial Models for Depression

Initially linear regressions were performed separately regressing the predictors of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on depression. These linear regression analyses were undertaken to replicate prior research indicating that these factors, when regressed individually, are significant predictors of maternal mental health problems. The results for the four separate regressions are shown in Table 3.

Table 3

Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Depression.

| Variable | b | SE | β | t |
|--|--------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | - 0.50 | .08 | -.35 | -5.93*** |
| Constant | 28.96 | 1.87 | | 15.48*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.29 | .34 | .24 | 3.85*** |
| Constant | 13.72 | 1.49 | | 9.19*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .56 | .11 | .30 | 4.96*** |
| Constant | 6.84 | 2.50 | | 2.74** |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .25 | .04 | .34 | 5.70*** |
| Constant | -3.37 | 3.94 | | -.86 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that all four variables, when individually regressed against depression, were significant predictors of depression.

Social support was a significant negative predictor of depression, $F(1,248)=35.11, p<.001$, indicating that social support is negatively associated with depression symptomatology. The overall model accounted for approximately 12% of the variance in depression, $R^2=.12$.

Conduct problems was a significant positive predictor of depression, $F(1,248)=14.81, p<.001$, indicating that conduct problems is positively associated with depression symptomatology. The overall model accounted for approximately 6% of the variance in depression, $R^2=.06$.

Autism symptom severity was also a significant positive predictor of depression, $F(1,248)=24.63, p<.001$, indicating that autism symptom severity is positively associated with depression symptomatology. The overall model accounted for approximately 9% of the variance in depression, $R^2=.09$.

Parental locus of control (with a higher score indicating a more externalised locus of control) was also a significant positive predictor of depression, $F(1,248)=32.50, p<.001$, indicating that parental locus of control is positively associated with depression symptomatology. The overall model accounted for approximately 12% of the variance in depression, $R^2=.12$.

Initial Models for Anxiety

Similar linear regressions were performed separately regressing the predictors of social support, conduct problems, autism symptom severity and parental locus of control on anxiety. The results for the four separate regressions are shown in Table 4.

Table 4
Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Anxiety.

| Variable | B | SE | β | t |
|--|--------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | - 0.24 | .08 | -.20 | -3.16** |
| Constant | 18.42 | 1.71 | | 10.76*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.46 | .29 | .31 | 5.08*** |
| Constant | 7.77 | 1.28 | | 6.08*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .59 | .10 | .36 | 6.10*** |
| Constant | .95 | 2.14 | | .44 |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .17 | .04 | .27 | 4.40*** |
| Constant | -1.85 | 3.53 | | -.53 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that all four variables, when individually regressed against anxiety, were significant predictors of anxiety. Social support was a significant negative predictor of anxiety, $F(1,248)=10.01$, $p < .01$, indicating that social support is negatively associated with anxiety symptomatology. The overall model accounted for approximately 4% of the variance in anxiety, $R^2=.04$.

Conduct problems was a significant positive predictor of anxiety, $F(1,248)=25.76$, $p < .001$, indicating that conduct problems is positively associated with anxiety symptomatology. The overall model accounted for approximately 9% of the variance in anxiety, $R^2=.09$.

Autism symptom severity was also a significant positive predictor of anxiety, $F(1,248)=37.15$, $p < .001$, indicating that autism symptom severity is positively

associated with anxiety symptomatology. The overall model accounted for approximately 13% of the variance in anxiety, $R^2=.13$.

Parental locus of control was also a significant positive predictor of anxiety, $F(1,248)=19.38$, $p<.001$, indicating that parental locus of control is positively associated with anxiety symptomatology. The overall model accounted for approximately 7% of the variance in anxiety, $R^2=.07$.

Initial Models for Stress

Similar linear regressions were performed separately regressing the predictors of social support, conduct problems, autism symptom severity and parental locus of control on stress. The results for the four separate regressions are shown in Table 5.

Table 5
Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Maternal Stress.

| Variable | b | SE | β | t |
|--|--------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | - 0.27 | .07 | -.23 | -3.63*** |
| Constant | 29.58 | 1.64 | | 18.04*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.42 | .28 | .31 | 5.12*** |
| Constant | 18.61 | 1.23 | | 15.12*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .43 | .10 | .28 | 4.50*** |
| Constant | 14.95 | 2.12 | | 7.04*** |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .23 | .04 | .38 | 6.43*** |
| Constant | 3.45 | 3.27 | | 1.06 |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that all four variables, when individually regressed against stress, were significant predictors of stress.

Social support was a significant negative predictor of stress, $F(1,248)=13.16$, $p<.01$, indicating that social support is negatively associated with stress symptomatology. The overall model accounted for approximately 5% of the variance in stress, $R^2=.05$.

Conduct problems was a significant positive predictor of stress, $F(1,248)=26.17$, $p<.001$, indicating that conduct problems is positively associated with stress symptomatology. The overall model accounted for approximately 10% of the variance in stress, $R^2=.10$.

Autism symptom severity was also a significant positive predictor of stress, $F(1,248)=20.21$, $p<.001$, indicating that autism symptom severity is positively associated with stress symptomatology. The overall model accounted for approximately 8% of the variance in stress, $R^2=.08$.

Parental locus of control was also a significant positive predictor of stress, $F(1,248)=41.32$, $p<.001$, indicating that parental locus of control is positively associated with stress symptomatology. The overall model accounted for approximately 14% of the variance in stress, $R^2=.14$.

Stepwise Models for Depression

Forward Stepwise Regression was employed to regress 13 predictors - Social Support, Mother's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Maternal Involvement, Autism

Symptom Severity and Parental Locus of Control – against depression. The statistical criteria for entry was a probability of $F \leq .05$, with the criteria for subsequent removal probability of $F \geq .1$. Before interpretation, general assumptions of multiple regression were tested for the final model. VIF was less than 10 and Tolerance greater than .2 for all variables indicating an absence of colinearity in data (Bowerman & O’Connell, 1990; Menard, 1995). The Durbin-Watson test indicated that the independence of errors assumption was upheld. Further analysis revealed no evidence of heteroscedasticity, and that distribution of errors was normal. From these analyses the model was deemed to meet the assumptions of multiple regression, and thus the model was accepted.

Only the variables shown to significantly predict depression, as described in the final step of the stepwise regression model, are reported below.

At the first step social support was entered, accounting for approximately 12% of the variance in depression, $R^2=.12$. At the second step, parental locus of control was entered, accounting for approximately an additional 7% of the variance in depression, $\Delta R^2=.07$, with aggressive behaviour added at the last step accounting for approximately an additional 3% of the variance in depression, $\Delta R^2=.03$. The final model was a significant predictor of depression, $F(3,246)=23.03$, $p<.001$, accounting for 22% of the variance in depression, $R^2=.22$. The results for each predictor in the final model from the stepwise regression are shown in Table 6.

Table 6
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Maternal Depression.

| Variable | b | SE | β | t |
|---|--------|------|---------|----------|
| Stepwise Regression - Final Step (Step 3) | | | | |
| Social Support | - 0.40 | .08 | -.28 | -4.91*** |
| Parental Locus of Control | .16 | .05 | .22 | 3.52** |
| Aggressive Behaviour | 2.72 | .98 | .17 | 2.79** |
| Constant | 11.32 | 4.57 | | 2.48* |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$
 b = unstandardized estimate, SE = standard error, β = standardised value

From Table 7, the results indicate that social support is negatively associated with depression symptomatology and is marginally the most important predictor in the model. Parental locus of control and aggressive behaviour are both positive predictors of depression.

Stepwise Models for Anxiety

Forward Stepwise Regression was employed to regress 13 predictors -Social Support, Mother's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Maternal Involvement, Autism Symptom Severity and Parental Locus of Control - on anxiety. The statistical criteria for entry was the same as for the previous stepwise regression undertaken for the depression variable. Assumption testing was also the same as for the previous analysis, and all results indicated the model met the assumptions of multiple regression, and thus the model was accepted.

At the first step autism symptom severity was entered, accounting for approximately 13% of the variance in anxiety, $R^2 = .13$. At the second step, perceived limit setting ability was entered, accounting for approximately an additional 6% of the

variance in anxiety, $\Delta R^2=.06$, with mother's age added at the last step, accounting for approximately an additional 5% of the variance in anxiety, $\Delta R^2=.05$. The final model was a significant predictor of anxiety, $F(3,246)=26.08$, $p<.001$, accounting for 24% of the variance in anxiety, $R^2=.24$. The results for each predictor in the final model from the stepwise regression are shown in Table 7.

Table 7
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Maternal Anxiety.

| Variable | b | SE | β | t |
|---|-------|------|---------|----------|
| Stepwise Regression - Final Step (Step 3) | | | | |
| Autism Symptom Severity | .48 | .09 | .30 | 5.17*** |
| Perceived Limit Setting Ability | -.48 | .12 | -.24 | -4.20*** |
| Mother's Age | -.37 | .09 | -.23 | -4.05*** |
| Constant | 26.16 | 4.78 | | 5.47*** |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$
b = unstandardized estimate, SE = standard error, β = standardised value

From Table 8, the results indicate that autism symptom severity is a positive predictor of anxiety, and is the most important predictor in the model. Perceived limit setting ability and mother's age are both negative predictors of anxiety.

Stepwise Models for Stress

Forward Stepwise Regression was employed to regress 13 predictors -Social Support, Mother's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Maternal Involvement, Autism Symptom Severity and Parental Locus of Control - on stress. The statistical criteria for entry was the same as for the previous stepwise regressions undertaken for depression and anxiety. Assumption testing was also the same as for the previous

analyses, and all results indicated the model met the assumptions of multiple regression, and thus the model was accepted.

At the first step perceived limit setting ability was entered, accounting for approximately 17% of the variance in stress, $R^2=.17$. At the second step, mother's age was entered, accounting for approximately an additional 5% of the variance in stress, $\Delta R^2=.05$. At the third step, autism symptom severity was entered, accounting for approximately an additional 3% of the variance in stress, $\Delta R^2=.03$. At the fourth step, social support was entered, accounting for approximately an additional 2% of the variance in stress, $\Delta R^2=.02$. At the fifth step, parental locus of control was entered, accounting for an additional 1% of the variance in stress, $\Delta R^2=.01$. Economic support was added at the last step, accounting for approximately an additional 2% of the variance in stress, $\Delta R^2=.02$. The final model was a significant predictor of stress, $F(6,243)=17.16, p<.001$, accounting for 30% of the variance in stress, $R^2=.30$. The results for each predictor in the final model from the stepwise regression are shown in Table 8.

Table 8
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Stress.

| Variable | b | SE | β | t |
|---|-------|------|---------|----------|
| Stepwise Regression - Final Step (Step 6) | | | | |
| Perceived Limit Setting Ability | -.46 | .13 | -.24 | -3.51** |
| Mother's Age | -.38 | .09 | -.24 | -4.36*** |
| Autism Symptom Severity | .19 | .09 | .12 | 2.08* |
| Social Support | -.26 | .08 | -.22 | -3.19** |
| Parental Locus of Control | .11 | .04 | .17 | 2.48* |
| Economic Support | .64 | .27 | .16 | 2.35* |
| Constant | 36.37 | 6.65 | | 5.47*** |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$

b = unstandardized estimate, SE = standard error, β = standardised value

From Table 8, the results indicate that perceived limit setting ability, mother's age and social support are all negative predictors of stress. Perceived limit setting ability and mother's age are marginally the most important predictors in the model. Autism symptom severity, parental locus of control and economic support are all positive predictors of stress.

Section 5.3 – Study One – Discussion

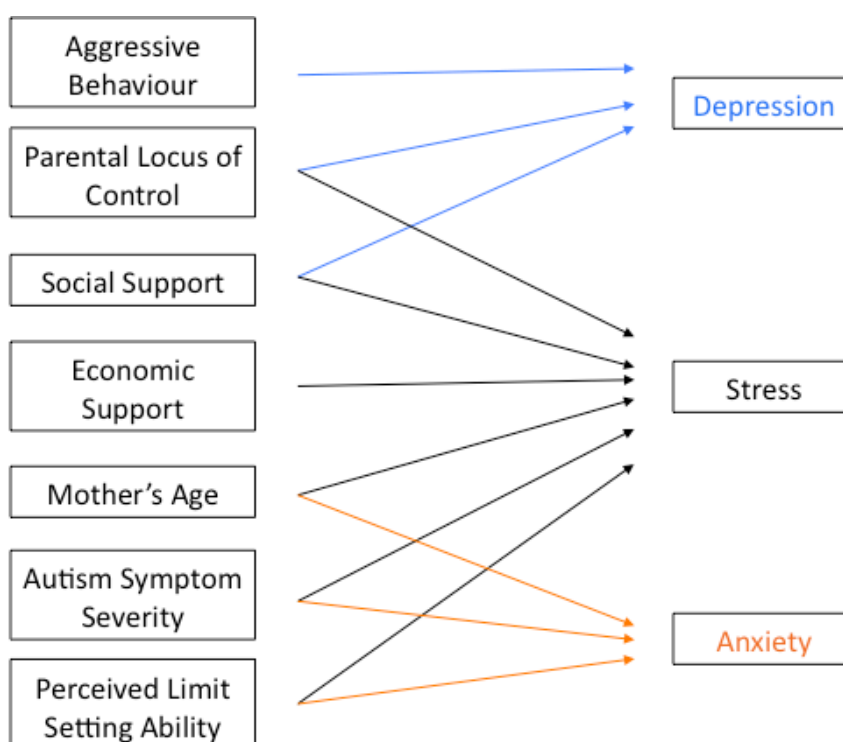
The aim of Study One was to examine the factors predicting stress, anxiety and depression in the mothers of children with autism. Although the existing literature has identified that conduct problems, autism symptom severity and social support significantly predict stress, anxiety or depression in the mothers of children with autism (Civick, 2008, Gray, 2003; Gray & Holden 1992; Lecavelier et al., 2005; Shieve, 2007), there is an inconsistency in both the dependent and independent variables used across the existing studies. It was hypothesised in the introduction to this study that conduct problems, autism symptom severity, social support and parental locus of control (Hassall et al., 2005) would significantly predict maternal stress, anxiety and depression when regressed separately from other variables, but that these variables may not predict maternal mental health problems when regressed together with other potential predictors. It was also hypothesised that the pattern of predictors would differ across dependent variable (i.e. maternal stress, anxiety and depression).

The results of Study One indicated these stated hypotheses to be valid. Although conduct problems, autism symptom severity, social support and parental locus of control did predict maternal stress, anxiety and depression in linear

regression analyses, these variables did not universally predict maternal stress, anxiety and depression in the stepwise regression analyses. There was also a different pattern of predictors across these three dependent variables. Based on the results of the analysis, the predictive relationship between the three dependent and 13 independent variables can be described as shown in Figure 1 below.

Figure 1

Proposed Path Diagram Representing the Variables Significantly Predicting Stress, Anxiety and Depression in the Mothers of Children with Autism.



Variables Not Predicting Stress, Anxiety or Depression – Age of Child, Hyperactive Behaviour, Developmental Age, Conduct Problems, Satisfaction with Parenting, Perceived Mother-Child Involvement.

Of the 13 independent variables entered into the Stepwise regression model, only three were shown, in the final model, to be significant predictors of depression. These variables were Aggressive Behaviour, Parental Locus of Control and Social Support. As would be expected, Aggressive Behaviour (defined in this study as aggressive behaviour towards adults) is a positive predictor of depression. Social

Support (with a higher score indicating a greater level of perceived social support) was a negative predictor of depression, and Parental Locus of Control (with a higher score indicating a more externalized locus of control) was a positive predictor of depression.

Of particular note, with reference to the model for depression, was that Autism Symptom Severity and Conduct Problems, two variables shown in the literature to be significant predictors of mental health problems in the parents of children with autism (Civick, 2008; Gray & Holden, 1992), were not included in the final model. However, when regressed individually against depression, both variables were shown to be significant predictors of depression. What this result indicates is that, in the presence of other variables, the variance in depression contributed by Autism Symptom Severity and Conduct Problems may be explained by other variables, demonstrating why any investigation into the predictors of maternal depression in this parental group must include all potentially significant variables. An analysis only including one or two variables is, in a sense, artificial, as it is not representative of the multiple conflicting stressors impacting upon mothers of children with autism in real life.

Another key point to note from the results is that the predictors of anxiety in the mothers of children with autism differ from the predictors of depression. As for depression, only three variables were shown to be significant predictors of anxiety. Autism Symptom Severity (with a higher score indicating more severe symptoms) was a positive predictor of anxiety, Mother's Age was a negative predictor of anxiety, and Perceived Limit Setting Ability (with a higher score indicating a greater perceived ability to set behavioural limits for the child with autism) was also a negative predictor of anxiety.

As for depression, it is interesting to note that variables shown in the literature (and in the linear regressions performed in this study) to be significant predictors of mental health problems in the mothers of children with autism are not significant predictors of anxiety in the presence of other variables. For anxiety, those variables were Social Support and Conduct Problems. The variance in anxiety contributed by these two variables may be explained by other independent variables included in the stepwise regression analysis.

The difference in the models for depression and anxiety also has relevance for support programs targeted at mothers of children with autism. If the predictors of depression and anxiety in this maternal group are different, as indicated by the results of this study, then applying the same intervention to a mother presenting with depression and a mother presenting with anxiety may prove ineffectual. The results of these analyses indicate that the potential predictors of maternal stress, anxiety and depression differ across mental health variables. For an intervention to be effective, this difference in potential predictors need to be taken into account.

Of the three variables predicting anxiety in this analysis, it is interesting to note that Mother's Age is a negative predictor of anxiety (i.e. younger mothers are likely to experience more anxiety than older mothers). There are many theoretical reasons for this result – younger mothers may have less life experience with which to cope with having a child with autism, may be at an earlier stage in their relationship with their partner, or may experience a greater sense of loss regarding the impact of their child's diagnosis upon their own future opportunities. These interpretations are, however, purely speculative, and further research in this area if warranted.

Six of the 13 independent variables included in this study were shown to be significant predictors of maternal stress. Five of these variables were also significant

predictors of either depression or anxiety. The predictive model for stress appears therefore to be a combination of the predictive models for anxiety and depression. The variable shown to be a significant predictor of depression, but not included in the model for stress, was Aggressive Behaviour.

Before any theoretical conclusions are drawn from this result, it should be noted that the result is not altogether unexpected. Factor analysis of the DASS has shown that stress, though having a distinct factor structure from anxiety and depression, is closely correlated with both (Crawford and Henry, 2003). Thus it would be expected, in using the DASS as a measure of all three dependent variables in this study, that the predictive model for stress would closely mirror that of depression and anxiety. Arguably, this provides a means of confirming the validity of the data gathered as part of this study. That the predictive models generated by this study reflect the factor structure of the DASS arguably demonstrates the strength of the data gathered.

Again, however, as for depression and anxiety, Conduct Problems is not included in the predictive model for stress (even though the existing literature and the linear regressions conducted as part of this study show it to be a significant predictor of maternal stress). Again, the conclusion that can be drawn from this is that the variance in stress contributed by Conduct Problems may be being explained by other variables. The result does however highlight the need to reassess the support programs offered to mothers of children with autism. Assuming that parent training in managing externalizing child behaviours will have an effect on reducing maternal stress, anxiety and depression would, according to the results of this study, be incorrect. Conduct Problems is not a significant predictor of any of these mental health variables (when assessed in the context of other key stressors), and thus should

not be the sole target for interventions seeking to reduce maternal stress, anxiety or depression. Though such behavioural management programs are certainly highly relevant, they are unlikely, in isolation, to have a significant impact on reducing maternal mental health problems. The results of this study would indicate that more holistic interventions, focused on the child, the parent and the family environment - and not just the child's behaviour - may be more effective. Additionally, as the factors predicting stress, anxiety and depression in this parental group are different, interventions may also be more effective if modified based on the mother's mental health presentation.

The sixth variable (i.e. the variable not predictive of either anxiety or depression) included in the final stepwise regression model for stress was Economic Support (where a higher score was indicative of greater economic support from friends and family). Interestingly, Economic Support was shown to be a positive predictor of stress (i.e. the higher the level of economic support received, the higher the perceived level of stress). The observed score would appear to be contrary to existing studies demonstrating that parents of children with autism with access to less financial support experience more mental health problems (Hu, 2009; Lee, 2009). However, another possible explanation is that the two-item measure used in this study to assess Economic Support is measuring financial dependence on others as opposed to financial security. Both items (*'You have a special person who is willing and able to help you financially'* and *'You have some family or friends who are willing and able to help you financially'*) are assessing whether the mother has people able to provide additional financial assistance (rather than assessing the mother's overall economic status). Mothers who are financially independent, and who do not need financial support from others, are likely to answer negatively for both items (whether

or not there are family or friends willing and able to help them financially), as they are not usually in a position to require additional financial support. Thus the measure is more a measure of financial dependence on others rather than availability of economic support. In this context, it would thus make theoretical sense that Economic Support, as assessed in this study, would be a positive predictor of stress.

In conclusion, the results of this analysis support the hypothesis that the factors predicting stress, anxiety and depression in the mothers of children with autism differ for each mental health variable. It also demonstrates that similar studies including only one or two independent variables may be misleading. Though variables such as Conduct Problems and Autism Symptom Severity are indeed significant predictors of stress, anxiety and depression when regressed individually, this predictive relationship will not necessarily exist when other variables are included in the analysis. Mothers of children with autism experience a wide range of child-related, environmental, personal and cognitive stressors, and any analysis seeking to understand the experience of this maternal group needs to reflect this.

Chapter 6 - Study Two – The Factors Predicting Stress, Anxiety and Depression in the Fathers of Children with Autism

As has been shown in the Literature Review and General Introduction to this study, and the Introduction to Study One, the existing literature clearly shows that the parents of children with autism experience more stress, anxiety and depression than the parents of developmentally normal children (Benjak, 2009; Fiske, 2009; Lee, 2009; Sanders & Morgan, 1997; Weiss, 2002). Some of these studies have focused solely on mothers (Tomanik et al., 2004), but the majority have assessed both mothers and fathers (Bitsika & Sharpley, 2004; Civick, 2008; Davis & Carter, 2008; Hastings & Johnson, 2001). There are no existing papers, however, focused specifically on mental health problems in the fathers of children with autism.

Rodrigue, Morgan and Geffken, who conducted a 1992 study comparing the psychosocial adaptation of fathers of children with autism, fathers of children with Down syndrome and fathers of developmentally normal children, noted this gap in the literature. The study concluded that fathers of children with autism, although reporting more disruption to family activities than fathers of developmentally normal children, coped relatively well with the demands associated with raising a child with developmental disabilities. Rodrigue et al. (1992) noted no significant difference, in terms of paternal coping and adaptation, between the autism and Down syndrome groups. However, studies comparing mental health problems reported by fathers of children with autism and fathers of children with Down Syndrome demonstrate mental health problems to be significantly higher in the autism group (Sanders & Morgan, 1997; Yirmiya & Shaked, 2005).

A small body of research has compared fathers and mothers within the autism group. In general studies have found that mothers of children with autism experience more stress, anxiety and depression than fathers (even though both groups are elevated compared to controls) (Gray & Holden, 1992; Hastings et al., 2005; Sharpley et al., 1997). In a study of 172 parents of children with autism, Gray and Holden (1992) demonstrated that fathers of children with autism reported less anxiety and depression than mothers. Hastings et al. (2005), in a study of 41 mother-father dyads, replicated this difference in reported depression. A study conducted by Sharpley et al., (1997) demonstrated that mothers were more depressed and anxious than fathers, and also reported a nonsignificantly higher daily level of parenting stress in mothers.

There are only a few papers, however, that investigate why this difference between mothers and fathers exists. Rogers (2008) postulated that whilst maternal mental health problems are related to the demands of coping with a child with autism, paternal mental health problems are related to the emotional state of their partner. Gray (2003) concurred with this, hypothesizing, based on qualitative feedback, that father's are not significantly effected by their child's condition. Other papers have argued that, whilst both maternal and paternal mental health problems are influenced by their child's diagnosis and behaviours, the primary stressors differ between the two groups (Davis & Carter, 2008; Fiske, 2009). Fiske (2009) reported that paternal stress is more affected by the long-term impact of their child's diagnosis, whereas maternal stress relates primarily to specific daily stressors. Altieri and von Kluge (2009) found that fathers perceived a greater level of social isolation (lack of social support) than mothers, even within matched pairs.

In summary, the existing literature sheds little light on the experience of fathering a child with autism. Although the literature does demonstrate this parental

group experiences more stress, anxiety and depression than controls (Benjak, 2009; Fiske, 2009; Lee, 2009; Sanders & Morgan, 1997; Weiss, 2002), the factors associated with these elevated levels of mental health problems are not clearly understood. Child behaviour problems (Civick, 2008; Lecavalier et al., 2005), social support (Gray & Holden 1992; Lamminen, 2008), and autism symptom severity (Hastings & Johnson, 2001) have all been shown to predict mental health problems in fathers of children with autism (in studies including both mothers and fathers). However, as for mothers, these studies tend to include a limited subset of independent variables. It is possible, when analysed with other potential predictors, that these variables will no longer remain significant.

The objectives of Study Two are therefore twofold. The first is to investigate the factors predicting stress, anxiety and depression in the fathers of children with autism, and provide some insight into the specific stressors predicting mental health problems in this parental group. The second objective is to compare the predictive models for stress, anxiety and depression in fathers with the equivalent models identified, in Study one, for mothers. Do the same factors predict mental health problems in mothers and fathers, or is there a clear difference between the two genders? As for Study One, it is hypothesized that conduct problems, autism symptom severity, social support and parental locus of control will significantly predict paternal stress, anxiety and depression when individually regressed against each dependent variable, but that these variables may not remain significant predictors when regressed alongside other potential predictors. It is also hypothesized that the predictive models for fathers, for stress, anxiety and depression, will differ from the comparable predictive models for mothers described in Study One.

Section 6.1 – Study Two – Method

In order to compare the results of the two studies, the method used for Study two closely mirrored the method used for Study one. Obvious changes were made to change the gender vocabulary of test questions (i.e. ‘mother’ to ‘father’, ‘maternal’ to ‘paternal’ etc.). However, the participant selection, procedure and materials used were largely the same. A full method is therefore not provided here, for the sake of avoiding repetition. Instead this section documents any changes made to the Method described for Study one.

Participants

Eligible participants were fathers with one or more children aged between 4 years 0 months and 17 years 11 months reported to have received a diagnosis of autism or ASD (paternal report), mirroring participant selection for Study One. Each participant was requested to complete an online questionnaire. In total, there were 387 respondents. One hundred and fifty three respondents were discounted because they did not complete the online questionnaire in full. A further 5 respondents were discounted for reporting based on children with autism outside the specified age range. The sample incorporated within the present study therefore comprised 229 fathers. The mean age of participants was 41.66 years (range 21-65 years; SD=6.97 years). The mean age of the children reported on by study participants was 8.23 (range 4-17 years; SD=3.83 years).

Recruitment was undertaken by the same method used for Study One, and was again indebted to the support of a range of National and Regional Autism

Advocacy or Support Organisations. In addition to the organisations listed in the Study One method section, the following organisations provided support – www.autisable.com; www.positivelyautism.com; Sibling Australia Inc.; and Parenting Autism (www.parenting-autism.org).

Materials

The full study questionnaire is included in Appendix A.

Demographics. The demographic questionnaire was the same as the one used for Study One, although the following questions were removed – annual personal income and annual household income. The questionnaire software used did not provide a means for the participant to select a currency, and as participants were sourced internationally, an answer in ‘Australian Dollars’ to these questions is hard to interpret (as the participant may or may not have assumed a currency conversion before responding). The questions were therefore removed.

Social and economic support. The same questionnaire was used as for Study One. The Cronbach’s alpha score for internal consistency for the 10 ‘Social Support’ items was .87. The Cronbach’s alpha of internal consistency for the two questions providing a measure of ‘Economic Support’ was .81.

Stress, anxiety and depression. As for Study One, the short form of the Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995) was used to assess the presence and severity of stress, anxiety and depression. The Cronbach’s alpha of internal consistency for the DASS-21 for this study was .95.

Child demographic questions. The same questionnaire was used as for Study One, with appropriate changes to the gender orientation of questions.

Autism symptom severity. Autism symptom severity was again assessed using the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). The Cronbach's alpha of internal consistency for the SCQ for this study was .76.

As for Study One, children with SCQ scores at or less than 15 were not excluded. The SCQ is not designed as a diagnostic tool for autism (Rutter, Bailey, & Lord, 2003). Parents were asked if their child had been formally diagnosed with autism by a medical professional. An answer of 'yes' to this question was assumed to indicate a diagnosis of autism.

Developmental age. The same investigator-authored questionnaire was used to assess Developmental Age. The Cronbach's Alpha index for internal consistency for the Developmental Age measure was .76.

Maladaptive behaviour. As for Study One, Conduct Problems and Hyperactive Behaviour was assessed using selected questions from the Strengths and Difficulties Questionnaire (SDQ; Goodman, 2007.) The Cronbach's Alpha index for internal consistency for the SDQ for this study was .70 overall (.64 for the 5 questions related to Hyperactive Behaviour and .64 for the 5 questions related to Conduct Problems.)

Aggressive Behaviour was again assessed using the same method used for Study one. As this measure incorporate only one additional question, the Cronbach's alpha of internal consistency could not be measured.

Parent-child attachment. As for Study One, Perceived Limit Setting Ability, Perceived Paternal Involvement and Satisfaction with Parenting were assessed using the Parent-Child Relationship Inventory (PCRI; Gerard, 1994). The Cronbach's alpha of internal consistency of the PCRI for this study was .87.

Paternal locus of control. Parental locus of control was again assessed using the Parental Locus of Control Scale (PLOC; Campis, Lyman, & Prentice-Dunn, 1986). The Cronbach's alpha of internal consistency for the PLOC for this study was .89.

Procedure

The procedure was the same as for Study One.

Section 6.2 – Study Two – Results

Based on the number of participants (N= 229), not all the variables included in the questionnaire could be used in a multiple regression analysis. Therefore initial regression analyses were used to identify those variables with comparatively greater predictive relationships with the dependent variables (stress, anxiety and depression). Based on these initial analyses, the following variables were demonstrated to have no significant predictive relationship with the dependent variables - Sex of Child, Marital Status, Employment Status, Number of People in Household, Number of Children with Autism, Participant Medical Condition, Participant Mental Health Diagnosis, Older/Middle/Youngest/Only Child, Relationship with Child, Primary Carer or Other Mental Health Diagnoses (Child). These variables were therefore excluded from further analysis.

Descriptive Statistics for these excluded variables are shown in Table 9.

Table 9
Descriptive Statistics for Excluded Variables.

| Variable | SD | Mean | Descriptive |
|--|------|------|---|
| <u>Categorical Variables</u> | | | |
| Sex of Child | | | Female – 39 (17%); Male – 190 (83%) |
| Marital Status | | | Married/In a Relationship – 199 (87%); Single/Widowed/Divorced – 30 (13%) |
| Employment Status | | | Unemployed – 39 (17%); Part-Time – 23 (10%); Full-Time – 167 (73%) |
| | | | Yes – 92 (40%); No – 137 (60%) |
| Participant Mental Health Diagnosis | | | Yes – 82 (36%); No – 147 (64%) |
| Participant Medical Condition | | | Oldest – 95 (41%); Middle – 32 (14%); Youngest – 54 (24%); Only – 48 (21%); |
| Older/Middle/Youngest/Only Child | | | Biological Father – 215 (94%); Other – 14 (6%) |
| Relationship with Child | | | Yes – 98 (43%); No – 131 (57%) |
| Primary Carer for Child? | | | Yes – 55 (24%); No – 174 (76%) |
| Child Has Other Mental Health Diagnoses? | | | |
| <u>Continuous Variables</u> | | | |
| People in Household | 1.08 | 4.05 | |
| Children with Autism | .47 | 1.21 | |

Analysis

Data was analysed using multiple regression in SPSS. Means and standard deviations for the 13 remaining variables (those included in the main analysis) are as shown in Table 10 below.

Table 10
Descriptive Statistics for Variables Included in Regression Analyses

| Variable | SD | Mean |
|---------------------------------|-------|-------|
| Stress | 11.16 | 20.76 |
| Anxiety | 9.71 | 10.01 |
| Depression | 11.96 | 16.45 |
| Age of Father | 6.97 | 41.66 |
| Age of Child | 3.83 | 8.23 |
| Social Support | 8.19 | 21.58 |
| Economic Support | 2.47 | 3.57 |
| Hyperactive Behaviour | 2.10 | 7.38 |
| Conduct Problems | 2.22 | 3.78 |
| Aggressive Behaviour | 0.68 | 0.58 |
| Autism Symptom Severity | 5.87 | 19.83 |
| Developmental Age | 1.22 | 1.71 |
| Perceived Limit Setting Ability | 5.37 | 16.93 |
| Satisfaction with Parenting | 6.13 | 21.24 |
| Perceived Paternal Involvement | 6.24 | 29.18 |
| Parental Locus of Control | 18.69 | 85.00 |

Note: SD = standard deviation

The mean scores for Stress, Anxiety and Depression in the fathers of children with autism, as measured using the DASS (Lovibond & Lovibond, 1995) were significantly higher (t-test, $p < 0.05$) than scores in a general community sample (Crawford & Henry, 2003). In the community sample (Crawford & Henry, 2003), the mean for depression was 5.55, the mean for anxiety was 3.56 and the mean for stress was 9.27. The means for all three variables for fathers of children with autism were considerably higher. The DASS scores for fathers of children with autism were comparable to scores in a clinical sample of individuals presenting for treatment of anxiety (Brown, Chorpita, Kortotisch, & Barlow, 1997). As for mothers of children with autism, the mean score for depression in fathers of children with autism was higher than the mean score in this clinical sample, although it was lower than the comparable score in a clinical sample of individuals with diagnosed mood disorders (Brown et al., 1997).

The mean scores for depression, anxiety and stress in fathers of children with autism were all lower than the comparative scores in mothers of children with autism.

For mothers of children with autism, the mean scores for depression, anxiety and stress were 18.71 13.41 and 24.08 respectively. The comparable scores for fathers were 16.45, 10.01 and 20.76. The mean scores for both mothers and fathers are all within the 'Moderate' range for stress, anxiety and depression (Lovibond & Lovibond, 1995). However, drawing further conclusions regarding the differences between the two populations may be misleading. The populations were recruited independently, and do not contain any matched co-parenting dyads. In addition there were subtle differences in the recruitment methodologies used for mothers and fathers (the study was promoted through different support and advocacy groups).

Thirteen of the 229 children for whom Social and Communication Questionnaire (SCQ; Rutter et al., 2003) scores were collected as part of this study had total SCQ scores below the recommended cutoff score of 15 (indicative of possible Autism Disorder) (Rutter et al., 2003). However, as all parents confirmed that the child they reported on had received a formal diagnosis of Autism Disorder from a medical professional, the fathers of these 13 children were not excluded from the study. As discussed in the methodology section of this study, the SCQ is not designed as a definitive diagnostic tool for Autism Disorder (Rutter et al., 2003), and was used in this study as a measure of Autism Symptom Severity, not as a screening tool for excluding study participants.

Correlations

Correlation coefficients above .60 existed between stress, anxiety and depression (Appendix C). Based on the expected factor correlations for the DASS, the high level of correlations between these variables was expected. Correlation coefficients above .60 were also found between Conduct Problems and Aggressive

Behaviour (correlation coefficient .65), Conduct Problems and Perceived Limit Setting Ability (correlation coefficient -.62), Perceived Limit Setting Ability and Parental Locus of Control (correlation coefficient -.65) and Maternal Involvement and Satisfaction with Parenting (correlation coefficient .65). Overall, however, the correlation data indicates a low probability of variable colinearity (Appendix C).

Initial Models for Depression

Initially linear regressions were performed separately regressing the predictors of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on depression. These regression analyses were undertaken to replicate prior research indicating that these factors, when regressed individually, are significant predictors of paternal mental health problems. The results for the four separate regressions are shown in Table 11.

Table 11

Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Depression.

| Variable | b | SE | β | t |
|--|--------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | - 0.58 | .09 | -.40 | -6.49*** |
| Constant | 28.91 | 2.06 | | 14.07*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.69 | .34 | .31 | 4.98*** |
| Constant | 10.04 | 1.49 | | 6.74*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .30 | .13 | .15 | 2.25* |
| Constant | 10.48 | 2.78 | | 3.79*** |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .26 | .04 | .41 | 6.73*** |
| Constant | -5.75 | 3.38 | | -1.70 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that all four variables, when individually regressed against depression, were significant predictors of depression.

Social support was a significant negative predictor of depression, $F(1,228)=42.09$, $p < .001$, indicating that social support is negatively associated with depression symptomatology. The overall model accounted for approximately 16% of the variance in depression, $R^2=.16$.

Conduct problems was a significant positive predictor of depression, $F(1,228)=24.82$, $p < .001$, indicating that conduct problems is positively associated with depression symptomatology. The overall model accounted for approximately 10% of the variance in depression, $R^2=.10$.

Autism symptom severity was also a significant positive predictor of depression, $F(1,228)=5.06$, $p<.05$, indicating that autism symptom severity is positively associated with depression symptomatology. The overall model accounted for approximately 2% of the variance in depression, $R^2=.02$.

Parental locus of control (with a higher score indicating a more externalised locus of control) was also a significant positive predictor of depression, $F(1,228)=45.31$, $p<.001$, indicating that parental locus of control is positively associated with depression symptomatology. The overall model accounted for approximately 17% of the variance in depression, $R^2=.17$.

Initial Models for Anxiety

Similar linear regressions were performed separately regressing the predictors of social support, conduct problems, autism symptom severity and parental locus of control on anxiety. The results for the four separate regressions are shown in Table 12.

Table 12

Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Anxiety.

| Variable | B | SE | β | t |
|--|--------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | - 0.29 | .08 | -.25 | -3.81*** |
| Constant | 16.23 | 1.76 | | 9.24*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.12 | .28 | .26 | 4.00*** |
| Constant | 5.77 | 1.23 | | 4.68*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .10 | .11 | .06 | .93 |
| Constant | 8.00 | 2.27 | | 3.53*** |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .13 | .03 | .24 | 3.75*** |
| Constant | -.66 | 2.91 | | -.23 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that social support, conduct problems and parental locus of control, when individually regressed against anxiety, were significant predictors of anxiety. However, autism symptom severity, when individually regressed against anxiety, was not a significant predictor of anxiety.

Social support was a significant negative predictor of anxiety, $F(1,228)=14.48$, $p < .001$, indicating that social support is negatively associated with anxiety symptomatology. The overall model accounted for approximately 6% of the variance in anxiety, $R^2=.06$.

Conduct problems was a significant positive predictor of anxiety, $F(1,228)=15.89$, $p < .001$, indicating that conduct problems is positively associated

with anxiety symptomatology. The overall model accounted for approximately 7% of the variance in anxiety, $R^2=.07$.

Parental locus of control was also a significant positive predictor of anxiety, $F(1,228)=14.06$, $p<.001$, indicating that parental locus of control is positively associated with anxiety symptomatology. The overall model accounted for approximately 6% of the variance in anxiety, $R^2=.06$.

Initial Models for Stress

Similar linear regressions were performed separately regressing the predictors of social support, conduct problems, autism symptom severity and parental locus of control on stress. The results for the four separate regressions are shown in Table 13.

Table 13
Regression Statistics for the Four Separate Linear Regressions of Social Support, Conduct Problems, Autism Symptom Severity and Parental Locus of Control on Paternal Stress.

| Variable | b | SE | β | t |
|--|-------|------|---------|----------|
| Regression 1 - Social Support | | | | |
| Social Support | -.35 | .09 | -.26 | -4.03*** |
| Constant | 28.35 | 2.02 | | 14.06*** |
| Regression 2 - Conduct Problems | | | | |
| Conduct Problems | 1.59 | .32 | .32 | 5.01*** |
| Constant | 14.75 | 1.39 | | 10.62*** |
| Regression 3 – Autism Symptom Severity | | | | |
| Autism Symptom Severity | .23 | .13 | .12 | 1.80 |
| Constant | 16.28 | 2.59 | | 6.28*** |
| Regression 4 – Parental Locus of Control | | | | |
| Parental Locus of Control | .17 | .04 | .29 | 4.57*** |
| Constant | 6.02 | 3.30 | | 1.82 |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$

β = standardised value, b = unstandardized estimate, SE = standard error

The results for the four individual regression analyses indicate that social support, conduct problems and parental locus of control, when individually regressed against stress, were significant predictors of stress. However, autism symptom severity, when individually regressed against stress, was not a significant predictor of stress.

Social support was a significant negative predictor of stress, $F(1,228)=16.21$, $p<.01$, indicating that social support is negatively associated with stress symptomatology. The overall model accounted for approximately 7% of the variance in stress, $R^2=.07$.

Conduct problems was a significant positive predictor of stress, $F(1,228)=25.09$, $p<.001$, indicating that conduct problems is positively associated with stress symptomatology. The overall model accounted for approximately 10% of the variance in stress, $R^2=.10$.

Parental locus of control was also a significant positive predictor of stress, $F(1,228)=20.91$, $p<.001$, indicating that parental locus of control is positively associated with stress symptomatology. The overall model accounted for approximately 8% of the variance in stress, $R^2=.08$.

Stepwise Models for Depression

Forward Stepwise Regression was employed to regress 13 predictors - Social Support, Father's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Paternal Involvement, Autism Symptom Severity and Parental Locus of Control – against depression. The statistical criteria for entry was a probability of $F \leq .05$, with the criteria for subsequent

removal probability of $F \geq .1$. Before interpretation, general assumptions of multiple regression were tested for the final model. VIF was less than 10 and Tolerance greater than .2 for all variables indicating an absence of colinearity in data (Bowerman & O'Connell, 1990; Menard, 1995). The Durbin-Watson test indicated that the independence of errors assumption was upheld. Further analysis revealed no evidence of heteroscedasticity, and that distribution of errors was normal. From these analyses the model was deemed to meet the assumptions of multiple regression, and thus the model was accepted.

Only the final step of the model, which reflects the variables found to be significant predictors of depression, are reported below.

At the first step parental locus of control was entered, accounting for approximately 17% of the variance in depression, $R^2=.17$. At the second step, social support was entered accounting for approximately an additional 9% of the variance in depression, $\Delta R^2=.09$. At the third step, perceived limit setting ability was entered, accounting for approximately an additional 4% of the variance in depression, $\Delta R^2=.04$. At the fourth step, satisfaction with parenting was entered, accounting for approximately an additional 2% of the variance in depression, $\Delta R^2=.02$. At the final step, parental locus of control was removed, with the final model accounting for one% less of the variance in depression than model four. $\Delta R^2=-.01$. The final model was a significant predictor of depression, $F(3,225)=33.47, p<.001$, accounting for 31% of the variance in depression, $R^2=.31$. The results for each predictor in the final model from the stepwise regression are shown in Table 14.

Table 14
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Depression.

| Variable | b | SE | β | t |
|---|-------|------|---------|----------|
| Stepwise Regression - Final Step (Step 5) | | | | |
| Social Support | -.42 | .09 | -.29 | -4.93*** |
| Perceived Limit Setting Ability | -.66 | .13 | -.30 | -5.00*** |
| Satisfaction with Parenting | -.37 | .12 | -.19 | -3.11** |
| Constant | 44.65 | 2.94 | | 15.20*** |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$
 b = unstandardized estimate, SE = standard error, β = standardised value

From Table 16, the results indicate that social support, perceived limit setting ability and satisfaction with parenting are all negatively associated with depression symptomatology, and that perceived limit setting ability is marginally the most important predictor in the model.

Stepwise Models for Anxiety

Forward Stepwise Regression was employed to regress 13 predictors -Social Support, Father's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Paternal Involvement, Autism Symptom Severity and Parental Locus of Control - on anxiety. The statistical criteria for entry was the same as for the previous stepwise regression undertaken for the depression variable. Assumption testing was also the same as for the previous analysis, and all results indicated the model met the assumptions of multiple regression, and thus the model was accepted.

At the first step perceived limit setting ability was entered, accounting for approximately 8% of the variance in anxiety, $R^2 = .08$. At the second step, social support was entered, accounting for approximately an additional 4% of the variance in

anxiety, $\Delta R^2=.04$, with aggressive behaviour added at the last step, accounting for approximately an additional 2% of the variance in anxiety, $\Delta R^2=.02$. The final model was a significant predictor of anxiety, $F(3,225)=12.13$, $p<.001$, accounting for 14% of the variance in anxiety, $R^2=.14$. The results for each predictor in the final model from the stepwise regression are shown in Table 15.

Table 15
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Anxiety.

| Variable | b | SE | β | t |
|---|-------|------|---------|---------|
| Stepwise Regression - Final Step (Step 3) | | | | |
| Perceived Limit Setting Ability | -.31 | .13 | -.17 | -2.23* |
| Social Support | -.25 | .07 | -.21 | -3.37** |
| Aggressive Behaviour | 2.19 | 1.05 | .15 | 2.10* |
| Constant | 19.33 | 2.97 | | 6.52*** |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$
b = unstandardized estimate, SE = standard error, β = standardised value

From Table 17, the results indicate that perceived limit setting ability and social support are both negative predictors of anxiety, and aggressive behaviour is a positive predictor of anxiety. Social support is marginally the most important predictor in the model.

Stepwise Models for Stress

Forward Stepwise Regression was employed to regress 13 predictors -Social Support, Father's Age, Economic Support, Age of Child, Hyperactive Behaviour, Aggressive Behaviour, Developmental Age, Conduct Problems, Perceived Limit Setting Ability, Satisfaction with Parenting, Perceived Paternal Involvement, Autism Symptom Severity and Parental Locus of Control - on stress. The statistical criteria

for entry was the same as for the previous stepwise regressions undertaken for depression and anxiety. Assumption testing was also the same as for the previous analyses, and all results indicated the model met the assumptions of multiple regression, and thus the model was accepted.

At the first step perceived limit setting ability was entered, accounting for approximately 16% of the variance in stress, $R^2=.16$. At the second step, social support was entered, accounting for approximately an additional 4% of the variance in stress, $\Delta R^2=.04$. At the third step, father's age was entered, accounting for approximately an additional 3% of the variance in stress, $\Delta R^2=.03$. The final model was a significant predictor of stress, $F(3,225)=21.67, p<.001$, accounting for 22% of the variance in stress, $R^2=.22$. The results for each predictor in the final model from the stepwise regression are shown in Table 16.

Table 16
Regression Statistics for the Final Model in a Stepwise Regression of Predictors on Paternal Stress.

| Variable | b | SE | β | t |
|---|-------|------|---------|----------|
| Stepwise Regression - Final Step (Step 3) | | | | |
| Perceived Limit Setting Ability | -.72 | .12 | -.35 | -5.79*** |
| Social Support | -.28 | .08 | -.21 | -3.50** |
| Father's Age | -.27 | .10 | -.17 | -2.82* |
| Constant | 50.18 | 4.57 | | 10.99*** |

Note: * $p<.05$, ** $p<.01$, *** $p<.001$
b = unstandardized estimate, SE = standard error, β = standardised value

From Table 16, the results indicate that perceived limit setting ability, social support and father's age are all negative predictors of stress. Perceived limit setting ability is the most important predictor in the model.

Section 6.3 – Study Two - Discussion

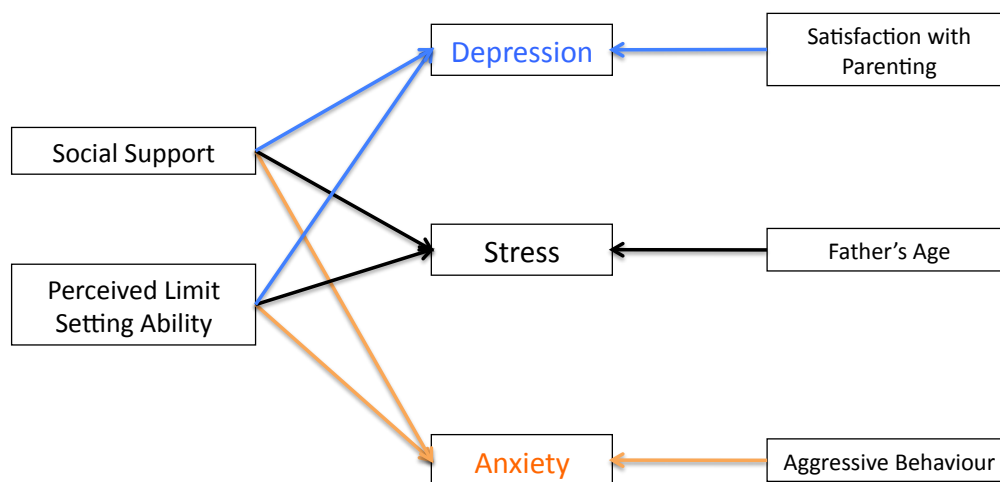
The aim of Study Two was to examine the factors predicting stress, anxiety and depression in the fathers of children with autism, and compare the resultant predictive models with the predictive models for stress, anxiety and depression in the mothers of children with autism. It was hypothesised that conduct problems, autism symptom severity, social support and parental locus of control would significantly predict paternal stress, anxiety and depression when regressed separately from other variables, but that these variables may not predict paternal mental health problems when regressed together with other potential predictors. It was also hypothesised that the predictive models for paternal stress, anxiety and depression would differ from the comparative models for mothers.

The results of Study Two indicated some, but not all, of these hypotheses to be valid. Although conduct problems, social support and parental locus of control did predict paternal stress, anxiety and depression in linear regression analyses, autism symptom severity was shown to be predictive of paternal depression, but not paternal stress or anxiety. Equally, although parental locus of control, autism symptom severity and conduct problems were not significant predictors in any of the stepwise regression analyses undertaken for fathers, social support remained a significant predictor for all three dependent variables, even when regressed together with other potential predictors. However, the predictive models identified for paternal stress, anxiety and depression did differ from the comparative predictive models for mothers. Whereas in mothers the predictive models for stress, anxiety and depression were noticeably different, the predictive models for stress, anxiety and depression in fathers were comparatively consistent.

Based on the results of the analysis undertaken for Study Two, the predictive relationship between the three dependent and 13 independent variables can be described as shown in Figure 2 below.

Figure 2

Proposed Path Diagram Representing the Variables Significantly Predicting Stress, Anxiety and Depression in the Fathers of Children with Autism.



Variables Not Predicting Stress, Anxiety or Depression – Age of Child, Hyperactive Behaviour, Developmental Age, Conduct Problems, Economic Support, Autism Symptom Severity, Perceived Mother-Child Involvement, Parental Locus of Control.

For all three stepwise regression models, for depression, anxiety and stress, the two primary (i.e. most significant) predictors were Social Support and Perceived Limit Setting Ability. In each model, there was one more variable shown to be significant. For depression, this was Satisfaction with Parenting, for anxiety, this was Aggressive Behaviour, and for Stress, this was Father's Age.

The first point to note from these results is that Conduct Problems and Autism Symptom Severity, two variables shown in the existing literature to be significant predictors of paternal mental health problems (Duarte et al., 2005; Hastings &

Johnson, 2001; Lecavalier et al., 2005), were not significant predictors in any model, highlighting the need for an inclusive approach to such analyses. As for mothers, Conduct Problems was shown to be significant predictors of stress, anxiety and depression in the linear regression conducted as part of this study. However, when other variables are included in the analysis, the variance in dependent variables contributed by Conduct Problems is explained by one or more of these other variables.

The linear regression analyses conducted as part of this study indicated that Autism Symptom Severity, whilst a significant predictor of depression, is not a significant predictor of stress or anxiety. It is possible that this finding is reflective of studies that have indicated that other variables, such as maladaptive behaviour, are more predictive of parental mental health problems than autism symptom severity (Davis & Carter, 2008). However, Study One showed a predictive relationship, in the linear regression analyses, between Autism Symptom Severity and maternal stress, anxiety and depression, contradicting Davis and Carter's 2008 study (which argued that autism symptom severity was not a significant predictor of mental health problems in either the mothers or fathers of children with autism). The observed difference between mothers and fathers may, therefore, be more reflective of studies showing a difference between the genders. Rogers (2008) argued that paternal mental health problems are, compared to mothers, less related to the demands of the child with autism, and more related to the emotional state of their partner. The observed result may reflect this finding (although, as with all regressions, the relationship between the independent variables is unclear). The fact that Aggressive Behaviour, a variable shown to predict depression in mothers, is predictive of anxiety in fathers, may also support Rogers' conclusion. Partner's emotional state was not included as a

participant-report variable in this study. However, if included, it may have demonstrated that it is perceived depression in the partner, rather than the Aggressive Behaviour in the child that predicts this, that is more closely associated with paternal anxiety. Of course, this is merely speculation. However, a partner-matched study including both variables would be a good way to investigate this further.

What is clear from these results is that the predictive models for fathers are more consistent than for mothers. Whereas for mothers the models for depression and anxiety were different, and the model for stress was an approximate combination of these, for fathers the same two variables, Social Support and Perceived Limit Setting Ability, were the primary predictors across all three. A number of existing studies have demonstrated that Social Support is a key predictor of paternal mental health problems (Lamminen, 2008; Sharpley et al., 1997). The present study corroborates those findings. As would be expected, social support was shown to be a negative predictor of paternal mental health problems. The less perceived social support received, the greater the ratings of mental health problems. That social support is such a key predictor for fathers may be reflective of Altieri and von Kluge's (2009) study, which showed fathers in matched pairs scored social support as lower than their opposite sex partners. Cognitive factors, or perception of circumstance (rather than circumstance itself), may therefore play a more significant role in predicting paternal mental health problems. The inclusion in all three models of Perceived Limit Setting Ability, a rating of how able fathers are at setting limits for their child, is arguably reflective of this. The result may also shed some light on why Conduct Problems shows up as non-significant in multiple regression models – the problem is less the actual behaviour of the child, and more the father's perception of control over that behaviour. Satisfaction with Parenting, another measure of cognitive factors, was

another significant predictor (in the model for depression). The finding supports the theory that cognitive factors, rather than child-related or environmental factors, are key predictors of paternal mental health problems.

In the model for stress, the final predictor was Father's Age. As for mothers (for whom this variable was predictive of both stress and anxiety), Father's Age was a negative predictor of stress – i.e. the younger the age of the father, the greater the perceived level of stress. As argued in the discussion of Study One, this may be reflective of a number of factors, such as life experience, length of time in a relationship and emotional maturity. However, it may also be reflective of Fiske's (2009) study, which showed that paternal stress is significantly affected by the long-term impact of their child's diagnosis (Fiske argued that this is a differentiator between mothers and fathers). The younger the father, the greater the perceived impact on their idealised future. Older fathers may feel they have had a chance to fulfil life goals prior to the birth of their child, and this may be a protective factor against stress. Again, this is purely conjecture. However, the fact that parental age has been shown to be a negative predictor of mental health problems for both mothers and fathers indicates that this is an area worthy of further research.

Chapter 7 - Study Three – Towards A Predictive Model of Psychological Distress in the Parents of Children of Autism

Studies One and Two have demonstrated that the factors predicting stress, anxiety and depression in the parents of children with autism vary by both mental health condition and gender. However, although multiple regression studies provide a good insight into the factors predicting mental health problems in this parental group, regression analysis cannot provide an insight into the relationship between independent variables.

In their 1987 paper analyzing the psychosocial predictors of depression using data from the 1965 US Human Population Survey, Kaplan, Roberts, Camacho and Coyne noted the multifactorial nature of depression and the complexity of the relationships between the various social, economic and environmental variables that were shown to be predictive of depression. Although multiple regression analysis can provide insight into the primary predictors of parental mental health problems, support services targeting solely those predictors shown to be significant will be limited in their efficacy. Although variables such as Conduct Problems were not shown to be significant predictors in stepwise regression analyses, externalizing behaviours still have a role to play, as evidenced by both the existing literature (Civick, 2008; Gray, 2003; Lecavalier et al., 2005) and the linear regressions undertaken in Studies One and Two.

What then is the relationship between externalizing behaviours and mental health problems in the parents of children with autism? The results of Study One and Two would indicate that a linear relationship, in the presence of other predictors, may not exist. It is therefore possible that one or more of these other predictors is

mediating the relationship between externalizing behaviours and parental health problems. The purpose of this study is to analyse the relationship between the various variables shown to be influencing parental mental health problems, and test the statistical validity of a model describing this relationship.

Based on the existing literature, there are three main groups of variables that influence the severity of mental health problems in the parents of children with autism. These three groups of variables are autism symptom severity (Duarte et al., 2005; Hastings & Johnson, 2001); externalizing behaviours (Civick, 2008; Gray, 2003; Lecavalier et al., 2005; and socio-economic support (Gray & Holden, 1992; Lamminen, 2008; Lee, 2009). Studies One and two have demonstrated that parental cognitions related to parental locus of control and the perceived parent-child relationship (in particular perceived limit-setting ability) also have a role to play.

Using the data collected for Studies One and Two, and in the context of formulating a model to statistically test the relationship between observed variables, the four groups of predictive variables described above, namely autism symptom severity, externalizing behaviours, socio-economic support and parental cognitions, can be represented as follows:

Autism symptom severity can be described using the four core factors of the Social and Communication Questionnaire (Berument et al., 1999). These four factors are Communication, Social Interaction, Abnormal Language and Stereotyped Behaviour. The scores for each factor for mothers and fathers are shown in Table 17.

Table 17

Factor Statistics by Gender for the Social and Communication Questionnaire (SCQ)

| Factor | Mothers | | Fathers | |
|-----------------------|---------|-------|---------|------|
| | SD | Mean | SD | Mean |
| Social Interaction | 4.61 | 10.32 | 4.09 | 9.52 |
| Communication Skills | 1.53 | 2.78 | 1.64 | 2.80 |
| Abnormal Language | 1.72 | 2.92 | 1.91 | 2.45 |
| Stereotyped Behaviour | 1.83 | 5.18 | 1.97 | 5.06 |

Externalizing behaviours can be described using Conduct Problems and Hyperactive Behaviour, the two variables assessed using the Strength and Difficulties Questionnaire (Goodman, 1997), and the Aggressive Behaviour variable, authored by the study investigator.

Socio-economic support can be described using the Social Support and Economic Support variables authored by the study investigator. Parental cognitions can be described using the Parental Locus of Control score, taken from the Parental Locus of Control Scale (Campis et al., 1986), and Satisfaction with Parenting, Involvement with Child and Perceived Limit Setting Ability, scores taken from the Parent-Child Relationship Inventory (Gerard, 1994).

Parental distress can be described using the three factors of the Depression Anxiety Stress Scales (Lovibond & Lovibond, 1995), Depression, Anxiety and Stress. In formulating a model to test the relationship between variables, the items detailed above were used to describe five latent factors, Autism Symptom Severity, Externalizing Behaviours, Socio-economic Support, Parental Cognitions and Parental Distress. Based on initial analysis of factor loadings, a number of variables had to be

discarded. Abnormal Language and Stereotyped Behaviour were shown not to load (based on a factor loading cut-off of .4 or above) onto the latent factor 'Autism Symptom Severity'. Hyperactive Behaviour was shown not to load onto the latent factor 'Externalizing Behaviours', and Satisfaction with Parenting and Involvement with Child were shown not to load onto the latent factor 'Parental Cognitions.'

In proposing a model describing the relationship between these five latent factors, the results of Study One and Two were used. Autism symptom severity, as measured by the total Social and Communication Questionnaire score (Berument et al., 1999), was shown to be predictive of anxiety and stress but not depression in mothers, and was not predictive of any mental health variable in fathers. Externalizing behaviours was also shown, for the most part, not to be a significant predictor in the regression analyses. Although Aggressive Behaviour was a significant predictor of depression in mothers and anxiety in fathers, it was not a significant predictor in the other four stepwise regression models (stress and anxiety in mothers, and depression and stress in fathers). Conduct Problems, as stated earlier, was not a significant predictor for any mental health variable in mothers or fathers.

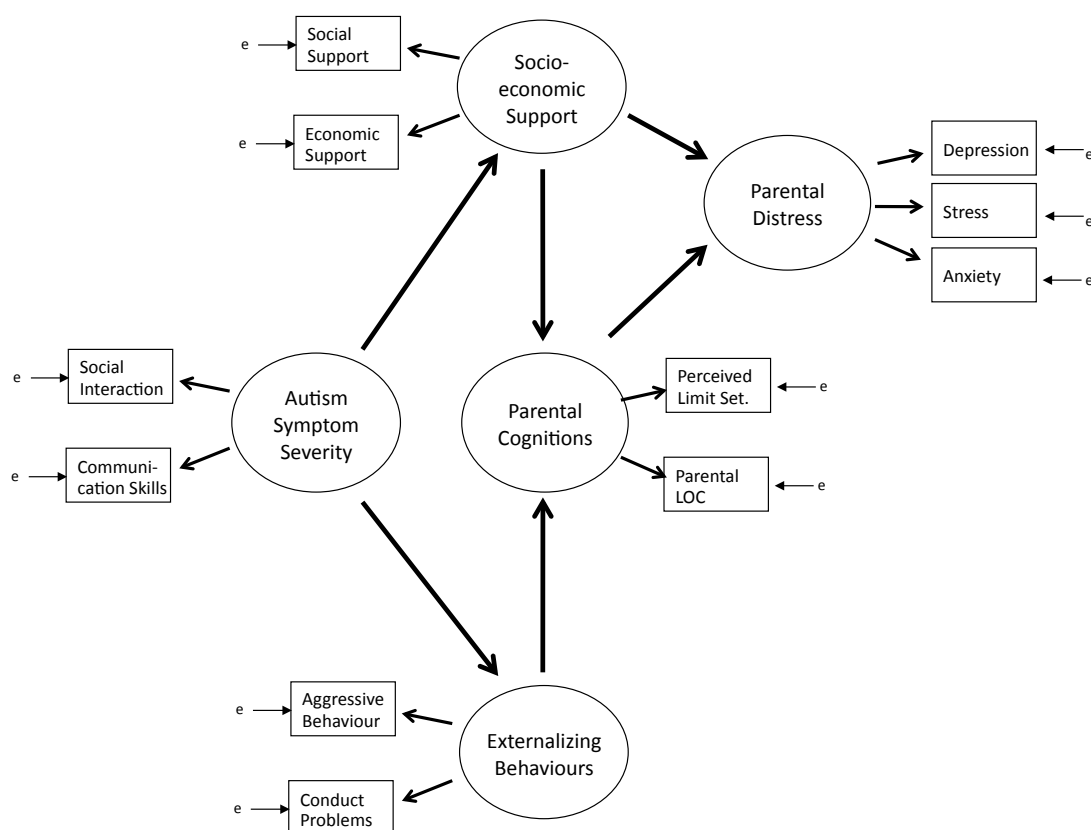
In contrast, Social Support was shown to be a significant predictor in five of the six stepwise regression models, the exception being anxiety in mothers. Parental cognitions were also shown to be a key predictor of parental mental health problems. Perceived Limit Setting Ability was shown to be a significant predictor in five of the six stepwise regression models. The exception was depression in mothers, for which Parental Locus of Control, another measure of parental cognitions, was shown to be a significant predictor.

Based on these results, it is possible that parental cognitions and socio-economic support are mediating the relationship between both externalizing behaviours and autism symptom severity and parental distress. If this was shown to be the case, it would have significant implications for parental support services. Currently parent support services tend to focus on the child, providing strategies to help the parent manage externalizing behaviours, and providing psychoeducation on autism and its behavioral and developmental implications (Keen, 2010; Tonge et al., 2006). However, it may be that such support is leaving a key area of need unmet. Neither Keen nor Tonge et al. include psychotherapeutic support for the parent as a component of their intervention programs. As reported by a mother who commented on the Facebook site set up for the study, *‘Why is it always about my child? I don’t always want to talk about my child. Health professionals seem to forget that I exist independent of my child.’*

Based on the assumption that parental cognitions and socio-economic support mediates the relationship between ‘child-centric’ variables (i.e. autism symptom severity and externalizing behaviours) and parental psychological distress, the following model (Figure 3) is proposed as being a good fit with the observed data (i.e. the data collected for mothers and fathers of children with autism as part of Studies One and Two.)

Figure 3

Model ('Model A') Describing the Relationship Between Parental Distress and Predictive Variables in the Parents of Children with Autism



Note: Perceived Limit Set. = Perceived Limit Setting Ability; Parental LOC = Parental Locus of Control.

The proposed model, as shown in Figure 3, consists of 5 latent factors, Parental Distress, Socio-economic Support, Parental Cognitions, Externalizing Behaviours and Autism Symptom Severity. Parental Distress is associated with three indicators, Stress, Anxiety and Depression; Socio-economic Support is associated with two indicators, Social Support and Economic Support; Parental Cognitions is associated with two indicators, Perceived Limit Setting Ability and Parental Locus of Control; Externalizing Behaviours is associated with two indicators, Aggressive

Behaviour and Conduct Problems; Autism Symptom Severity is also associated with two indicators, Social Interaction and Communication Skills. Parental Distress is predicted by Socio-economic Support and Parental Cognitions; Parental Cognitions is predicted by Socio-economic Support and Externalizing Behaviours; Socio-economic Support and Externalizing Behaviours are both predicted by Autism Symptom Severity. There is no correlation between error terms and no cross-loading of indicators.

The model described in Figure 3 assumes no direct relationship between parental distress and either autism symptom severity or externalizing behaviours, based on the assumptions stated earlier in this Introduction. The model assumes that autism symptom severity is predictive of both externalizing behaviours and lower scores on measures of socio-economic support, based on existing studies focused on the relationship between these variables (Gray & Holden, 1992; Macintosh & Dissayanake, 2006; Lamminen, 2008). Lastly, based on the results of the regression analyses undertaken in Studies One and Two, the model assumes that externalizing behaviours and socio-economic support are predictive of negative parental cognitions, and that it is these negative parental cognitions, along with perceived socio-economic support, that predict parental distress.

The relationship between autism symptom severity and externalizing behaviours is already documented in the existing literature. In a chronological and mental age-matched study of 20 children with high-functioning autism, 19 children with Asperger's Syndrome and 17 developmentally normal children, Macintosh and Dissanayake (2006) demonstrated that children with autism (and Asperger's Syndrome) exhibited more problematic externalizing behaviours than children in the developmentally normal group. It has also been demonstrated in the literature that

parents of children with autism report lower scores on scales of socio-economic support than parents of developmentally normal children (Gray & Holden 1992; Lamminen, 2008). What the model in Figure 3 proposes is that the relationship between these variables and parental distress is mediated, partially in the case of socio-economic support, and fully, in the case of externalizing behaviours, by parental cognitions. Should this model be shown to be a good fit with the observed data (for mother, fathers or both), it would suggest a new approach is needed to support this parental group – a focus on psychotherapeutic support for the adult rather than solely parental training related to the child.

An additional aim of the study, if the model was shown to be a good fit for both mothers and fathers, was to test for invariance between the two groups. If it can be shown that the model has, at minimum, structural invariance across gender, it can arguably be concluded that the model forms a useful basis for informing support services targeting this specific parental group.

Section 7.1 – Study Three – Method

Participants for this study were the same as those used for Studies One and Two ($N = 250$ for mothers and $N = 229$ for fathers). MPlus's (Version 6.1, Muthén & Muthén, 2010) maximum likelihood estimation extraction procedure was used to evaluate Model A and Model B for mothers and fathers.

Overall model fit was determined with the chi-square statistic (χ^2), the comparative fit index (CFI; Bentler, 1990), and the root-mean-square error of approximation (RMSEA; MacCallum, Browne & Sugawara, 1996). As this study incorporated a large sample size ($N=250$ for mothers; $N=229$ for fathers), it is likely

that the χ^2 score for model fit will be significant (indicating poor model fit). χ^2 values are almost always significant with large samples sizes (Brown, 2006). It is postulated, therefore, that the CFI and RMSEA scores will provide better assessments of model fit. CFI and RMSEA scores range from 0.00 to 1.00. A CFI value of close to or above .95 (with a minimum acceptable value of .90) and an RMSEA value of close to or below .06 (with a maximum acceptable value of .08) are considered necessary to conclude that there is a relatively good fit between the hypothesized model and the observed data (Hu & Bentler, 1999).

Invariance and partial invariance testing between models for mothers and fathers was evaluated using MPlus's (Version 6.1, Muthén & Muthén, 2010) robust maximum likelihood estimation extraction procedure. Comparative fit between models was determined using the Satorra-Bentler chi-square difference test ($\Delta SB\chi^2$; Satorra & Bentler, 2001). The Satorra-Bentler chi-square difference test was undertaken using the 'sbdiff' software program (Crawford, 2007).

Section 7.2 – Study Three – Results

Model Fit Indices

The model fit statistics for the five factor path model of parental distress (Model A) are shown in Table 18.

Table 18

Model Fit Indices for Model A for Mothers and Fathers of Children with Autism

| Models | <i>df</i> | χ^2 | CFI | RMSEA |
|-------------------|-----------|----------|-------|-------------------------------|
| Model A – Mothers | 38 | 63.89** | 0.974 | 0.052 (0.028- 0.074)*** |
| Model A – Fathers | 38 | 82.91* | 0.954 | 0.072 (0.051- 0.093)*** |

Note: * $p < .001$; ** $p < .01$ ***90% confidence interval range for RMSEA scores.
df: degrees of freedom; χ^2 : chi-squared scaled statistic; CFI: comparative fit index; RSMEA: robust root mean-square error of approximation

For both mothers and fathers, the χ^2 score was significant ($p < .001$ for fathers and $p < .01$ for mothers), indicating poor model fit. However, as χ^2 values are nearly always significant with large samples (Brown, 2006), it was judged that the CFI and RMSEA scores provided more accurate assessments of model fit.

For mothers, the CFI estimate was 0.974, above both the acceptable lower limit of 0.90 and the recommended cut-off of 0.95, and the RMSEA estimate was 0.052, below both the acceptable upper limit of 0.08 and the recommended cut-off of 0.06. These results would indicate that Model A is a good fit with the observed data for mothers.

For fathers, the CFI estimate was 0.954, above both the acceptable lower limit of 0.90 and the recommended cut-off of 0.95, and the RMSEA estimate was 0.072, below the acceptable upper limit of 0.08 but above the recommended cut-off of 0.06. These results would indicate that Model A is also a good fit with the observed data for fathers.

Factor Loadings

The factor loadings and factor prediction estimates for Model A for mothers, using standardized scores, are shown in Table 19.

Table 19
Factor Loading and Factor Prediction Estimates for Model A for Mothers of Children with Autism.

| Factor | Observed Variable | Estimate | SE | Estimate/SE |
|--------------|---------------------------------|----------|------|-------------|
| AUT | Social Interaction | 0.91 | 0.09 | 10.62* |
| | Communication Skills | 0.60 | 0.07 | 8.65* |
| EXTB | Conduct Problems | 0.88 | 0.04 | 20.10* |
| | Aggressive Behaviour | 0.69 | 0.05 | 14.96* |
| PCOG | Perceived Limit Setting Ability | 0.81 | 0.04 | 19.76* |
| | Parental Locus of Control | -0.72 | 0.04 | -16.71* |
| SOCS | Social Support | 0.94 | 0.12 | 9.02* |
| | Economic Support | 0.58 | 0.08 | 7.63* |
| PDIS | Depression | 0.81 | 0.03 | 26.55* |
| | Anxiety | 0.76 | 0.03 | 23.06* |
| | Stress | 0.89 | 0.03 | 34.56* |
| SOCS on AUT | | -0.28 | 0.08 | -3.60* |
| EXTB on AUT | | 0.38 | 0.08 | 4.92* |
| PCOG on SOCS | | 0.18 | 0.06 | 2.90** |
| PCOG on EXTB | | -0.69 | 0.06 | -12.37* |
| PDIS on PCOG | | -0.52 | 0.06 | -8.36* |
| PDIS on SOCS | | -0.16 | 0.06 | -2.58*** |

Note: * $p < .001$; ** $p < .01$; *** $p < .05$

AUT: Autism Symptom Severity; EXTB: Externalizing Behaviours; PCOG: Parental Cognitions; SOCS: Socio-Economic Support; PDIS: Parental Distress.

The results indicate that for all five latent factors (Autism Symptom Severity, Externalizing Behaviours, Parental Cognitions, Socio-economic Support and Parental Distress), factor loadings for all respective observed variables were significant ($p < .001$). Parental Locus Of Control, with a higher score indicating a more externalized

locus of control, loaded negatively onto Parental Cognitions, as would be expected from theory (Perceived Limit Setting Ability, with a higher score indicating a higher perceived ability to set limits for the child with autism, loaded positively onto this latent factor). All other factor loadings were positive.

All predictive pathways included in the model were significant ($p < .05$ or lower). Socio-economic support was negatively predicted by Autism Symptom Severity (i.e. the higher the autism symptom severity, the lower the perceived level of socio-economic support); Externalizing Behaviours was positively predicted by Autism Symptom Severity (i.e. the higher the autism symptom severity, the higher the reported severity of maladaptive behaviours); Parental Cognitions was positively predicted by Socio-economic Support (i.e. the higher the perceived level of socio-economic support, the more 'positive' the parental cognitions); Parental Cognitions was negatively predicted by Externalizing Behaviours (i.e. the higher the reported severity of maladaptive behaviours, the more 'negative' the parental cognitions); and Parental Distress was negatively predicted by both Socio-economic Support and Parental Cognitions (i.e. the higher the perceived level of socio-economic support and the more 'positive' the parental cognitions, the lower the reported levels of parental distress).

The factor loadings and factor prediction estimates for Model A for fathers, using standardized scores, are shown in Table 20.

Table 20

Factor Loading and Factor Prediction Estimates for Model A for Fathers of Children with Autism.

| Factor | Observed Variable | Estimate | SE | Estimate/SE |
|--------------|---------------------------------|----------|------|-------------|
| AUT | Social Interaction | 0.83 | 0.14 | 5.95* |
| | Communication Skills | 0.66 | 0.12 | 5.72* |
| EXTB | Conduct Problems | 0.86 | 0.04 | 23.54* |
| | Aggressive Behaviour | 0.76 | 0.04 | 19.12* |
| PCOG | Perceived Limit Setting Ability | 0.92 | 0.04 | 25.04* |
| | Parental Locus of Control | -0.66 | 0.05 | -14.38* |
| | | | | |
| SOCS | Social Support | 1.14 | 0.20 | 5.59* |
| | Economic Support | 0.46 | 0.10 | 4.74* |
| PDIS | Depression | 0.86 | 0.03 | 31.85* |
| | Anxiety | 0.80 | 0.03 | 26.09* |
| | Stress | 0.85 | 0.03 | 31.45* |
| SOCS on AUT | | -0.19 | 0.08 | -2.38*** |
| EXTB on AUT | | 0.16 | 0.08 | 1.90 |
| PCOG on SOCS | | 0.10 | 0.05 | 1.90 |
| PCOG on EXTB | | -0.78 | 0.05 | -16.53* |
| PDIS on PCOG | | -0.46 | 0.06 | -7.11* |
| PDIS on SOCS | | -0.25 | 0.08 | -3.29** |

Note: * $p < .001$; ** $p < .01$; *** $p < .05$

AUT: Autism Symptom Severity; EXTB: Externalizing Behaviours; PCOG: Parental Cognitions; SOCS: Socio-Economic Support; PDIS: Parental Distress.

The results indicate that for all five latent factors (Autism Symptom Severity, Externalizing Behaviours, Parental Cognitions, Socio-economic Support and Parental Distress), factor loadings for all respective observed variables were significant ($p < .001$). Similarly to the results for mothers, all factor loadings were positive with the exception of Parental Locus of Control, which loaded negatively onto the Parental Cognitions latent factor.

The predictive pathways included in the model were not all significant ($p < .05$ or lower). Externalizing Behaviours was not significantly predicted by Autism Symptom Severity, and Parental Cognitions was not significantly predicted by Socio-economic Support. All other predictive relationships were significant. Socio-economic support was negatively predicted by Autism Symptom Severity; Parental Cognitions was negatively predicted by Externalizing Behaviours; and Parental Distress was negatively predicted by both Socio-economic Support and Parental Cognitions.

Measurement and Structural Invariance Across Gender

The results of measurement and structural invariance tests for Model A across gender are shown in Table 21.

Table 21

Measurement and Structural Invariance Tests for Model A across Gender (Mothers and Fathers)

| Model and Invariance Level | Overall Fit Indexes | | | | Model comparison | Comparative Fit Indexes | |
|---|---------------------|------|-------|------|------------------|-------------------------|-------------------|
| | SB χ^2 | df | RMSEA | CFI | | Δdf | $\Delta SB\chi^2$ |
| Mothers ($N = 250$) and Fathers ($N = 229$) | | | | | | | |
| M1 - Configural Invariance | 148.18* | 76 | .062 | .964 | - | - | - |
| M2 - Metric Invariance | 158.21* | 82 | .061 | .962 | M2 vs M1 | 6 | 9.91 |
| M3 - Scalar Invariance | 453.45* | 88 | .129 | .821 | M3 vs M2 | 6 | 364.45* |

Note: * $p < .001$

df = degrees of freedom; SB χ^2 = Satorra-Bentler chi-squared scaled statistic; CFI = comparative fit index; RMSEA = root mean-square error of approximation; Δ = difference between the comparison and nested model.

For all models, the SB χ^2 of overall model fit was significant. However, as χ^2 values are nearly always significant with large samples (Brown, 2006), it was judged that the CFI and RMSEA scores provided more accurate assessments of model fit.

CFI and RMSEA values for the configural (form) invariance and metric (weak) invariance models indicated good fit with the observed data (above .95 for the CFI and below .08 for the RMSEA). However, the CFI and RMSEA estimates for the scalar (strong) invariance model indicated poor fit with the observed data.

The Satorra-Bentler chi-squared difference test score for the metric invariance model was non-significant ($p > .05$), providing support for measurement invariance for Model A across gender at the weak invariance level. However, the Satorra-Bentler chi-squared difference test score for the scalar invariance model was significant ($p < .001$), indicating that Model A does not demonstrate measurement invariance across gender at the strong invariance level.

Section 7.3 – Study Three – Discussion

The aims of this study were to test the validity of a path model describing the predictors of stress, anxiety and depression in the parents of children with autism. The primary hypothesis was that the relationship between the ‘child-centric’ variables (i.e. autism symptom severity and externalizing behaviours) and parental psychological distress would be mediated by socio-economic support and parental cognitions. The secondary hypothesis was that the proposed model (Model A) would demonstrate structural invariance across gender.

The results of the study provide support for both hypotheses. The proposed model (Model A) was a good fit with the observed data for both the mothers and fathers of children with autism, and demonstrated both structural (form) and weak (metric) invariance across gender. Model A, as shown in Figure 3, describes four latent factors that predict psychological distress in the parents of children with autism.

It also describes a predictive relationship between those factors in which autism symptom severity and child externalizing behaviours, two variables indicated in the literature to have a direct relationship with parental stress, anxiety and/or depression (Civick 2008; Gray, 2003; Hastings & Johnson, 2001; Lecavalier et al., 2005), are in fact mediated by socio-economic support and parental cognitions.

Analysis of the model indicated good fit with the observed data for both mothers and fathers. However, although the model showed invariance by gender at the structural and weak measurement level, the data also demonstrated clear differences in the perceived experiences of mothers and fathers parenting a child with autism. The data for fathers, for example, demonstrated a non-significant predictive relationship between autism symptom severity and externalizing behaviours. As all the data collected for this study was parent-report, it indicates that fathers may view their child's externalizing behaviours as being partially unrelated to the child's diagnosis of autism (unlike mothers, who arguably perceive a direct relationship between the two). Of course, this is purely speculation, and there is no current literature investigating the validity of this distinction. However, such a distinction would provide some insight into why paternal stress, anxiety and depression are all significantly predicted by Perceived Limit Setting Ability. Fathers may perceive that they 'should' be able to control their children's behaviour, and a perceived failure to be able to do so may be a key predictor of psychological distress. The data for fathers also indicated a non-significant predictive relationship between socio-economic support and parental cognitions, whereas for mothers this relationship was significant. Fathers of children with autism have been shown to perceive themselves to be more socially isolated than their partners (Altiere & von Kluge, 2009), so this result may indicate that the negative cognitions experienced by fathers (those cognitions

predictive of psychological distress) are less associated with social support than the negative cognitions of mothers – i.e. increasing the levels of social support made available to families may be more effective in reducing psychological distress in mothers than fathers. It should be noted, however, that this is purely speculation.

The proposed model does, however, provide a good groundwork for developing a clearer understanding of the experience of parenting a child with autism. The model highlights that a direct relationship between autism symptom severity and parental distress does not exist, and that services aimed at supporting this parental group needs to focus as much on the parent as they do on the child. Even if a parent is provided with the practical knowledge they need to manage their child's behaviours, this may not change their internal schema of themselves and their perceived relationship with their child. And it may also be that their distress is unrelated to their child – it may be related to their sense of loss about their lives (Myers, 2009), their sense of social isolation (Wright & Williams, 2007) or their perceived inability to adapt to an altered relationship dynamic with their partner (Rogers, 2008). Understanding the problem requires an understanding of the parental experience. Without this understanding, support services will remain, as reported by one parent on the Facebook site set-up for this study, '*...totally alienating. I was made to feel useless at being a good mother and guilty about not caring if I was a good mother or not. No one understands what it is like...*'

Chapter 8 - Thesis Conclusions - Defining the Problem

Structuring a definitive model to describe parental depression, stress and anxiety for any parental group would be an impossible task. The number of environmental, genetic, personal and existential variables that predict, protect against, maintain and counteract mental health problems varies at the personal level. Every person is an individual, and as such every person's experience of parenthood will be different. However, if support services are to be of help to parents, they must be reflective of that parent's first-hand experience, not society's perception of that experience.

The need for tailored support services is especially true for parents of children with autism. Although the existing literature has demonstrated that these parents experience more mental health problems than other parental groups (Benjak, 2009; Bitsika & Sharpley, 2004; Micali et al., 2004), the interventions designed to support this parental group generally assume these mental health problems primarily relate to the practical challenges of parenting a child with autism (Keen, 2010; Tonge, 2006). However, although behavioural management training programs such as those described by Keen (2010) and Tonge et al. (2006) have been demonstrated to be effective in the short-term, providing longer term support to parents of children with autism requires a more holistic approach.

Research focused on understanding the elevated levels of mental health problems in this parental group have also erred on the side of specificity. Although a number of studies exist that focus on the predictors of mental health problems in the parents of children with autism (Bitsika & Sharpley, 2004; Civick, 2008; Farrugia, 2005; Fiske, 2009; Hastings & Johnson, 2001; Lecavalier et al., 2005), the majority of

these studies focus on a small subset of predictive variables and a single dependent variable (usually stress, anxiety or depression). Although certainly valuable research, what these studies do not provide is a holistic view of the experience of parenting a child with autism, and the overall dynamics between variables that is predictive of, or protective against, mental health problems. Although social support (Gray & Holden, 1992; Lamminen, 2008), child externalizing behaviours (Gray, 2003; Lecavalier et al., 2005), and autism symptom severity (Hastings & Johnson, 2001; Duarte et al., 2005) have been shown to significantly predict stress, anxiety or depression in the parents of children with autism when assessed aside from other possible predictors, that does not mean these variables will be predictive of stress, anxiety *and* depression in this parental group, or that these variables will demonstrate a linear predictive relationship in the presence of other possible predictors.

If research is to provide a starting point for the development of parental support services, then this lack of a holistic view is a problem. Parents who present to services are not uniform in their presentation – some may present with stress, some with depression and some with a complex combination of symptoms spanning two or more possible diagnoses. Additionally, parents in the real world will be affected by a diverse and changeable set of potentially contributory factors. Although, in this parental group, having a child with autism is an obvious common denominator, the contribution of other environmental, personal and situational factors will be multifaceted and specific to the individual. Therefore this study, in aiming to provide a groundwork for structuring relevant support services, takes a more inclusive approach. It looks at all three of the major mental health problems parents tend to present with – stress, anxiety and depression - and includes a wide range of potential predictors in the analysis. The included subset of predictors still remains limited. It

would be difficult for any study to include all the variables that could potentially contribute to parental mental health problems. However, by being as inclusive as possible (and by ensuring the selection of predictors is based on empirical findings), this study aimed to provide a holistic view of not only the key predictors of mental health problems in the parents of children with autism, but also the relationship between those predictors.

Section 8.1 – Thesis Conclusions - The Study Population

Some of the existing studies assessing the predictors of mental health problems in the parents of children with autism have recruited participants presenting to support services (Duarte et al., 2005; Hastings & Johnson, 2001), creating a potential skew in the study population. Many parents will not present to support services, irrespective of whether or not they would benefit from support. Thus the present study aimed to recruit parents direct from the community, and as such recruited via Facebook, a widely used social media network. As of April 2010, when recruitment to this study was initiated, an estimated 41.6% of the US population had a Facebook account (Wells, 2010). The current study recruited internationally, and limited its participants solely based on whether or not they had one or more children of school age (4 to 17 years 11 months) with a diagnosis of autism.

However, even using this inclusive approach to recruitment, there remains a notable bias in participant selection. Recruitment via Facebook occurred through promotion of study-specific Facebook Web-pages (one for mothers and one for fathers) by autism advocacy and community groups with a Facebook presence (such as Autism Tasmania (www.autismtas.org.au); Autism Victoria

(www.autismvictoria.org.au); the Olga Tennison Autism Research Centre at La Trobe University, Melbourne (<http://www.latrobe.edu.au/otarc/centre.html>); the National Autistic Society, UK (www.autism.org.uk); the National Autism Association, US (www.nationalautismassociation.org); the Autism File magazine (www.autismfile.com) and Carers UK (www.carersuk.org.) Thus parents recruited to the study were primarily those with an active awareness of one or more of these Facebook-based information or advocacy groups, and thus, arguably, had an active interest in either learning about autism or interacting with other families or professionals with experience of autism. Evidence of this potential ‘skew’ can be found in the percentage of participants who reported being a primary carer for their child with autism – 99% of mothers and 43% of fathers. The study population therefore reflects those parents taking an active role in the care of their children, and is not as representative of parents who are less actively involved with their child with autism. The predictors of mental health problems in parents less actively involved with their child may be different to the predictors of mental health problems in those closely involved in childcare. When drawing conclusions from the study results, this needs to be taken into account.

The study demographic data reveals some other interesting features of the study population. Sixty-six percent of mothers reported a past or present mental health diagnosis for themselves, compared to only forty percent of fathers. However, according to the cut-offs for depression and anxiety provided for the Depression, Anxiety and Stress Scales (DASS; Lovibond & Lovibond, 1995) of 10 or above for depression and 8 or above for anxiety, seventy-four percent of participating mothers and sixty-five percent of fathers reported mild or greater levels of depression, and sixty-seven percent of mothers and fifty-three percent of fathers reported mild or

greater levels of anxiety. It is arguable that this indicates that there is a comparative underdiagnosis of mental health problems in fathers, and that fathers are therefore potentially receiving less support from mental health professionals than mothers. As both depression and anxiety can be associated with negative cognitions related to the self and perceptions of isolation from others, this may contribute to the finding reported by Altieri and von Kluge (2009) that fathers report lower levels of social support, and greater levels of social isolation, than their partners.

Another interesting finding from the demographic data is that both fathers and mothers report a comparatively high proportion of children with autism being the oldest child (40% in participating mothers; 41% in participating fathers). To provide a comparison, only 28% were reported by mothers as being the youngest child (24% by fathers). Although not a statistically significant difference, a possible conclusion that can be drawn from this is that when parents have a child with autism, they will often choose to have additional children. The qualitative feedback collected as part of this study indicates that parents experience a sense of grief or loss after having a child with autism. Based on comments submitted by participants, this sense of grief relates to the expectations they had prior to becoming a parent, and the belief that those expectations will never be fulfilled. In order to cope with this, parents may try for additional children to ‘make up’ for what they perceive they have lost. . As one mother commented on the Facebook Website for this study. *‘I am glad to find this site because I was feeling alone myself. Having to block the world out because they don't understand why my kid is happily screaming. Knowing that other mothers do not accept my children or me in their happy friendship circle and play group activities. I have gotten used to (being) hurt and excluded, but it is still painful. Sometimes I think*

I should have another child, just so I can be a normal Mum and be accepted. But then I hate myself for thinking that.'

Section 8.2 – Thesis Conclusions - Study One Results

The results of the linear regressions conducted as part of Study One indicated that stress, anxiety and depression in the mothers of children with autism are significantly predicted by conduct problems (Gray, 2003; Lecavelier et al., 2005), social support (Gray & Holden, 1992; Lamminen, 2008) and autism symptom severity (Duarte et al., 2005; Hastings & Johnson, 2001), when these predictors are regressed individually against each mental health variable. The results also showed that parental locus of control, a factor shown to predict mental health problems in the parents of children with an intellectual disability (Hassall, Rose & McDonald, 2005), is a predictor of stress, anxiety and depression in the mothers of children with autism.

The results of the stepwise regression analysis for mothers, however, indicated a clear difference in the predictors for anxiety and depression. Whereas anxiety was predicted by maternal age, the mother's perceived ability to set behavioural limits for their child and autism symptom severity, depression was predicted by the child's aggression towards adults, a perceived lack of social support and an externalized parental locus of control. The observed result has arguably significant implications for parental support services. When a mother of a child with autism presents with depression, the underlying contributors to the problem will not necessarily be the same as a mother of a child with autism presenting with anxiety. However, although the pattern of predictors between depression and anxiety is clearly different, there is

still, arguably, a core theme central to both, and that is ‘perception of control.’

Although Parental Locus of Control and Perceived Limit Setting Ability are measuring different phenomena – the former describing a perception of parental influence over their child’s emotional and behavioural development and the latter specific to a perceived ability to set limits on maladaptive behaviour patterns – they are still measures of parental perception of control. And in both situations, where the parent perceives they do not have a direct (or sufficient) influence over their child, it is predictive of elevated mental health problems.

What is key here is the word ‘perception.’ Neither variable is measuring whether the parent actually has an appropriate level of influence or behavioural control over their child(ren). The variables are measuring the parent’s perception of that control. Some of the comments left on the study Facebook page provide some insight into this difference. One mother commented that *‘I get very depressed. My three sons are on the spectrum. My youngest doesn't speak much and has Hypotonia and he seems so unhappy. And I feel so guilty because I should be able to help him. I feel like such a bad mother.’* Another mother commented *‘dont you just hate it when your child has a tantrum in a supermarket and everyone looks, and then we shout and say 'what, he has autism' and then they smile and walk off. They dont even bother to ask you what is autism, and its pointless anyway because there's nothing you can do.’*

Parents of children with autism face challenges not commonly experienced by other parents. As noted in the introduction to this study, children with autism can be difficult to understand, due to their atypical personal responsiveness (Busch, 2009) and demonstrate more maladaptive externalizing behaviours than developmentally normal children (Macintosh & Dissanayake, 2006). Thus the results of effective, consistent parenting in a child with autism may be difficult to assess. Parents who are

in fact managing to set limits and assist their child's emotional development may not receive clear reinforcement, in terms of 'positive' changes in their child's behaviour or demeanour. Thus they may start to perceive themselves as being ineffective parents. Providing these parents with additional means of managing behaviour (i.e. behavioural management plans) may not make a significant difference. If the parent already perceives themselves as ineffectual, new behavioural management plans, even if effectively practiced, may not change this perception. And, as noted by Schieve et al. (2007), parents who perceive themselves as ineffectual (and suffer from associated depression and anxiety) may lack the motivation to comply with behavioural management recommendations in the first place.

There are two primary conclusions, therefore, that can arguably be drawn from the results of Study One. The first is that mothers with different mental health presentations are being affected by a different pattern of contributory factors. Thus applying a 'one size fits all' intervention focused on behavioural management for the child may not be effective. The second conclusion is that the child's autism symptomology and externalizing behaviours, although certainly related to maternal mental health problems, are not the core predictor of maternal psychological distress. The core predictor, and the main focus of any successful intervention, is maternal cognitions. A limitation of this study is that it only measured cognitions related to parenting. It may be that cognitions unrelated to parenting (e.g. general locus of control and not just parental locus of control) would be just as significant in predicting mental health problems in this maternal group. However, until this research is undertaken, cognitions related to parenting, and more specifically to perceptions of control, should be a central focus for interventions looking to reduce maternal stress, anxiety and depression. Acceptance and Commitment Therapy, as an example, has

been demonstrated to be effective in helping parents of children with autism cope with negative cognitions (Blackledge & Hayes, 2006). Providing parenting skills training without challenging the underlying belief systems related to the ability to implement those skills may, in the long run, be less effective than a more holistic and parent-centric approach.

Section 8.3 – Thesis Conclusions - Study Two Results

The results of the linear regressions conducted as part of Study Two confirmed that stress, anxiety and depression in the fathers of children with autism are significantly predicted by conduct problems (Gray, 2003; Lecavelier et al., 2005) and social support (Gray & Holden, 1992; Lamminen, 2008), when these predictors are regressed individually against each mental health variable. The results also showed that parental locus of control, a factor shown to predict mental health problems in the parents of children with an intellectual disability (Hassall et al., 2005), is a predictor of stress, anxiety and depression in the fathers of children with autism. However, although autism symptom severity was shown to significantly predict depression in the fathers of children with autism, it did not predict stress and anxiety in the fathers of children with autism, even when regressed individually against these mental health variables. The result contradicts the findings of Hastings and Johnson, (2001), who found a significant correlation between autism symptom severity and stress for both mothers and fathers of children with autism. As noted in the introduction to this study, the study conducted by Hastings and Johnson only recruited parents presenting to support services for assistance in managing their children with autism. The sample group for the present study is arguably more reflective of the general population.

The results of the stepwise regression analysis conducted as part of Study Two also contrasted with the results of Study One. Whereas for mothers the predictors of stress, anxiety and depression differed, the same two variables were the primary predictors of stress, anxiety and depression in fathers. These two variables were Social Support and Perceived Limit Setting Ability. The observed difference between the genders has important implications for the delivery of support services to this parental group.

The significance of Social Support as a predictor of paternal mental health problems corroborates with existing research on fathers of children with autism (Gray & Holden, 1992; Lamminen, 2008), and mirrors the results of Study One. Social Support was a significant predictor of depression and stress (but not anxiety) in mothers. However, a limitation of regression analysis is that it does not provide an insight into the relationship between the predictors. Is there any relationship between a lack of social support and having a child with autism (i.e. does having a child with autism cause parents to become more socially isolated?) A comment left by a father on the Facebook page for this study provided some insight into this – *‘The biggest cause of stress, anxiety and depression for me is the lack of access to services for my two boys with Autism (11yrs & 13yrs), and the financial hardship associated with trying to meet their needs. We have also lost all family support along the way, which has been devastating,’*

In modelling the relationship between the predictors included in this study and parental distress, as part of Study Three, an assumption was made that this predictive relationship does exist – i.e. having a child with autism is predictive of perceived lower levels of social support, which in turn is predictive of parental psychological distress. However, further research would be warranted here, to both confirm if social

support available to parents does reduce post-diagnosis of a child with autism, and whether this reduction in social support is resultant from the child's behaviour, the parents' behaviour or the reaction of family and friends to the diagnosis. Another possible area for further research is to assess whether the lower levels of social support reported by parents of children with autism reflect perception or reality. As noted by Woodgate et al. (2008), parents report that they are 'living in a world of our own.' However, is this sense of isolation real or perceived? Studies in the general community (not specific to autism) have demonstrated that the relationship between received and perceived social support is not always linear (Haber, Cohen, Lucas, & Baltes, 2007). A limitation of the current study, however is that the information gathered is all based on parent perception. Thus a comparison between 'real-world' (received) and perceived social support is not possible.

The other primary predictor of stress, anxiety and depression in fathers was Perceived Limit Setting Ability. Again, this mirrors the results of Study One (Perceived Limit Setting Ability was a significant predictor of anxiety and stress, but not depression, in mothers), and highlights the role parental cognitions may play in mediating the relationship between child factors (autism severity and externalizing behaviours) and parental mental health problems.

The other three variables shown to be significant predictors of paternal mental health problems were Satisfaction with Parenting (a significant predictor of depression), Father's Age (a significant predictor of stress) and Aggressive Behaviour (a significant predictor of anxiety).

A study conducted by Gray (2003) identified that parents of children with autism who displayed aggressive behaviour were more likely to report parental stress than parents of children with autism who did not display aggressive behaviour.

However, this does not mean that aggressive behaviour towards adults, a behaviour-type that is widely reported by parents of children with autism (Woodgate et al., 2008), is a more significant predictor of parental mental health problems than other child externalizing behaviours. Both variables were included in this study and, whereas Aggressive Behaviour was a significant predictor of depression in mothers and anxiety in fathers, Conduct Problems was not shown to be a significant predictor in any of the regression models. Again, this does not mean Conduct Problems do not play a role in predicting parental mental health problems. In all linear regressions carried out as part of this research, Conduct Problems were shown to significantly predict stress, anxiety and depression. However, it may be that the variance in mental health variables being contributed by Conduct Problems is explained by autism-specific maladaptive behaviours, such as aggressive behaviour towards adults. It should be noted, however, that the measure used to assess aggressive behaviour in this study consisted of a single item, and thus is subject to misinterpretation when included in statistical analysis. Further research aiming to define the specific externalizing behaviours that predict parental psychological distress would be warranted.

Satisfaction with Parenting, as noted earlier, was a significant negative predictor of depression in fathers. As reported by Myers (2009), parents of children with autism report a feeling of loss and grief regarding their own future life opportunities. Myers described parents feeling that they had lost the ability to live their own lives. In the words of one father who commented on the Facebook site for this study, *'I always wanted to be a parent. But I'm not a parent, I'm just a carer and I don't have much of a relationship with my son. I do get depressed sometimes.'* The decision to have children is, arguably, based partially on the expectation that it will be

a rewarding personal experience. As reported by Busch (2009), parents of children with autism describe their children as ‘impossible to reach’. Busch described that parents of children with autism felt unable to form productive two-way relationships with their children. The perceived parent-child relationship, as hypothesised in the aims of this study, does therefore play in role in predicting parental mental health problems, for fathers at least. Helping parents adapt their pre-existing expectations of parenthood (through a process of cognitive restructuring, such as Cognitive Behavioural Therapy), and providing reassurance that it is acceptable for parents to feel a sense of loss and grief, may assist in helping parents adapt to the demands of parenting a child with autism.

Parental age was shown to be a significant predictor of stress for both mothers and fathers (and anxiety, for mothers). For both mothers and fathers, age was a negative predictor of stress – i.e. the younger the parent, the more likely the parent was to report high levels of stress. There are many possible explanations for this – younger parents may be less emotionally able to cope with parenting a child with autism, may be less secure in their relationship with their partner, or less financially secure. Beyond such speculation, however, this study provides no insights into why younger parents of children with autism are at greater risk of mental health problems. Further research into this area, investigating the personal, economic and psychosocial factors that affect younger parents of children with autism, would be warranted.

Section 8.4 – Thesis Conclusions - Study Three Results

Although the regression analyses conducted in Studies One and Two provided a level of insight into the differing predictors of stress, anxiety and depression in the parents of children with autism, what these studies did not take into account is the relationship between the various predictive variables. As demonstrated by the linear regression results, child-specific factors such as conduct problems have a significant predictive relationship with parental psychological distress. Although the stepwise regression results indicated that this predictive relationship is not linear, and may or may not be mediated or moderated by other factors, conduct problems still has a clear role to play in predicting mental health problems in this parental group.

Study three therefore sought to build a theoretical model describing the relationship between parental psychological distress and the various predictive variables measured as part of this study, and test the statistical fit of this model with the observed data for both mothers and fathers.

Based on the results of Studies One and Two, it was hypothesised that autism symptom severity and child externalizing behaviours did not directly influence parental psychological distress, and that the relationship between these two sets of variables was mediated by parental cognitions and socio-economic support. The model fit statistics for both mothers and fathers indicated that this model was a good fit with the observed data. Although invariance testing between the model for mothers and fathers only indicated weak (metric) invariance, the results provide support for the development of support services that focus on parental cognitions as well as behavioural management training – i.e. a therapeutic approach rather than solely an autism and child-centric approach.

Certain limitations need to be taken into account before any clear conclusions can be drawn from the study results. Firstly, as with any study looking at the factors predicting stress, anxiety and depression, this study included a restricted subset of potentially predictive variables. Perceived stigmatization was not taken into account, and cognitions unrelated to parenting were also not assessed. The current study provides only a surface level insight into the actual types of cognitions that predict and maintain stress, anxiety and depression in the parents of children with autism. A suggestion for further research would be a qualitative study seeking to understand the negative cognitions of parents with a diagnosis of stress, anxiety and depression, and the role these cognitions play in maintaining mental health problems and minimizing adherence to recommended behavioural management programs for the child with autism (Schieve et al., 2007). Secondly, this study recruited mothers and fathers separately from the general population. It did not recruit matched pairs of mothers and fathers. Any differences observed in predictive variables between mothers and fathers is therefore subject to variance within the study populations. As discussed earlier, 99% of participating mothers and 43% of participating fathers reported being primary carers for their child(ren) with autism. As 74% of mothers and 87% of fathers reported being married or in a relationship, it is unlikely the study population is reflective of those parents less actively involved with their child(ren) with autism. Recruiting matched pairs of mothers and fathers would provide a more comprehensive source of comparison of the factors predicting parental mental health problems. A suggestion for further research would be to test the model devised in Study Three using a matched pair study design.

Another weakness of the study was the development of new questionnaires to measure Social Support and Economic Support. Although a number of standardized

measures of social support were considered for this study, including the Social Support Questionnaire (Sarason et al., 1983) and the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981), a decision was made that a questionnaire including at least one question focused specifically on social support relevant to caring for a child with autism would provide a measure more relevant to the aims of the study (see Question 12 from the included Social Support questionnaire – “*You have some family and friends who help you care for your child(ren) with autism?*”) Rather than modify an existing measure, a decision was made to develop a new questionnaire specific to this study. A secondary rationale was that the user questionnaire needed to be of limited length, to maximize participant completion of the questionnaire, and a brief measure of Social Support would be beneficial. The included study questionnaire consists of 10 items, as opposed to the 27 items included in the Social Support Questionnaire, and the 47 items (9 items per identified ‘significant person’ and 2 additional items) include in the Norbeck Social Support Questionnaire. Brevity could, however, have been effectively achieved by using the Short Form Social Support Questionnaire (Sarason, Sarason, Shearin, & Pierce, 1987), which consists of three items demonstrated to correlate with the results of the long form Social Support Questionnaire (Sarason et al., 1983). The use of a non-standardized questionnaire limits the ability of the study findings to be generalized and compared to other studies assessing Social Support.

The Economic Support measure used in this study was also shown to be problematic. As discussed in the Study One Conclusions, the measure was a significant positive predictor of stress, and the wording of the two items included in the measure, which assessed whether friends and family were able and willing to provide financial support to the parent, could be interpreted as a measure of financial

dependence as opposed to economic support. It is possible that a negative response to this item indicates that the participant is financially independent and does not require financial support from friends and family, as opposed to indicating a lack of available support. For this reason, and due to the brevity of the measure, it is difficult to draw any clear conclusions from this study regarding the role of Economic Support as a predictor of mental health problems in the parents of children with autism.

Section 8.5 - Final Conclusions

The results of this study indicated that, although stress, anxiety and depression are elevated in the parents of children with autism compared to the parents of developmentally normal children (Benjak, 2009; Bitsika and Sharpley, 2004; Singer, 2006), child-related factors such as autism symptom severity and externalizing behaviours are not the primary predictors of these elevated mental health problems. Socio-economic support and parental cognitions, specifically those cognitions related to the role of the parent, are the primary predictors of mental health problems in this parental group, and these factors mediate the relationship between child-related factors and parental psychological distress.

Based on these results, it can be concluded that support services focused solely on autism psychoeducation and behavioural management training, as proposed by Tonge (2006) and Keen (2010), may have a short-term efficacy, as these approaches do not provide parents with skills to cope with their underlying conditions. Combining elements of these programs with psychological therapy and respite care for the child would, theoretically, provide more long term benefit in reducing parental mental health problems and encouraging adherence to behavioural management plans.

There are multiple areas that would benefit from further research. Replicating these results in a study using a matched pair design, and conducting qualitative research into the specific cognitions that predict and maintain mental health problems, would provide information of more direct and practical use to structuring an effective parental support program. Replicating this research in a sample population with a clinical diagnosis of anxiety or depression would also be of benefit. The current study recruited participants from the general community, and the results are not solely representative of those parents of children with autism presenting with a diagnosable mental illness. Further research into the role of parental age would also be of interest, as for both mothers and fathers there is a negative predictive relationship between parental age and at least one mental health variable (anxiety and stress for mothers, and stress for fathers).

As a basis for structuring effective services to support the parents of children with autism, however, this study has identified a key factor missing from the existing body of research – the role played by parental cognitions. Having a child with autism, although an obvious differentiating factor, is not the primary predictor of stress, anxiety and depression in this parental group. The behaviours exhibited by that child, although certainly a contributory factor, are not necessarily the primary target for effective interventions. If support services for this parental group are to be effective in the long-term, the role played by parental cognitions needs to be taken into account. Without an understanding of the psychological impact of parenting a child with autism, and without providing parents with the skills to cope with associated beliefs and cognitions, interventions are unlikely to be effective. In providing support to parents of children with autism, the focus must not only be on the child.

References

- Altieri, M., & von Kluge S. (2009). Family Functioning and Coping Behaviors in Parents of Children with Autism, *Journal of Child and Family Studies*, 18, 83-92.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders*. 4th, text revision.
- Anderson, J. M., & Elfert, H. (1989). Managing chronic illness in the family – women as caretakers. *Journal of Advanced Nursing*, 14, 735-743.
- Aneshensel, C.S. (1992). Social stress: Theory and research. *Annual Review of Sociology*, 18, 15-38.
- Baron-Cohen, S. (2009). Autism: The Empathizing-Systemizing (E-S) Theory. *The Year in Cognitive Neuroscience: Annals of the New York Academy of Science*, 1156, 68-80.
- Bayley N. (2006). *Bayley Scales of Infant and Toddler Development*. San Antonio, TX The Psychological Corporation.
- Benjak, T. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. *Croatian Medical Journal*, 50, 403-409.
- Bentler, P.M. (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, 107, 238-246.

- Berument, S. K., Rutter, M., Lord, C., Pickles, A. & Bailey, A. (1999). Autism screening questionnaire: Diagnostic validity. *British Journal of Psychiatry*, 175, 444-451.
- Bitsika, V., & Sharpley, C. (2004). Stress, anxiety and depression among parents of children with Autism Spectrum Disorder. *Australian Journal of Guidance and Counseling*, 14, 151-161.
- Blackledge, J. T., & Hayes, S. C. (2006). Using acceptance and commitment therapy training in the support of parents of children diagnosed with autism. *Child & Family Behaviour Therapy*, 28, 1-18.
- Bowerman, B., & O'Connell, R. (1990). *Linear statistical models: An applied approach*. PWS-Kent Pub. Co. (Boston).
- Brown, T.A. (2006). *Confirmatory Factor Analysis for Applied Research*. New York: Guildford Press.
- Brown T. A., Chorpita, B. F., Korotitsch, W. & Barlow, D. H. (1997). Psychometric properties of the Depression Anxiety and Stress Scales (DASS) in clinical samples. *Behaviour Research and Therapy*, 35, 79-89.
- Busch, E. C. (2009). Using acceptance and commitment therapy with parents of children with autism: The application of a theory. *ProQuest Dissertations and Theses 0622* (0971). Umi Dissertation Publishing.
- Civick, P. (2008). Maternal and paternal differences in parental stress levels and marital satisfaction levels in parents of children diagnosed with autism spectrum disorders. *ProQuest Dissertations and Theses 0622* (0925). Umi Dissertation Publishing.

- Crawford, J.R. (2007). sbdiff.exe [Computer software].
- Crawford, J. R., & Henry J. D. (2003). The depression anxiety stress scales (DASS): Normative data and latent structure in a large non-clinical sample. *British Journal of Clinical Psychology, 42*, 111-131.
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*, 278-1291.
- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism, 9*, 416-427.
- Farrugia, D. (2009). Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness, 31*, 1011-1027.
- Fiske, K. (2009). A cross-sectional study of patterns of renewed stress among parents of children with autism. *ProQuest Dissertations and Theses* 0621 (0190).
- Gerard, A. B. (1994). *Parent–Child Relationship Inventory (PCRI) Manual* (Los Angeles, CA, Western Psychological Services).
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology, Psychiatry, and Allied Disciplines, 38*, 581-586.
- Goodman, R. (1999). The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden. *Journal of Child Psychology, Psychiatry, and Allied Disciplines, 40*, 791-799.

- Goodman, R., & Scott, S. (1999). Comparing the Strengths and Difficulties Questionnaire and the Child Behavior Checklist: Is small beautiful? *Journal of Abnormal Child Psychology*, 27, 17-24.
- Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire (SDQ). *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337-1345.
- Gray, D. E. (2002). "Everybody just freezes. Everybody is just embarrassed": Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24, 734-749.
- Gray, D. E. (2003). Gender and Coping: The parents of children with high functioning autism, *Social Science and Medicine* 56, 631-642.
- Gray D. E., & Holden W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83-93.
- Haber, M. G., Cohen, J. L., Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology*, 39, 133-144.
- Hartley, S. L., Barker, E. T., Seltzer, M.M. Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24, 449-457.
- Happé, F., Ronald, A., & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience*, 9, 1218-20.

- Happé, F., & Ronald, A. (2008). The 'fractionable autism triad': a review of evidence from behavioural, genetic, cognitive and neural research. *Neuropsychology Review, 18*, 287–304.
- 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., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*, 635-644.
- Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31*, 327-336.
- Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology, 44*, 227-239.
- Heinze, M. C. & Grisso, T. (1996). Review of instruments assessing parenting competencies used in child custody evaluations, *Behavioral Sciences and the Law, 14*, 293–313.
- Hoppes, K., & Harris, S. (1990). Perceptions of child attachment and maternal gratification in mothers of children with autism and Down syndrome. *Journal of Clinical Child Psychology, 19*, 365-370.

- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212–29.
- Hu, H. (2009). The role of caregiving on quality of life of parents with children having autism in Taiwan, *Dissertation Abstracts International Section A: Humanities and Social Sciences* 70, 702.
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling*, 6, 1–55.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems and Health*, 29, 232-252.
- Kaplan, G. E., Roberts, R. E., Camacho, T. C., & Coyne, J. C. (1987). Psychosocial predictors of depression – prospective evidence from the human population laboratory studies. *American Journal of Epidemiology*, 125, 206-220.
- Keen, D. et al. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, 4, 229-241.
- Ingersoll, B., & Hambrick, D. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 337-344.
- Lamminen, L. (2008). Family functioning and social support in parents of children with Autism Spectrum Disorders, *ProQuest Dissertations and Theses*, 0519(0102).

- Lecavalier, L., Leone, S., & Wiltz, J. (2005). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders, *Journal of Intellectual Disability Research*, 3, 172-183.
- Lee, G.K. (2009). Health-related quality of life of parents of children with high-functioning Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities* 24, 227-239.
- Leslie, K. C., Lyman, R. D., & Prentice-Dunn, S. (1986). The Parental Locus of Control Scale: Development and validation. *Journal of Clinical Child Psychology*, 15, 260-267.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659-685.
- Lounds, J., Seltzer, M., Greenberg, J., Shattuck, P., & MacLean, Jr. W. (2007). Transition and Change in Adolescents and Young Adults With Autism: Longitudinal Effects on Maternal Well-Being. *American Journal on Mental Retardation*, 112, 401-417.
- Lovibond, S. & Lovibond, P. (1995). *Manual for the Depression Anxiety Stress Scales*. (2nd. Ed.) Sydney: Psychology Foundation.
- MacCallum, R. C., Browne, M. W., & Sugawara, H. M. (1996). Power analysis and determination of sample size for covariance structure modeling. *Psychological Methods*, 1, 130-149.

- Macintosh, K., & Dissanayake, C. (2006). Social skills and problem behaviours in school-aged children with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, 36, 1065-1076.
- Malmberg, M., Rydell, A. M., & Smedje, H. (2003). Validity of the Swedish version of the Strengths and Difficulties Questionnaire (SDQ). *Nordic Journal of Psychiatry*, 57, 357-363.
- Menard, S. (2002). *Applied Logistic Regression Analysis*, 2nd edition. California: Sage Publications.
- Micali, N. Chakrabarti, S., & Fombonne, E. (2004). The broad autism phenotype: Findings from an epidemiological survey. *Autism*, 8, 21-37.
- Milshtein, S. (2010). Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics, *Journal of Autism and Developmental Disorders*, 40, 89-99.
- Moore, T.R. (2009). Adherence to Behavioral and Medical Treatment Recommendations by Parents of Children with Autism Spectrum Disorders, *Journal of Autism and Developmental Disorders*, 39, 1173-1184.
- Muthén, L. K., & Muthén, B. O. (2010). *Mplus User's Guide* (3rd Ed.). Los Angeles, CA: Muthén & Muthén.
- Myers, B.J. (2009). "My Greatest Joy and My Greatest Heart Ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3, 670-684.

- Myers, S.M., & Johnson, C.P. (2007). Management of children with autism spectrum disorders. *Pediatrics*, 120, 1162–82.
- Norbeck, J.S., Lindsey, A. M., & Carrieri, V.L. (1981). The development of an instrument to measure social support. *Nursing Research*, 30, 264-269.
- Roberts, C.S., & Feetham, S. L. (1982). Assessing family functioning across three areas of relationships. *Nursing Research*, 31, 231-235.
- Rodrigue, J. R., Morgan S. B., & Geffken, G. R. (1992). Psychosocial adaptation of fathers of children with autism, Down syndrome and normal development. *Journal of Autism and Developmental Disorders*, 22, 249-263.
- Rogers, M. L. (2008). Can marital satisfaction of parents raising children with autism be predicted by child and parental stress, *ProQuest Dissertation and Theses*, 0451 (1389).
- Rutgers, A. et al. (2004). Autism and attachment: a meta-analytic review. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 45, 1123-1134.
- Rutter, M., Bailey, A., & Lord, C. (2003). SCQ: Social Communication Questionnaire. Western Psychological Services: Los Angeles, CA.
- Sanders, J. L., & Morgan, S. B. (1997). Family Stress and Adjustment as Perceived by Parents of Children with Autism and Down Syndrome: Implications for Intervention, *Child & Family Behavior Therapy*, 19, 15-32.
- Sarason, I., Levine, H., Basham, R., & Sarason, B (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology*, 44, 127-139.

- Sarason, I., Sarason, B., Sarason, E. Shearin, B., & Pierce, G. (1987). A brief measure of social support: Practical and theoretical implications. *Journal of Social and Personal Relationships*, 4, 497-510.
- Satorra, A., & Bentler, P. M. (2001). A scaled difference chi-square test statistic for moment structure analysis. *Psychometrika*, 66, 507-514.
- Sawyer, M., Bittman, M., La Greca, A., Crettenden, A., Harchak, T., & Martin, J. (2009). Time demands of caring for children with autism: What are the implications for maternal mental health? *Journal of Autism and Developmental Disorders*, 40, 620-628.
- Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119, 114-12.
- Sharpley, C. F., Bitsika, V. & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability*, 22, 19-28.
- Singer, G. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111, 155-169.
- Sparrow, S. S., Balla, D., & Cicchetti, D. (1984). *Vineland Adaptive Behavior Scales (Survey Form)* Circle Pines, MN: American Guidance Service.
- Stefanatos, G.A. (2008). Regression in autistic spectrum disorders. *Neuropsychology Review*, 18, 305-19.

- Thoits, P.A. (1991). Gender differences in coping emotional distress. *The Social Context of Coping* (Ed. J. Eckenrode). Plenum Press, New York, 107-138.
- Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress, *Journal of Intellectual and Developmental Disability*, 29, 16-26.
- Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: A randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45, 561-569.
- Tuchman, R., & Rapin, I. (1997). Regression in pervasive developmental disorders: Seizures and epileptiform electroencephalogram correlates. *Pediatrics*, 1999, 560-566.
- Weiss, M. J., (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115-130.
- Wells, R. (2010). 41.6% of the US Population has a Facebook account. *Social Media Today*. Retrieved from <http://socialmediatoday.com/roywells1/158020/416-us-population-has-facebook-account>
- Woodgate, R.L., Ateah, C., & Secco, L. (2008). Living in a World of our Own: the Experience of Parents who have a Child with Autism. *Qualitative Health Research* 18, 1075-1083.

Wright, B., & Williams, C. (2007). *Intervention and Support for Parents and Carers of Children and Young People on the Autism Spectrum: A Resource for Trainers*. Child, Kingsley Publishers.

Yirmiya, N., & Shaked, M. (2005). Psychiatric disorders in parents of children with autism. *Journal of Child Psychology and Psychiatry* 46, 69-83.

Zigmond, R., & Snaith, P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Appendix A – Study One Questionnaire

This questionnaire is divided into six sections, and should take between 45-60 minutes to complete. Please remember that all information is treated fully confidentially. Please answer as honestly as possible. Your completion and submission of this online questionnaire implies consent for us to use your data in our research. Thank you very much for your assistance.

Before proceeding, please check the following box to confirm you are aged 18 or over ☐

Section 1. (Background Questions)

The following background questions are related to you and your family.

What Is Your Year of Birth: _____

What is the highest level of education you have completed: _____

Including yourself, how many people live in your household? _____

How many children, under the age of 18, currently live in your household? _____

How many of your children have received a diagnosis of autism _____

Have any of your children received a diagnosis, now, or in the past, of any of the following:

Attention Deficit Hyperactivity Disorder ☐

Oppositional Defiant Disorder ☐

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Learning Disorder ☐

Conduct Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Asperger's Syndrome ☐

Other (Please State) _____

What is your marital status? Married/partner ☐ Separated/Divorced ☐ Widowed ☐
Single ☐

Are you currently employed? Full time ☐ Part time ☐ Not employed ☐

Is your total annual income, before taxes: \$0-19,999 ☐ \$20-49,999 ☐ \$50-79,999 ☐

Over \$ 80,000 ☐ Not applicable ☐

Is your total household income, before taxes: \$0-19,999 ☐ \$20-49,999 ☐ \$50-79,999 ☐
\$80-120,000 ☐ Over \$120,000 ☐

Have you ever received a diagnosis of, or ever been treated for, any of the following:

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Social Phobia ☐

Asperger's Syndrome ☐

Autism ☐

Other Mental Disorder (Please State) _____

Do you have any current diagnosed medical conditions for which you are receiving treatment? Yes ☐ No ☐

If 'yes', what medical conditions are you currently receiving treatment for?

| |
|------------------------------------|
| Section 2. (Social Support) |
|------------------------------------|

The following questions relate to your social support network.

Please read each of the statements below, and indicate the extent of your agreement / disagreement by selecting one of the numbers 1(strongly disagree) to 5(strongly agree):

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Neither Agree Nor Disagree
- 4 Agree
- 5 Strongly Agree

- | | | | | | |
|--|---|---|---|---|---|
| 1. There is a special person who is around when you are in need. | 1 | 2 | 3 | 4 | 5 |
| 2. There is a special person who is a real source of comfort to you. | 1 | 2 | 3 | 4 | 5 |
| 3. You have a special person who is willing and able to help you financially. | 1 | 2 | 3 | 4 | 5 |
| 4. Your family really tries to help you. | 1 | 2 | 3 | 4 | 5 |
| 5. You get the emotional help and support you need from your family. | 1 | 2 | 3 | 4 | 5 |
| 6. Your friends really try to help you. | 1 | 2 | 3 | 4 | 5 |
| 7. You can count on your friends when things go wrong. | 1 | 2 | 3 | 4 | 5 |
| 8. You can really talk about your problems with your family. | 1 | 2 | 3 | 4 | 5 |
| 9. You have friends with whom you can share your joys and sorrows. | 1 | 2 | 3 | 4 | 5 |
| 10. Your family is willing to help you make decisions. | 1 | 2 | 3 | 4 | 5 |
| 11. You have some family or friends who are willing and able to help you financially. | 1 | 2 | 3 | 4 | 5 |
| 12. You have some family and friends who help you care for your child(ren) with autism? | 1 | 2 | 3 | 4 | 5 |

Section 3. (How You are Currently Feeling)

The following questions relate to how you felt over the past seven days. Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

| | | | | | |
|----|--|---|---|---|---|
| 1 | I found it hard to wind down | 0 | 1 | 2 | 3 |
| 2 | I was aware of dryness of my mouth | 0 | 1 | 2 | 3 |
| 3 | I couldn't seem to experience any positive feeling at all | 0 | 1 | 2 | 3 |
| 4 | I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 5 | I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |
| 6 | I tended to over-react to situations | 0 | 1 | 2 | 3 |
| 7 | I experienced trembling (eg, in the hands) | 0 | 1 | 2 | 3 |
| 8 | I felt that I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| 9 | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 10 | I felt that I had nothing to look forward to | 0 | 1 | 2 | 3 |
| 11 | I found myself getting agitated | 0 | 1 | 2 | 3 |
| 12 | I found it difficult to relax | 0 | 1 | 2 | 3 |
| 13 | I felt down-hearted and blue | 0 | 1 | 2 | 3 |
| 14 | I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| 15 | I felt I was close to panic | 0 | 1 | 2 | 3 |
| 16 | I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| 17 | I felt I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| 18 | I felt that I was rather touchy | 0 | 1 | 2 | 3 |
| 19 | I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 20 | I felt scared without any good reason | 0 | 1 | 2 | 3 |
| 21 | I felt that life was meaningless | 0 | 1 | 2 | 3 |

| |
|--|
| Section 4. (Your Child With Autism) |
|--|

The following questions relate to your child with a diagnosis of autism. If you have more than one child with a diagnosis of autism, please complete these questions for only ONE child diagnosed with autism between the ages of 6 years and 17 years 11 months.

How old is your child? _____ Years _____ Months

What sex is your child? Male ☐ Female ☐

Is your child an eldest, middle, youngest or only child? Eldest ☐ Middle ☐ Youngest ☐ Only Child ☐

What kind of school does your child attend? Mainstream School ☐ Special Needs Day School ☐ Special Needs Boarding School ☐ Full-Time Home Care ☐ Institutional/Hospital Care ☐ Other (Please State) _____

When at home, are you the primary carer for your child? Yes ☐ No ☐

What is your relationship with your child? Biological mother ☐ Step Mother ☐ Foster Mother ☐ Other (Please State) _____

Has your child with a diagnosis of autism additionally received a diagnosis, now, or in the past, of any of the following:

Attention Deficit Hyperactivity Disorder ☐

Oppositional Defiant Disorder ☐

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Learning Disorder ☐

Conduct Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Asperger's Syndrome ☐

Other (Please State) _____

For the following eleven items, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour ***over the last six months.***

| | Not True | Somewhat True | Certainly True |
|---|--------------------------|--------------------------|--------------------------|
| Often has temper tantrums or hot tempers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Restless, overactive, cannot stay still for long | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Generally well-behaved, usually does what adults request | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Constantly fidgeting or squirming | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often fights with other children or bullies them | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Easily distracted, concentration wanders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often lies or cheats | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Thinks things out before acting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Takes things without permission from home, school or elsewhere | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sees tasks through to the end, good attention span | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often aggressive or violent towards adults | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

For the following set of items, also related to your child with autism, please answer each question by choosing *yes* or *no*. A few questions ask about several related types of behavior; please circle *yes* if *any* of these behaviours were present during the ***past 3 months.*** Although you may be uncertain about whether some behaviors were present or not, please answer *yes* or *no* to every question on the basis of what you think.

- Is she/he now able to talk using short phrases or sentences? If *no*, skip to question 8. Yes No
- Do you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said? Yes No
- Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)? Yes No
- Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times? Yes No

- | | | |
|---|-----|----|
| 5. Does she/he ever get her/his pronouns mixed up (e.g., saying <i>you</i> for <i>she/he</i> for <i>I</i>)? | Yes | No |
| 6. Does she/he ever use words that she/he seems to have invented or made up her/himself; put things in odd, indirect ways; or use metaphorical ways of saying things (e.g., saying hot rain for steam)? | Yes | No |
| 7. Does she/he ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again? | Yes | No |
| 8. Does she/he ever have things that she/he seems to have to do in a very particular way or order or rituals that she/he insists that you go through? | Yes | No |
| 9. Does her/his facial expression usually seem appropriate to the particular situation, as far as you can tell? | Yes | No |
| 10. Does she/he ever use your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger or putting your hand on a doorknob to get you to open the door)? | Yes | No |
| 11. Does she/he ever have any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)? | Yes | No |
| 12. Does she/he ever seem to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than in using the object as it was intended? | Yes | No |
| 13. Does she/he ever have any special interests that are unusual in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains or dinosaurs)? | Yes | No |
| 14. Does she/he ever seem to be unusually interested in the sight, feel, sound, taste, or smell of things or people? | Yes | No |
| 15. Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes? | Yes | No |
| 16. Does she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down? | Yes | No |
| 17. Does she/he ever injure her/himself deliberately, such as by biting her/his arm or banging her/his head? | Yes | No |

| | | |
|---|-----|----|
| 18. Does she/he ever have any objects (other than a soft toy or comfort blanket) that she/he has to carry around? | Yes | No |
| 19. Does she/he have any particular friends or a best friend? | Yes | No |
| 20. Does she/he ever talk with you just to be friendly (rather than to get something)? | Yes | No |
| 21. Does she/he ever spontaneously copy you (or other people) or what you are doing (such as vacuuming, gardening, or mending things)? | Yes | No |
| 22. Does she/he ever spontaneously point at things around her/him just to show you things (not because she/he wants them)? | Yes | No |
| 23. Does she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wants? | Yes | No |
| 24. Does she/he nod her/his head to indicate yes? | Yes | No |
| 25. Does she/he shake her/his head to indicate no? | Yes | No |
| 26. Does she/he usually look at you directly in the face when doing things with you or talking with you? | Yes | No |
| 27. Does she/he smile back if someone smiles at her/him? | Yes | No |
| 28. Does she/he ever show you things that interest her/him to engage your attention? | Yes | No |
| 29. Does she/he ever offer to share things other than food with you? | Yes | No |
| 30. Does she/he ever seem to want you to join in her/his enjoyment of something? | Yes | No |
| 31. Does she/he ever try to comfort you if you are sad or hurt? | Yes | No |
| 32. If she/he wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention? | Yes | No |
| 33. Does she/he show a normal range of facial expressions? | Yes | No |
| 34. Does she/he ever spontaneously join in and try to copy the actions in social games, such as The Mulberry Bush or London Bridge Is Falling Down? | Yes | No |
| 35. Does she/he play any pretend or make-believe games? | Yes | No |
| 36. Does she/he seem interested in other children of approximately the same age whom she/he does not know? | Yes | No |
| 37. Does she/he respond positively when another child approaches her/him? | Yes | No |

- | | | |
|--|-----|----|
| 38. If you come into a room and start talking to her/him without calling her/his name, does she/he usually look up and pay attention to you? | Yes | No |
| 39. Does she/he ever play imaginative games with another child in such a way that you can tell that each child understands what the other is pretending? | Yes | No |
| 40. Does she/he play cooperatively in games that need some form of joining in with a group of other children, such as hide-and-seek or ball games? | Yes | No |
| 41. Is she/he able to dress independently, or without considerable assistance from someone else? (Note: <i>needing help to tie shoelaces would not be considered 'considerable assistance'</i>) | Yes | No |
| 42. Is she/he able to go to the toilet independently, or without considerable assistance from someone else? (Note: <i>needing to be reminded to wash hands or flush the toilet would not be considered 'considerable assistance'</i>) | Yes | No |
| 43. Is she/he able to bath/shower independently, or without considerable assistance from someone else? (Note: <i>needing help turning on the shower or running the bath would not be considered 'considerable assistance'</i>) | Yes | No |

Section 5. (Your Relationship with Your Child With Autism)

The statements below describe different ways some parents feel about their children. For each statement, decide how you feel. When the question refers to 'my child', it is referring to the same child with autism you were asked about in the previous section of this questionnaire. For each question, please answer as follows: If you *strongly disagree*, select the 1 next to the statement number. If you *disagree*, select the 2. If you *agree*, select the 3. If you *strongly agree*, select the 4. Please make sure you select the correct response.

Try to respond to all of the statements. If you aren't sure you you feel, mark the response that comes closest to your feelings at this time. *There are no right or wrong answers.*

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

- | | | | | |
|--|---|---|---|---|
| 1. I have trouble disciplining my child. | 1 | 2 | 3 | 4 |
| 2. I get as much satisfaction from my child as other parents do. | 1 | 2 | 3 | 4 |
| 3. I have a hard time getting through to my child. | 1 | 2 | 3 | 4 |
| 4. I spend a great deal of time with my child. | 1 | 2 | 3 | 4 |
| 5. My feelings about being a parent change from day to day. | 1 | 2 | 3 | 4 |
| 6. My child is more difficult to care for than most children are. | 1 | 2 | 3 | 4 |
| 7. Being a parent comes naturally to me. | 1 | 2 | 3 | 4 |
| 8. I sometimes give in to my child to avoid a tantrum. | 1 | 2 | 3 | 4 |
| 9. I love my child just the way he or she is. | 1 | 2 | 3 | 4 |
| 10. My child is never jealous of others. | 1 | 2 | 3 | 4 |
| 11. I often wonder what the rewards are in raising children. | 1 | 2 | 3 | 4 |
| 12. I wish I could set firmer limits with my child. | 1 | 2 | 3 | 4 |
| 13. I get a great deal of satisfaction from having | | | | |

| | | | | |
|--|---|---|---|---|
| children. | 1 | 2 | 3 | 4 |
| 14. I regret having children. | 1 | 2 | 3 | 4 |
| 15. My child is out of control much of the time. | 1 | 2 | 3 | 4 |
| 16. Being a parent isn't as satisfying as I thought it would be. | 1 | 2 | 3 | 4 |
| 17. I never worry about my child. | 1 | 2 | 3 | 4 |
| 18. I wish my child would not interrupt when I'm talking to someone else. | 1 | 2 | 3 | 4 |
| 19. I feel very close to my child. | 1 | 2 | 3 | 4 |
| 20. I never have had any problems with my child. | 1 | 2 | 3 | 4 |
| 21. I often lose my temper with my child. | 1 | 2 | 3 | 4 |
| 22. I am very involved with my child's sports or other activities. | 1 | 2 | 3 | 4 |
| 23. I have never been embarrassed by anything my child has said or done. | 1 | 2 | 3 | 4 |
| 24. My child really knows how to make me angry. | 1 | 2 | 3 | 4 |
| 25. My child never puts off doing things that should be done right away. | 1 | 2 | 3 | 4 |
| 26. Being a parent is one of the most important things in my life. | 1 | 2 | 3 | 4 |
| 27. I feel I don't really know my child. | 1 | 2 | 3 | 4 |
| 28. I sometimes find it hard to say no to my child. | 1 | 2 | 3 | 4 |
| 29. I wonder if I did the right thing having children. | 1 | 2 | 3 | 4 |
| 30. I would really rather do a lot of other things than spend time with my child. | 1 | 2 | 3 | 4 |
| 31. It's a parent's responsibility to protect his or her child from harm. | 1 | 2 | 3 | 4 |
| 32. I sometimes wonder how I would survive if anything were to happen to my child. | 1 | 2 | 3 | 4 |
| 33. My child rarely interacts with me unless he or she wants something. | 1 | 2 | 3 | 4 |
| 34. I spend very little time interacting with my child. | 1 | 2 | 3 | 4 |

- | | | | | |
|---|---|---|---|---|
| 35. I feel there is a great distance between me and my child. | 1 | 2 | 3 | 4 |
| 36. I often threaten to punish my child but never do. | 1 | 2 | 3 | 4 |
| 37. If I had it to do over, I would probably not have had children. | 1 | 2 | 3 | 4 |
| 38. Some people would say that my child is a bit spoiled. | 1 | 2 | 3 | 4 |
| 39. I seldom have time to spend with my child. | 1 | 2 | 3 | 4 |
| 40. I carry a photograph of my child in my wallet or purse. | 1 | 2 | 3 | 4 |
| 41. I feel I don't know how to communicate with my child in a way that he or she really understands. | 1 | 2 | 3 | 4 |

| |
|--|
| Section 6. (Your Thoughts on Parenting) |
|--|

The following questions relate to your thoughts and opinions on parenting. When the question refers to 'my child', it is referring to the same child with autism you were asked about in the previous sections of this questionnaire. Please read each of the statements below, and indicate the extent of your agreement / disagreement by circling one of the numbers 1 (strongly disagree) to 5 (strongly agree):

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Neither Agree Nor Disagree
- 4 Agree
- 5 Strongly Agree

- | | | | | | |
|---|---|---|---|---|---|
| 1. What I do has little effect on my child's behaviour. | 1 | 2 | 3 | 4 | 5 |
| 2. When something goes wrong between me and my child, there is little I can do to correct it. | 1 | 2 | 3 | 4 | 5 |
| 3. Parents should address problems with their children because ignoring them won't make them go away. | 1 | 2 | 3 | 4 | 5 |
| 4. If your child tantrums no matter what you try, you might as well give up. | 1 | 2 | 3 | 4 | 5 |
| 5. My child usually ends up getting his/her way, so why try | 1 | 2 | 3 | 4 | 5 |
| 6. No matter how hard a parent tries, some children will never learn to mind. | 1 | 2 | 3 | 4 | 5 |
| 7. I am often able to predict my child's behaviour in situations. | 1 | 2 | 3 | 4 | 5 |
| 8. It is not always wise to expect too much from my child because many things turn out to be a matter of good or bad luck anyway. | 1 | 2 | 3 | 4 | 5 |
| 9. When my child gets angry, I can usually deal with him/her if I stay calm. | 1 | 2 | 3 | 4 | 5 |
| 10. When I set expectations for my child, I am almost | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| certain that I can help him/her meet them ` | 1 | 2 | 3 | 4 | 5 |
| 11. There is no such thing as good or bad children- just good or bad parents. | 1 | 2 | 3 | 4 | 5 |
| 12. When my child is well-behaved, it is because he/she is responding to my efforts. | 1 | 2 | 3 | 4 | 5 |
| 13. Parents who can't get their children to listen to them don't understand how to get along with their children. | 1 | 2 | 3 | 4 | 5 |
| 14. My child's behavior problems are no one's fault but my own. | 1 | 2 | 3 | 4 | 5 |
| 15. Capable people who fail to become good parents have not followed through on their opportunities. | 1 | 2 | 3 | 4 | 5 |
| 16. Children's behavior problems are often due to mistakes their parents made. | 1 | 2 | 3 | 4 | 5 |
| 17. Parents whose children make them feel helpless just aren't using the best parenting techniques. | 1 | 2 | 3 | 4 | 5 |
| 18. Most childrens' behavior problems would not have developed if their parents had had better parenting skills. | 1 | 2 | 3 | 4 | 5 |
| 19. I am responsible for my child's behaviour. | 1 | 2 | 3 | 4 | 5 |
| 20. The misfortunes and successes I have had as a parent are the direct result of my behaviour. | 1 | 2 | 3 | 4 | 5 |
| 21. My life is chiefly controlled by my child. | 1 | 2 | 3 | 4 | 5 |
| 22. My child does not control my life. | 1 | 2 | 3 | 4 | 5 |
| 23. My child influences the number of friends I have. | 1 | 2 | 3 | 4 | 5 |
| 24. I feel like what happens in my life is mostly determined by my child. | 1 | 2 | 3 | 4 | 5 |
| 25. It is easy for me to avoid and function independently of my child's attempts to have control over me. | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 26. When I make a mistake with my child I am usually able to correct it. | 1 | 2 | 3 | 4 | 5 |
| 27. Even if your child frequently tantrums, a parent should not give up. | 1 | 2 | 3 | 4 | 5 |
| 28. Being a good parent often depends on being lucky enough to have a good child. | 1 | 2 | 3 | 4 | 5 |
| 29. I'm just one of those lucky parents who happened to have a good child. | 1 | 2 | 3 | 4 | 5 |
| 30. I have often found that when it comes to my children, what will happen will happen. | 1 | 2 | 3 | 4 | 5 |
| 31. Fate was kind to me-if I had had a bad child I don't know what I would have done. | 1 | 2 | 3 | 4 | 5 |
| 32. Success in dealing with children seems to be more a matter of the child's moods and feelings at the time rather than one's own actions. | 1 | 2 | 3 | 4 | 5 |
| 33. Neither my child nor myself is responsible for his/her behavior | 1 | 2 | 3 | 4 | 5 |
| 34. In order to have my plans work, I make sure they fit in with the desires of my child. | 1 | 2 | 3 | 4 | 5 |
| 35. Most parents don't realize the extent to which how their children turn out is influenced by accidental happenings. | 1 | 2 | 3 | 4 | 5 |
| 36. Heredity plays the major role in determining a child's personality. | 1 | 2 | 3 | 4 | 5 |
| 37. Without the right breaks one cannot be an effective parent. | 1 | 2 | 3 | 4 | 5 |
| 38. I always feel in control when it comes to my child | 1 | 2 | 3 | 4 | 5 |
| 39. My child's behavior is sometimes more than I can handle. | 1 | 2 | 3 | 4 | 5 |
| 40. Sometimes I feel that my child's behavior is hopeless. | 1 | 2 | 3 | 4 | 5 |
| 41. It is often easier to let my child have his/her way | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| than to put up with a tantrum. | 1 | 2 | 3 | 4 | 5 |
| 42. I find that sometimes my child can get me to do things I really did not want to do. | 1 | 2 | 3 | 4 | 5 |
| 43. My child often behaves in a manner very different from the way I would want him/her to behave. | 1 | 2 | 3 | 4 | 5 |
| 44. Sometimes when I'm tired I let my children do things I normally wouldn't. | 1 | 2 | 3 | 4 | 5 |
| 45. Sometimes I feel that I do not have enough control over the direction my child's life is taking. | 1 | 2 | 3 | 4 | 5 |
| 46. I allow my child to get away with things. | 1 | 2 | 3 | 4 | 5 |
| 47. It is not too difficult to change my child's mind about something. | 1 | 2 | 3 | 4 | 5 |

Thank you for taking the time to complete this questionnaire. Your assistance with our research is greatly appreciated.

Appendix B – Study Two Questionnaire

This questionnaire is divided into six sections, and should take between 45-60 minutes to complete. Please remember that all information is treated fully confidentially. Please answer as honestly as possible. Your completion and submission of this online questionnaire implies consent for us to use your data in our research. Thank you very much for your assistance.

Before proceeding, please check the following box to confirm you are aged 18 or over ☐

| |
|--|
| Section 1. (Background Questions) |
|--|

The following background questions are related to you and your family.

What Is Your Year of Birth: _____

What is the highest level of education you have completed: _____

Including yourself, how many people live in your household? _____

How many children, under the age of 18, currently live in your household? _____

How many of your children have received a diagnosis of autism _____

Have any of your children received a diagnosis, now, or in the past, of any of the following:

Attention Deficit Hyperactivity Disorder ☐

Oppositional Defiant Disorder ☐

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Learning Disorder ☐

Conduct Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Asperger's Syndrome ☐

Other (Please State) _____

What is your marital status? Married/partner ☐ Separated/Divorced ☐ Widowed ☐
Single ☐

Are you currently employed? Full time ☐ Part time ☐ Not employed ☐

Have you ever received a diagnosis of, or ever been treated for, any of the following:

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Social Phobia ☐

Asperger's Syndrome ☐

Autism ☐

Other Mental Disorder (Please State) _____

Do you have any current diagnosed medical conditions for which you are receiving treatment? Yes ☐ No ☐

If 'yes', what medical conditions are you currently receiving treatment for?

| |
|------------------------------------|
| Section 2. (Social Support) |
|------------------------------------|

The following questions relate to your social support network.

Please read each of the statements below, and indicate the extent of your agreement / disagreement by selecting one of the numbers 1(strongly disagree) to 5(strongly agree):

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Neither Agree Nor Disagree
- 4 Agree
- 5 Strongly Agree

- | | | | | | |
|--|---|---|---|---|---|
| 1. There is a special person who is around when you are in need. | 1 | 2 | 3 | 4 | 5 |
| 2. There is a special person who is a real source of comfort to you. | 1 | 2 | 3 | 4 | 5 |
| 3. You have a special person who is willing and able to help you financially. | 1 | 2 | 3 | 4 | 5 |
| 4. Your family really tries to help you. | 1 | 2 | 3 | 4 | 5 |
| 5. You get the emotional help and support you need from your family. | 1 | 2 | 3 | 4 | 5 |
| 6. Your friends really try to help you. | 1 | 2 | 3 | 4 | 5 |
| 7. You can count on your friends when things go wrong. | 1 | 2 | 3 | 4 | 5 |
| 8. You can really talk about your problems with your family. | 1 | 2 | 3 | 4 | 5 |
| 9. You have friends with whom you can share your joys and sorrows. | 1 | 2 | 3 | 4 | 5 |
| 10. Your family is willing to help you make decisions. | 1 | 2 | 3 | 4 | 5 |
| 11. You have some family or friends who are willing and able to help you financially. | 1 | 2 | 3 | 4 | 5 |
| 12. You have some family and friends who help you care for your child(ren) with autism? | 1 | 2 | 3 | 4 | 5 |

Section 3. (How You are Currently Feeling)

The following questions relate to how you felt over the past seven days. Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

| | | | | | |
|----|--|---|---|---|---|
| 1 | I found it hard to wind down | 0 | 1 | 2 | 3 |
| 2 | I was aware of dryness of my mouth | 0 | 1 | 2 | 3 |
| 3 | I couldn't seem to experience any positive feeling at all | 0 | 1 | 2 | 3 |
| 4 | I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| 5 | I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |
| 6 | I tended to over-react to situations | 0 | 1 | 2 | 3 |
| 7 | I experienced trembling (eg, in the hands) | 0 | 1 | 2 | 3 |
| 8 | I felt that I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| 9 | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| 10 | I felt that I had nothing to look forward to | 0 | 1 | 2 | 3 |
| 11 | I found myself getting agitated | 0 | 1 | 2 | 3 |
| 12 | I found it difficult to relax | 0 | 1 | 2 | 3 |
| 13 | I felt down-hearted and blue | 0 | 1 | 2 | 3 |
| 14 | I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| 15 | I felt I was close to panic | 0 | 1 | 2 | 3 |
| 16 | I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| 17 | I felt I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| 18 | I felt that I was rather touchy | 0 | 1 | 2 | 3 |
| 19 | I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| 20 | I felt scared without any good reason | 0 | 1 | 2 | 3 |
| 21 | I felt that life was meaningless | 0 | 1 | 2 | 3 |

| |
|--|
| Section 4. (Your Child With Autism) |
|--|

The following questions relate to your child with a diagnosis of autism. If you have more than one child with a diagnosis of autism, please complete these questions for only ONE child diagnosed with autism between the ages of 6 years and 17 years 11 months.

How old is your child? _____ Years _____ Months

What sex is your child? Male ☐ Female ☐

Is your child an eldest, middle, youngest or only child? Eldest ☐ Middle ☐ Youngest ☐ Only Child ☐

When at home, are you the primary carer for your child? Yes ☐ No ☐

What is your relationship with your child? Biological father ☐ Step Father ☐ Foster Father ☐ Other (Please State) _____

Has your child with a diagnosis of autism additionally received a diagnosis, now, or in the past, of any of the following:

Attention Deficit Hyperactivity Disorder ☐

Oppositional Defiant Disorder ☐

Anxiety ☐

Depression ☐

Bipolar Disorder ☐

Learning Disorder ☐

Conduct Disorder ☐

Anorexia ☐

Bulimia ☐

Schizophrenia ☐

Asperger's Syndrome ☐

Other (Please State) _____

For the following eleven items, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour ***over the last six months.***

| | Not True | Somewhat True | Certainly True |
|---|--------------------------|--------------------------|--------------------------|
| Often has temper tantrums or hot tempers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Restless, overactive, cannot stay still for long | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Generally well-behaved, usually does what adults request | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Constantly fidgeting or squirming | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often fights with other children or bullies them | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Easily distracted, concentration wanders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often lies or cheats | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Thinks things out before acting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Takes things without permission from home, school or elsewhere | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sees tasks through to the end, good attention span | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Often aggressive or violent towards adults | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

For the following set of items, also related to your child with autism, please answer each question by choosing *yes* or *no*. A few questions ask about several related types of behavior; please circle *yes* if *any* of these behaviours were present during the ***past 3 months.*** Although you may be uncertain about whether some behaviors were present or not, please answer *yes* or *no* to every question on the basis of what you think.

- Is she/he now able to talk using short phrases or sentences? If *no*, skip to question 8. Yes No
- Do you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said? Yes No
- Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)? Yes No
- Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times? Yes No

- | | | |
|---|-----|----|
| 5. Does she/he ever get her/his pronouns mixed up (e.g., saying <i>you</i> for <i>she/he</i> for <i>I</i>)? | Yes | No |
| 6. Does she/he ever use words that she/he seems to have invented or made up her/himself; put things in odd, indirect ways; or use metaphorical ways of saying things (e.g., saying hot rain for steam)? | Yes | No |
| 7. Does she/he ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again? | Yes | No |
| 8. Does she/he ever have things that she/he seems to have to do in a very particular way or order or rituals that she/he insists that you go through? | Yes | No |
| 9. Does her/his facial expression usually seem appropriate to the particular situation, as far as you can tell? | Yes | No |
| 10. Does she/he ever use your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger or putting your hand on a doorknob to get you to open the door)? | Yes | No |
| 11. Does she/he ever have any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)? | Yes | No |
| 12. Does she/he ever seem to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than in using the object as it was intended? | Yes | No |
| 13. Does she/he ever have any special interests that are unusual in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains or dinosaurs)? | Yes | No |
| 14. Does she/he ever seem to be unusually interested in the sight, feel, sound, taste, or smell of things or people? | Yes | No |
| 15. Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes? | Yes | No |
| 16. Does she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down? | Yes | No |
| 17. Does she/he ever injure her/himself deliberately, such as by biting her/his arm or banging her/his head? | Yes | No |

| | | |
|---|-----|----|
| 18. Does she/he ever have any objects (other than a soft toy or comfort blanket) that she/he has to carry around? | Yes | No |
| 19. Does she/he have any particular friends or a best friend? | Yes | No |
| 20. Does she/he ever talk with you just to be friendly (rather than to get something)? | Yes | No |
| 21. Does she/he ever spontaneously copy you (or other people) or what you are doing (such as vacuuming, gardening, or mending things)? | Yes | No |
| 22. Does she/he ever spontaneously point at things around her/him just to show you things (not because she/he wants them)? | Yes | No |
| 23. Does she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wants? | Yes | No |
| 24. Does she/he nod her/his head to indicate yes? | Yes | No |
| 25. Does she/he shake her/his head to indicate no? | Yes | No |
| 26. Does she/he usually look at you directly in the face when doing things with you or talking with you? | Yes | No |
| 27. Does she/he smile back if someone smiles at her/him? | Yes | No |
| 28. Does she/he ever show you things that interest her/him to engage your attention? | Yes | No |
| 29. Does she/he ever offer to share things other than food with you? | Yes | No |
| 30. Does she/he ever seem to want you to join in her/his enjoyment of something? | Yes | No |
| 31. Does she/he ever try to comfort you if you are sad or hurt? | Yes | No |
| 32. If she/he wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention? | Yes | No |
| 33. Does she/he show a normal range of facial expressions? | Yes | No |
| 34. Does she/he ever spontaneously join in and try to copy the actions in social games, such as The Mulberry Bush or London Bridge Is Falling Down? | Yes | No |
| 35. Does she/he play any pretend or make-believe games? | Yes | No |
| 36. Does she/he seem interested in other children of approximately the same age whom she/he does not know? | Yes | No |
| 37. Does she/he respond positively when another child approaches her/him? | Yes | No |

- | | | |
|--|-----|----|
| 38. If you come into a room and start talking to her/him without calling her/his name, does she/he usually look up and pay attention to you? | Yes | No |
| 39. Does she/he ever play imaginative games with another child in such a way that you can tell that each child understands what the other is pretending? | Yes | No |
| 40. Does she/he play cooperatively in games that need some form of joining in with a group of other children, such as hide-and-seek or ball games? | Yes | No |
| 41. Is she/he able to dress independently, or without considerable assistance from someone else? (Note: <i>needing help to tie shoelaces would not be considered 'considerable assistance'</i>) | Yes | No |
| 42. Is she/he able to go to the toilet independently, or without considerable assistance from someone else? (Note: <i>needing to be reminded to wash hands or flush the toilet would not be considered 'considerable assistance'</i>) | Yes | No |
| 43. Is she/he able to bath/shower independently, or without considerable assistance from someone else? (Note: <i>needing help turning on the shower or running the bath would not be considered 'considerable assistance'</i>) | Yes | No |

Section 5. (Your Relationship with Your Child With Autism)

The statements below describe different ways some parents feel about their children. For each statement, decide how you feel. When the question refers to 'my child', it is referring to the same child with autism you were asked about in the previous section of this questionnaire. For each question, please answer as follows: If you *strongly disagree*, select the 1 next to the statement number. If you *disagree*, select the 2. If you *agree*, select the 3. If you *strongly agree*, select the 4. Please make sure you select the correct response.

Try to respond to all of the statements. If you aren't sure you you feel, mark the response that comes closest to your feelings at this time. *There are no right or wrong answers.*

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

- | | | | | |
|--|---|---|---|---|
| 1. I have trouble disciplining my child. | 1 | 2 | 3 | 4 |
| 2. I get as much satisfaction from my child as other parents do. | 1 | 2 | 3 | 4 |
| 3. I have a hard time getting through to my child. | 1 | 2 | 3 | 4 |
| 4. I spend a great deal of time with my child. | 1 | 2 | 3 | 4 |
| 5. My feelings about being a parent change from day to day. | 1 | 2 | 3 | 4 |
| 6. My child is more difficult to care for than most children are. | 1 | 2 | 3 | 4 |
| 7. Being a parent comes naturally to me. | 1 | 2 | 3 | 4 |
| 8. I sometimes give in to my child to avoid a tantrum. | 1 | 2 | 3 | 4 |
| 9. I love my child just the way he or she is. | 1 | 2 | 3 | 4 |
| 10. My child is never jealous of others. | 1 | 2 | 3 | 4 |
| 11. I often wonder what the rewards are in raising children. | 1 | 2 | 3 | 4 |
| 12. I wish I could set firmer limits with my child. | 1 | 2 | 3 | 4 |
| 13. I get a great deal of satisfaction from having | | | | |

| | | | | |
|--|---|---|---|---|
| children. | 1 | 2 | 3 | 4 |
| 14. I regret having children. | 1 | 2 | 3 | 4 |
| 15. My child is out of control much of the time. | 1 | 2 | 3 | 4 |
| 16. Being a parent isn't as satisfying as I thought it would be. | 1 | 2 | 3 | 4 |
| 17. I never worry about my child. | 1 | 2 | 3 | 4 |
| 18. I wish my child would not interrupt when I'm talking to someone else. | 1 | 2 | 3 | 4 |
| 19. I feel very close to my child. | 1 | 2 | 3 | 4 |
| 20. I never have had any problems with my child. | 1 | 2 | 3 | 4 |
| 21. I often lose my temper with my child. | 1 | 2 | 3 | 4 |
| 22. I am very involved with my child's sports or other activities. | 1 | 2 | 3 | 4 |
| 23. I have never been embarrassed by anything my child has said or done. | 1 | 2 | 3 | 4 |
| 24. My child really knows how to make me angry. | 1 | 2 | 3 | 4 |
| 25. My child never puts off doing things that should be done right away. | 1 | 2 | 3 | 4 |
| 26. Being a parent is one of the most important things in my life. | 1 | 2 | 3 | 4 |
| 27. I feel I don't really know my child. | 1 | 2 | 3 | 4 |
| 28. I sometimes find it hard to say no to my child. | 1 | 2 | 3 | 4 |
| 29. I wonder if I did the right thing having children. | 1 | 2 | 3 | 4 |
| 30. I would really rather do a lot of other things than spend time with my child. | 1 | 2 | 3 | 4 |
| 31. It's a parent's responsibility to protect his or her child from harm. | 1 | 2 | 3 | 4 |
| 32. I sometimes wonder how I would survive if anything were to happen to my child. | 1 | 2 | 3 | 4 |
| 33. My child rarely interacts with me unless he or she wants something. | 1 | 2 | 3 | 4 |
| 34. I spend very little time interacting with my child. | 1 | 2 | 3 | 4 |

| | | | | |
|---|---|---|---|---|
| 35. I feel there is a great distance between me and my child. | 1 | 2 | 3 | 4 |
| 36. I often threaten to punish my child but never do. | 1 | 2 | 3 | 4 |
| 37. If I had it to do over, I would probably not have had children. | 1 | 2 | 3 | 4 |
| 38. Some people would say that my child is a bit spoiled. | 1 | 2 | 3 | 4 |
| 39. I seldom have time to spend with my child. | 1 | 2 | 3 | 4 |
| 40. I carry a photograph of my child in my wallet or purse. | 1 | 2 | 3 | 4 |
| 41. I feel I don't know how to communicate with my child in a way that he or she really understands. | 1 | 2 | 3 | 4 |

| |
|--|
| Section 6. (Your Thoughts on Parenting) |
|--|

The following questions relate to your thoughts and opinions on parenting. When the question refers to 'my child', it is referring to the same child with autism you were asked about in the previous sections of this questionnaire. Please read each of the statements below, and indicate the extent of your agreement / disagreement by circling one of the numbers 1 (strongly disagree) to 5 (strongly agree):

The rating scale is as follows:

- 1 Strongly Disagree
- 2 Disagree
- 3 Neither Agree Nor Disagree
- 4 Agree
- 5 Strongly Agree

- | | | | | | |
|---|---|---|---|---|---|
| 1. What I do has little effect on my child's behaviour. | 1 | 2 | 3 | 4 | 5 |
| 2. When something goes wrong between me and my child, there is little I can do to correct it. | 1 | 2 | 3 | 4 | 5 |
| 3. Parents should address problems with their children because ignoring them won't make them go away. | 1 | 2 | 3 | 4 | 5 |
| 4. If your child tantrums no matter what you try, you might as well give up. | 1 | 2 | 3 | 4 | 5 |
| 5. My child usually ends up getting his/her way, so why try | 1 | 2 | 3 | 4 | 5 |
| 6. No matter how hard a parent tries, some children will never learn to mind. | 1 | 2 | 3 | 4 | 5 |
| 7. I am often able to predict my child's behaviour in situations. | 1 | 2 | 3 | 4 | 5 |
| 8. It is not always wise to expect too much from my child because many things turn out to be a matter of good or bad luck anyway. | 1 | 2 | 3 | 4 | 5 |
| 9. When my child gets angry, I can usually deal with him/her if I stay calm. | 1 | 2 | 3 | 4 | 5 |
| 10. When I set expectations for my child, I am almost | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| certain that I can help him/her meet them ` | 1 | 2 | 3 | 4 | 5 |
| 11. There is no such thing as good or bad children- just good or bad parents. | 1 | 2 | 3 | 4 | 5 |
| 12. When my child is well-behaved, it is because he/she is responding to my efforts. | 1 | 2 | 3 | 4 | 5 |
| 13. Parents who can't get their children to listen to them don't understand how to get along with their children. | 1 | 2 | 3 | 4 | 5 |
| 14. My child's behavior problems are no one's fault but my own. | 1 | 2 | 3 | 4 | 5 |
| 15. Capable people who fail to become good parents have not followed through on their opportunities. | 1 | 2 | 3 | 4 | 5 |
| 16. Children's behavior problems are often due to mistakes their parents made. | 1 | 2 | 3 | 4 | 5 |
| 17. Parents whose children make them feel helpless just aren't using the best parenting techniques. | 1 | 2 | 3 | 4 | 5 |
| 18. Most childrens' behavior problems would not have developed if their parents had had better parenting skills. | 1 | 2 | 3 | 4 | 5 |
| 19. I am responsible for my child's behaviour. | 1 | 2 | 3 | 4 | 5 |
| 20. The misfortunes and successes I have had as a parent are the direct result of my behaviour. | 1 | 2 | 3 | 4 | 5 |
| 21. My life is chiefly controlled by my child. | 1 | 2 | 3 | 4 | 5 |
| 22. My child does not control my life. | 1 | 2 | 3 | 4 | 5 |
| 23. My child influences the number of friends I have. | 1 | 2 | 3 | 4 | 5 |
| 24. I feel like what happens in my life is mostly determined by my child. | 1 | 2 | 3 | 4 | 5 |
| 25. It is easy for me to avoid and function independently of my child's attempts to have control over me. | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| 26. When I make a mistake with my child I am usually able to correct it. | 1 | 2 | 3 | 4 | 5 |
| 27. Even if your child frequently tantrums, a parent should not give up. | 1 | 2 | 3 | 4 | 5 |
| 28. Being a good parent often depends on being lucky enough to have a good child. | 1 | 2 | 3 | 4 | 5 |
| 29. I'm just one of those lucky parents who happened to have a good child. | 1 | 2 | 3 | 4 | 5 |
| 30. I have often found that when it comes to my children, what will happen will happen. | 1 | 2 | 3 | 4 | 5 |
| 31. Fate was kind to me-if I had had a bad child I don't know what I would have done. | 1 | 2 | 3 | 4 | 5 |
| 32. Success in dealing with children seems to be more a matter of the child's moods and feelings at the time rather than one's own actions. | 1 | 2 | 3 | 4 | 5 |
| 33. Neither my child nor myself is responsible for his/her behavior | 1 | 2 | 3 | 4 | 5 |
| 34. In order to have my plans work, I make sure they fit in with the desires of my child. | 1 | 2 | 3 | 4 | 5 |
| 35. Most parents don't realize the extent to which how their children turn out is influenced by accidental happenings. | 1 | 2 | 3 | 4 | 5 |
| 36. Heredity plays the major role in determining a child's personality. | 1 | 2 | 3 | 4 | 5 |
| 37. Without the right breaks one cannot be an effective parent. | 1 | 2 | 3 | 4 | 5 |
| 38. I always feel in control when it comes to my child | 1 | 2 | 3 | 4 | 5 |
| 39. My child's behavior is sometimes more than I can handle. | 1 | 2 | 3 | 4 | 5 |
| 40. Sometimes I feel that my child's behavior is hopeless. | 1 | 2 | 3 | 4 | 5 |
| 41. It is often easier to let my child have his/her way | | | | | |

| | | | | | |
|--|---|---|---|---|---|
| than to put up with a tantrum. | 1 | 2 | 3 | 4 | 5 |
| 42. I find that sometimes my child can get me to do things I really did not want to do. | 1 | 2 | 3 | 4 | 5 |
| 43. My child often behaves in a manner very different from the way I would want him/her to behave. | 1 | 2 | 3 | 4 | 5 |
| 44. Sometimes when I'm tired I let my children do things I normally wouldn't. | 1 | 2 | 3 | 4 | 5 |
| 45. Sometimes I feel that I do not have enough control over the direction my child's life is taking. | 1 | 2 | 3 | 4 | 5 |
| 46. I allow my child to get away with things. | 1 | 2 | 3 | 4 | 5 |
| 47. It is not too difficult to change my child's mind about something. | 1 | 2 | 3 | 4 | 5 |

Thank you for taking the time to complete this questionnaire. Your assistance with our research is greatly appreciated.

Appendix C

Correlation Statistics – Study One

Correlation statistics for Study One are shown in Table 22 below.

Table 22

Pearson Correlation Statistics For Variables Included in Regression Analyses.

| Variable | Stress | Anx | Dep | Age M | Age C | Soc S | Eco S | Hyp |
|---------------|--------|--------|---------|--------|-------|--------|--------|--------|
| <i>Stress</i> | - | - | - | - | - | - | - | - |
| <i>Anx</i> | .68** | - | - | - | - | - | - | - |
| <i>Dep</i> | .71* | .61* | - | - | - | - | - | - |
| <i>Age M</i> | -.25** | -.25** | -.09 | - | - | - | - | - |
| <i>Age C</i> | -.13* | -.080 | -.01 | .54** | - | - | - | - |
| <i>Soc S</i> | -.23** | -.20** | -.35** | -.08 | -.11 | - | - | - |
| <i>Eco S</i> | -.04 | -.07 | -.200** | -.03 | -.13* | .60** | - | - |
| <i>Hyp</i> | .29** | .21** | .23** | -.20** | -.12 | -.15* | -.04 | - |
| <i>Cond</i> | .31** | .31** | .24** | -.11 | .00 | -.10 | -.08 | .36** |
| <i>Aggr</i> | .28** | .30** | .27** | -.16* | -.07 | -.10 | -.10 | .24** |
| <i>Aut</i> | .28** | .36** | .30** | -.05 | .01 | -.26** | -.19** | .30** |
| <i>Dev</i> | -.16* | -.16* | -.16* | .28** | .45** | .09 | -.04 | -.31** |
| <i>Lim</i> | -.41** | -.32** | -.31** | .06 | .04 | .19** | .07 | -.28** |
| <i>Satis</i> | -.17** | -.06 | -.22** | -.05 | -.00 | .20** | .01 | -.08 |
| <i>Inv</i> | -.21** | -.12 | -.23** | .03 | -.08 | .16* | .09 | -.15* |
| <i>LoC</i> | .38** | .27** | .34** | -.01 | .04 | -.23** | -.20** | .20** |

| Variable | Cond | Aggr | Aut | Dev | Lim | Satis | Inv | LoC |
|---------------|--------|--------|--------|------|--------|--------|-------|-----|
| <i>Stress</i> | - | - | - | - | - | - | - | - |
| <i>Anx</i> | - | - | - | - | - | - | - | - |
| <i>Dep</i> | - | - | - | - | - | - | - | - |
| <i>Age M</i> | - | - | - | - | - | - | - | - |
| <i>Age C</i> | - | - | - | - | - | - | - | - |
| <i>Soc S</i> | - | - | - | - | - | - | - | - |
| <i>Eco S</i> | - | - | - | - | - | - | - | - |
| <i>Hyp</i> | - | - | - | - | - | - | - | - |
| <i>Cond</i> | - | - | - | - | - | - | - | - |
| <i>Aggr</i> | .61** | - | - | - | - | - | - | - |
| <i>Aut</i> | .35** | .36** | - | - | - | - | - | - |
| <i>Dev</i> | -.03 | -.18** | -.30** | - | - | - | - | - |
| <i>Lim</i> | -.53** | -.35** | -.23** | .00 | - | - | - | - |
| <i>Satis</i> | -.25** | -.15* | -.13* | .00 | .34** | - | - | - |
| <i>Inv</i> | -.31** | -.18** | -.27** | .02 | .28** | .61** | - | - |
| <i>LoC</i> | .41** | .35** | .35** | -.11 | -.59** | -.33** | -.36* | - |

Note: SD = standard deviation, Anx = Anxiety, Dep = Depression, Age M = Age of Mother, Age C = Age of Child, Soc S = Social Support, Eco S = Economic Support, Hyp = Hyperactive Behaviour, Cond = Conduct Problems, Aggr = Aggressive Behaviour, Aut = Autism Symptom Severity, Dev = Developmental Age, Lim = Perceived Limit Setting Ability, Satis = Satisfaction with Parenting, Inv = Perceived Maternal Involvement, LoC = Parental Locus of Control, ** = Correlation is significant at the 0.01 level (2-tailed), * = Correlation is significant at the 0.05 level (2-tailed)

Correlation Statistics – Study Two

Correlation statistics for Study Two are shown in Table 23 below.

Table 23

Pearson Correlation Statistics For Variables Included in Regression Analyses.

| Variable | Stress | Anx | Dep | Age F | Age C | Soc S | Eco S | Hyp |
|---------------|--------|--------|--------|--------|-------|--------|--------|--------|
| <i>Stress</i> | - | - | - | - | - | - | - | - |
| <i>Anx</i> | .71** | - | - | - | - | - | - | - |
| <i>Dep</i> | .73** | .68** | - | - | - | - | - | - |
| <i>Age F</i> | -.20** | -.08 | -.09 | - | - | - | - | - |
| <i>Age C</i> | -.05 | -.06 | -.01 | .49** | - | - | - | - |
| <i>Soc S</i> | -.26** | -.25** | -.26** | -.01 | -.03 | - | - | - |
| <i>Eco S</i> | -.17 | -.14* | -.18** | .01 | .01* | .53** | - | - |
| <i>Hyp</i> | .28** | .15* | .19** | -.23** | -.15* | -.15* | -.11* | - |
| <i>Cond</i> | .32** | .26** | .31** | -.18** | .02 | -.13* | -.20** | .32** |
| <i>Aggr</i> | .22** | .26** | .25** | -.07 | .03 | -.05 | -.23** | .24** |
| <i>Aut</i> | .12* | .06 | .15* | -.05 | .02 | -.17** | -.09 | .33** |
| <i>Dev</i> | -.01 | -.02 | -.07 | .19** | .41** | .01 | .02 | -.15* |
| <i>Lim</i> | -.40** | -.28** | -.41** | .11 | .00 | .15* | .17** | -.34** |
| <i>Satis</i> | -.22** | -.10 | -.39** | -.03 | -.08 | .32** | .17** | -.13* |
| <i>Inv</i> | -.15* | -.09 | -.26** | .03 | -.13* | .34** | .20** | -.11* |
| <i>LoC</i> | .29** | .24** | .41** | .03 | -.01 | -.25** | -.16** | .21** |

| Variable | Cond | Aggr | Aut | Dev | Lim | Satis | Inv | LoC |
|---------------|--------|--------|--------|--------|--------|--------|--------|-----|
| <i>Stress</i> | - | - | - | - | - | - | - | - |
| <i>Anx</i> | - | - | - | - | - | - | - | - |
| <i>Dep</i> | - | - | - | - | - | - | - | - |
| <i>Age M</i> | - | - | - | - | - | - | - | - |
| <i>Age C</i> | - | - | - | - | - | - | - | - |
| <i>Soc S</i> | - | - | - | - | - | - | - | - |
| <i>Eco S</i> | - | - | - | - | - | - | - | - |
| <i>Hyp</i> | - | - | - | - | - | - | - | - |
| <i>Cond</i> | - | - | - | - | - | - | - | - |
| <i>Aggr</i> | .65** | - | - | - | - | - | - | - |
| <i>Aut</i> | .18** | .16** | - | - | - | - | - | - |
| <i>Dev</i> | -.03 | -.06 | -.31** | - | - | - | - | - |
| <i>Lim</i> | -.62** | -.54** | -.18** | .02 | - | - | - | - |
| <i>Satis</i> | -.23** | -.12* | -.17** | .03 | .35** | - | - | - |
| <i>Inv</i> | -.28** | -.08 | -.24** | .02 | .30** | .65** | - | - |
| <i>LoC</i> | .42** | .40** | .23** | -.19** | -.65** | -.46** | -.34** | - |

Note: SD = standard deviation, Anx = Anxiety, Dep = Depression, Age F = Age of Father, Age C = Age of Child, Soc S = Social Support, Eco S = Economic Support, Hyp = Hyperactive Behaviour, Cond = Conduct Problems, Aggr = Aggressive Behaviour, Aut = Autism Symptom Severity, Dev = Developmental Age, Lim = Perceived Limit Setting Ability, Satis = Satisfaction with Parenting, Inv = Perceived Paternal Involvement, LoC = Parental Locus of Control, ** = Correlation is significant at the 0.01 level (2-tailed), * = Correlation is significant at the 0.05 level (2-tailed)