

Predictors of Better Health Outcomes in Mothers of Children with
Autistic Spectrum Disorder

by

Paula S. Hutchinson

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy

at

Dalhousie University
Halifax, Nova Scotia
April 2010

© Copyright by Paula S. Hutchinson, 2010

DALHOUSIE UNIVERSITY

DALHOUSIE UNIVERSITY

DATE: April 13, 2010

AUTHOR: Paula S. Hutchinson

TITLE: Predictors of Better Health Outcomes in Mothers of Children with
Autistic Spectrum Disorder

DEPARTMENT OR SCHOOL: Interdisciplinary PHD Program

DEGREE: PHD CONVOCATION: May YEAR: 2010

Permission is herewith granted to Dalhousie University to circulate and to have copied for non-commercial purposes, at its discretion, the above title upon the request of individuals or institutions.

Signature of Author

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

The author attests that permission has been obtained for the use of any copyrighted material appearing in the thesis (other than the brief excerpts requiring only proper acknowledgement in scholarly writing), and that all such use is clearly acknowledged.

I dedicate this dissertation to:

Sylvia MacDonald for teaching me about courage and resilience;

Elizabeth Allard for inspiring my thirst for knowledge;

Dawn LeBlanc for sharing my passion and optimism that we can make a difference...

“Don’t let reality discourage you!”;

Susan Bryson for teaching me how to assimilate my persistence, knowledge, and passion
into a positive “voice” for change.

Table of Contents

List of Tables	viii
List of Figures	ix
List of Abbreviations Used	x
Abstract	xi
Acknowledgements	xii
Chapter 1 Introduction	1
Autistic Spectrum Disorders	2
Autistic Spectrum Disorder as a Stressor	4
Distress in Mothers of Children with Autism	7
Supports	10
Perceptions of the Stressor and Coping	14
Maternal Strengths	15
Self-efficacy	16
Empowerment	19
Positive Perceptions of Parenting	21
Strengths-based ABCX Model of Maternal Adjustment	24
Present Study	27
Chapter 2 Method	30
Participants	30
Procedure	33
Measures of the Strengths-based ABCX Model	35
Demographics	35

Stressor (A).....	35
Children’s Difficult Behaviour.....	35
Resources (B).....	36
Informal and Formal support.....	36
Perception of Strengths (C).....	36
Self-Efficacy.....	36
Empowerment.....	37
Adjustment Outcome (X).....	38
Maternal Distress.....	38
Positive Perceptions of Parenting.....	38
Data Analyses.....	39
Power Analysis.....	39
Data Analyses Overview.....	39
Chapter 3 Results.....	41
Preliminary Exploratory Analysis.....	41
Missing Data Analysis.....	41
Exploratory Descriptive, Correlation and Regression Analysis.....	41
Main Analyses.....	43
Descriptive Analyses.....	43
Correlation Analyses of Demographics with Predictor and Outcome Variables.....	45
Correlations of Predictor and Outcome Variables.....	47
Hierarchical Multiple Regression Analyses: Overview.....	48
Hierarchical Multiple Regression Analysis: Maternal Distress.....	48

Hierarchical Multiple Regression Analysis: Positive Perceptions of Parenting.....	52
Mediation Analyses: Maternal Distress.....	54
Mediation Analyses: Positive Perceptions of Parenting.....	56
Summary of Findings.....	57
Chapter 4 Discussion	60
Limitations	74
Directions for Future Research.....	76
Conclusions and Implications for Practice	79
References.....	81
Appendix A. Recruitment Letter to Parents.....	92
Appendix B. Demographic Questionnaire.....	93
Appendix C. Family Support Scale	95
Appendix D. Difficult Behaviour Self-Efficacy Scale	96
Appendix E. Family Empowerment Scale.....	97
Appendix F. Kansas Inventory of Parental Perceptions	99

List of Tables

Table 1. Mother Demographics	32
Table 2. Child Demographics	33
Table 3. Strengths-based ABCX Model Variables and Survey Measures.....	34
Table 4. Correlations among Predictor Variables.....	43
Table 5. Variable Means (SD) and Range	45
Table 6. Correlations between Demographic and Predictor Variables.....	46
Table 7. Correlations between Demographic and Outcome Variables.....	47
Table 8. Correlations for Predictor and Outcome Variables.....	48
Table 9. Summary of Hierarchical Regression Analysis for Variables Predicting Maternal Distress.....	51
Table 10. Summary of Hierarchical Regression Analysis for Variables Predicting Mothers' Positive Perceptions	53
Table 11. Summary of Hierarchical Regression for the Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Maternal Distress	55
Table 12. Summary of Hierarchical Regression for the Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Positive Perceptions of Parenting	57

List of Figures

Figure 1. Partial Regression Plot	50
Figure 2. Partial Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Maternal Distress.....	55
Figure 3. Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Positive Perceptions of Parenting	57

List of Abbreviations Used

ASD	Autistic Spectrum Disorder
DBC-P	Developmental Behaviour Checklist – Primary Carer Version
FES	Family Empowerment Scale
FSS	Family Support Scale
HADS	Hospital Anxiety and Depression Scale
KIPP-PC	Kansas Inventory of Parental Perceptions – Positive Contributions Scale
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder

Abstract

Caring for children with autism place mothers at high risk for poor health outcomes and compromises the health of all family members (e.g., Bristol, 1987; Hastings et al., 2005a). Although poor outcomes prevail, some mothers do well despite their caregiving challenges. While ample research exists on mothers' supports and stress, virtually nothing is known about their strengths. Emerging research suggests that parental self-efficacy and empowerment may contribute to better outcomes in mothers of children with autism. The purpose of the present study was to identify predictors of better outcomes in mothers of children with autism. Relationships among child disruptive behaviour, supports, self-efficacy, empowerment, maternal distress and positive perceptions of parenting were examined using a postal survey design. Mothers ($N = 114$) of school-age children with autism provided demographic information and completed various scales (i.e., the Developmental Behaviour Checklist, Family Support, Difficult Behaviour Self-Efficacy, Family Empowerment, Hospital Anxiety and Depression, Positive Contribution). Overall, 35% of the variance was explained in maternal distress (i.e., anxiety and depression). After accounting for mothers' age and child disruptive behaviour, support and empowerment were subsumed by parental self-efficacy in predicting lower levels of maternal distress. Collectively, 17% of the variance was explained in mothers' positive perceptions of parenting. Self-efficacy partially mediated the moderate effect of disruptive behaviour on mothers' distress and fully mediated the small effect of disruptive behaviour on mothers' positive perceptions of parenting. Thus, parental self-efficacy for managing children's difficult behaviour is very promising for preserving mothers' health. While discussion focuses on outstanding issues to be addressed, the findings suggest that tailoring formal services to enhance parental efficacy, rather than providing support and consultation services alone, would be more in line with mothers' needs and possibly improve both children's and families' outcomes.

Acknowledgements

I would like to thank a number of people for their generosity and support throughout my doctoral program.

I extend my sincerest gratitude to my faculty advisor and mentor Dr. Susan Bryson. Thank you for the countless hours you dedicated to supporting my development as an academic. I have truly appreciated your love of clear thinking and writing. Thank you for encouraging me to pursue my interests, and for your valuable guidance and feedback. You have been an enormous support to me throughout this process and I am grateful.

I would also like to thank my committee members Dr. Penny Corkum, Dr. Isabel Smith and Dr. Jerry Singleton. Your feedback throughout the dissertation process was invaluable. Thank you for your interest in my topic and your willingness to give advice. I have learned a great deal from working with all of you.

Thank you to my external examiner, Dr. Richard Hastings, whose incredible research paved the way for this dissertation. It was an honour to have you as my external.

Thank you to Dr. Nancy Garon, Dr. David Hamilton, and Dr. Lori Francis for guiding me through the statistical analyses. Also, thank you to the students who provided assistance on various aspects of this project: Alison Heard, Julie Longard, and Marie McIntosh.

This project would not have been possible without the participation of the families. Thank you for your notes of encouragement and interest in this research. I also gratefully acknowledge the generous funding support for this project from the Autism

Research Training Program, IWK Health Centre, Joan and Jack Craig, and the Nova Scotia Health Research Foundation.

My deepest gratitude and thanks belongs to Vicki Harvey, Dawn LeBlanc, Anne MacRae, and Sandra McFadyen, my co-founders of the Nova Scotia Partnership on Respite, Family Health and Well-being. Thank you for helping me to translate this research into education for the families, professionals, and policy-makers who want to use evidence to make a difference in people's lives.

Finally, this work would not have been possible without the support of my friends and family. I especially want to thank my husband, Scott, and my children, Mitchell and Douglas, for reminding me what is important in life. Thank you for your unconditional love and support. Thank you for always making me smile and laugh, I could not have done this without you!

Chapter 1 Introduction

For many years researchers have sought to understand the challenges of parenting children with autistic spectrum disorders, thus exposing the extraordinarily high care demands that this complex and life-long disorder places on families and, in particular, mothers (Bristol, 1979; 1987; Gray, 2006; Hastings et al., 2005a; Koegel et al., 1992). Indeed, evidence indicates that mothers are at highest risk for poor health, and that their poor health affects the health of all family members (Hastings et al., 2005). While poor maternal outcomes are prevalent and related to parental perceptions of caregiving burden, some mothers seem to cope well (Bristol, 1987). In an effort to understand how mothers sustain their health, research has focused on supports and coping strategies that might buffer mothers from poor outcomes (e.g., Bristol, 1987; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). These studies have provided a better understanding of mothers' stressors and needs but only modest or inconsistent evidence for factors that lead to better maternal outcomes (Boyd, 2002; Hastings & Beck, 2004; Hutchinson & Bryson, in preparation). Thus, an outstanding and key question is why some mothers report poor outcomes whereas others report good outcomes.

In an attempt to address this question, this thesis examines the relationships among child disruptive behaviour, support, parental self-efficacy, empowerment, and maternal distress and well-being (i.e., both maternal anxiety and depression and positive perceptions related to parenting a child with autistic spectrum disorder). The primary aims of this study were to identify the types of supports and parental strengths that might be associated with and possibly mediate the relationship between autism-related stressors and maternal outcomes. For this purpose, a survey of mothers raising school-age children

with autistic spectrum disorders was conducted, employing McCubbin and Patterson's (1983) ABCX model of parental adjustment but also including a strengths-based approach (hereafter referred to as the Strengths-based ABCX model). Thus, the present study is theoretically guided by a Strengths-based ABCX model of adjustment which assumes that mothers experience better outcomes when they view their children's difficult behaviour as manageable, perceive their supports as helpful, and are confident in managing their family life and children's service needs.

The dissertation begins with a brief description of the nature of autistic spectrum disorders and its relationship with maternal and family pathology. This is followed by a review of the evidence on family support, maternal self-efficacy and empowerment. Next, these constructs are discussed with regard to their utility in extending the ABCX model to include maternal strengths and positive outcomes. I then describe the method and results of the present study, and conclude with a discussion of the findings, and by highlighting questions for further research.

Autistic Spectrum Disorders

The Autistic Spectrum Disorders (ASDs) are a group of related, chronic conditions that include Autism, Pervasive Developmental Disorders-Not Otherwise Specified and Asperger syndrome (American Psychiatric Association [APA], 2000). These disorders are characterized by impairments in communication, social interaction, and a tendency to engage in restricted and repetitive behaviours and routines (APA, 2000). In each of these domains, symptoms vary in presentation and severity across the spectrum. While the signs of autistic spectrum disorders become increasingly more evident to parents within the first and second year of development, most children are not

diagnosed until they are 4 years of age or older (Center for Disease Control [CDC], 2010; Landa & Garrett-Mayer, 2006). Prevalence of the ASDs is one in 100-150 individuals, and males are four times more likely to have ASD than females (CDC, 2010; Kogan et al., 2009). ASD symptoms not only vary with the developmental levels of those affected but also in severity. Therefore, although improvements can be realized through treatment and education, most individuals with ASD will need some form of ongoing support to cope with their daily communication, social and behavioural challenges (Howlin, 1998).

In ASD, communication deficits may be apparent in language delays, repetitive use of language (e.g., echolalia), and a lack of functional communication skills (Loucas et al., 2008). The social deficits include a lack of eye contact, difficulty sharing interests with others, and a lack of emotional reciprocity. Affected individuals also have a high need for routine, display a restricted range of interests, and engage in repetitive behaviors (Charman & Baird, 2002). In addition to the core diagnostic features, ASD's may co-occur with sensory processing deficits (e.g., hyper- and hypo-sensitivities), chronic medical conditions (e.g., epilepsy) and known genetic disorders such as tuberous sclerosis and Fragile X syndrome (Baranek, David, Poe, Stone, & Watson, 2006; Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004). Individually, each one of these difficulties can be challenging, but collectively they place a high demand on parents. Parents may feel overwhelmed by their children's developmental deficits, and their related sensory and/or medical conditions, particularly when families envision a poor prognosis and related long-term support needs (Midence & O'Neill, 1999; Gray, 2006). Thus, much research has been devoted to understanding the particular effects of ASD on parental and family adjustment. This literature typically refers to autistic spectrum

disorders as autism (e.g., Bebko, Konstantareas, & Springer, 1987; Donenberg & Baker, 1993; Hastings et al., 2005a; Howlin & Moore, 1997). Thus, hereafter the term “autism” will be used to represent the spectrum of autistic disorders.

Autistic Spectrum Disorder as a Stressor

In the early years and as children mature, parents are likely to express serious concerns about autistic symptoms (e.g., communication, social skills, narrow interests) and difficult behaviours (e.g., tantrums and physical aggression; Howlin & Moore, 1997). In order to address key parental concerns, several studies have been conducted to determine whether autistic symptoms or characteristics are differentially predictive of maternal stress, anxiety or depression.

In the first of a series of studies designed to understand which characteristics of autism are most stressful for parents, Bebko et al. (1987) compared clinicians’ and parents’ ratings of the severity of children’s autistic symptoms, and their relationship with parental stress. Independent of the children’s ages (range: 6 to 18 year-olds, with no mean reported), both groups rated the cognitive and communication impairments as most severe. Specifically, parents of both younger and older children were most concerned with social deficits and communication difficulties. These symptoms were related to high stress levels in both mothers and fathers of younger children. Mothers of older children reported lower stress levels than parents of younger children. In contrast, fathers’ stress levels remained high and comparable to those of parents with younger children. Bebko et al. (1987) suggested that low stress in mothers of older children was an indication of their acceptance of their children’s condition, whereas high stress in fathers might reflect the

realization that their older children with communication and social deficits would require long-term care.

Further evidence for autism-related stress in parents was found by Konstantareas and Homatidis (1989). They compared clinicians' and parents' ratings of symptom severity in young children ($M = 6.9$ years; range = 2.4 to 12.7 year-olds) with parents' self-reports of stress. Both clinicians and parents rated impaired verbal communication, uneven cognitive function, and lack of social skills as the most severe symptoms. Mothers' and fathers' stress scores were not significantly different but both were high and positively related to children's autistic symptoms. While parents' stress levels were similar, they were differentially related to their children's behaviour. Mothers' stress scores were predicted by their children's self-stimulatory behaviour, visual preoccupations and inappropriate affect, while fathers' stress scores were predicted by their children's lack of verbal communication and anxiety reactions. Thus, the findings indicate that different aspects of children's behaviour were more stressful for mothers than for fathers.

Donenberg and Baker (1993) conducted the first study to compare the behavioural profiles of young children for their effect on family functioning. For this purpose they surveyed mothers of young children (range = 3.5 to 6 year-olds) with three behavioural profiles (i.e., children with autism vs. typically developing with externalizing behavior vs. typically developing without externalizing behaviour). Stress scores for mothers of children with autism and mothers of children with externalizing behaviour were indistinguishable, but both were significantly higher than those for mothers of typically developing children without externalizing behaviour. These findings suggest that

syndrome-specific characteristics may not be the most salient predictor of stress in mothers of children with autism. Instead, maternal perceptions of children's externalizing behaviour regardless of the disorder may be a better predictor of maternal stress.

In a mainly descriptive study of families with children who have autism, Sharpley, Bitsika, and Efremidis (1997) examined parents' perceptions of their parenting confidence, stress, anxiety and depression. Over half of parents rated their daily stress as high to very high. Over one quarter of parents reported anxiety in the high to severe range, and 19% of parents reported depression ranging from moderate to severe. Mothers reported significantly higher levels of anxiety and depression than fathers. Parents ranked their children's behavioural difficulties as the most challenging aspect of parenting children with autism. Although most parents believed that they had the ability to manage their child's behavior, most were stretched beyond their limits and over half felt they were unable to cope. Taken together, the findings show that difficult behaviour is very stressful for parents, and that high levels of daily stress may lead to high levels of anxiety and depression, particularly in mothers. However, parents who believed they could manage their child's behaviour and also received assistance from caregivers whom they perceived as having a "clear understanding of the child's difficulties and needs" reported lower levels of stress, anxiety and depression (Sharpley et al., 1997).

Based on the studies reviewed here, children's autistic symptoms (e.g., communication and repetitive behaviour) were found to be stressful for parents (Donenberg & Baker, 1993; Konstantareas & Homatidis, 1989; Sharpley et al., 1997). However when children's autistic characteristics were compared, difficult externalizing behaviours were the most stressful for mothers (Konstantareas & Homatidis, 1989;

Sharpley et al., 1997). Indeed, difficult child behaviour may be particularly overwhelming and thus critical to include when examining maternal health outcomes. While raising children with autism has a profound effect on parents' stress, it seems to have a greater impact on mothers' health. Thus, investigators have compared the effects of parenting children with autism to parenting children with other types of disabilities and have examined whether these effects vary for maternal or paternal roles.

Distress in Mothers of Children with Autism

Stress in parents and particularly in mothers of children with autism is well established (Bristol, 1979; 1984; Hastings & Beck, 2004; Holroyd, Brown, Wikler, & Simmons, 1975). Early research indicated that parents of children with autism have more family-related difficulties and higher stress levels than parents of children with developmental delay alone or psychiatric disorders (Holroyd & McArthur, 1976). However, some authors have suggested that caregiving for a child with any type of disability is predictive of distress in mothers; whereas others assert that raising a child with autism is particularly stressful and has a high negative impact on mothers' health, especially for mothers of children with autism (Orr, Cameron, & Day, 1991; Quine & Pahl, 1991). In response to these findings, the first studies of families were designed to understand how raising children with autism differentially affects parental health, the extent to which family function is affected, and whether the effects differ from those on other families (e.g., Gray & Holden, 1992; Moes, Koegel, Schreibman, & Loos, 1992; Rodrigue, Morgan, & Geffken, 1990).

Several studies have focused on whether maternal caregiving experiences differ according to the developmental or medical condition in question. Bouma and Schweitzer

(1990) examined stress in mothers of children with autism, cerebral palsy, and those who are typically developing. They found that caring for a child with autism had the most detrimental effect on mothers' levels of stress. Further, Dumas, Wolf, Fisman, and Culligan (1991) examined the influence of the type of disability on stress and depression in parents of children with autism, behaviour disorders, Down syndrome, and typical development. Mothers of children with autism and those with behaviour disorders reported higher levels of parenting stress and depression, higher than fathers of children with autism or mothers and fathers of children with Down syndrome or typical development. This effect was particularly strong for mothers of younger children (i.e., under 7 years). Taken together, these findings suggest that the role of caregiving for children with autism and those with behaviour disorders have a more negative effect on maternal mental health than other developmental or chronic health conditions. Of particular interest was that mothers of children with autism experienced higher levels of stress and depression than fathers who live in the same household (Dumas et al., 1991; Moes et al., 1992). These findings led researchers to examine mothers' and fathers' parental roles and to compare the health of parents in families of children with autism.

In the first of two studies designed specifically to compare the roles of mothers and fathers of children with autism, Gray and Holden (1992) found that mothers identified themselves as primary caregivers, whether they worked full-time as homemakers or part- or full-time outside the home. In contrast, none of the fathers identified themselves as primary caregivers and all fathers worked full-time outside the home. Findings indicated that mothers were more likely than fathers to feel responsible for "maintaining family integration" and had higher levels of anxiety and depression.

Gray and Holden (1992) concluded that mothers' primary and more intense caregiving roles place them at higher risk for poor health.

As predicted, Moes et al. (1992) also found that mothers of children with autism were at greater risk for stress and depression than fathers. Indeed, mothers' levels of stress were higher than fathers', and mothers' depression scores were more than twice as high as those found in fathers. Again, mothers reported primary responsibility for both the day-to-day care of their children with autism and for other family members, regardless of whether they worked outside the home part- or full-time. In contrast to mothers, fathers' contributions to the family were not related to daily care but were mainly in the form of wages earned outside the home. Also consistent with the findings of Gray and Holden (1992), mothers were responsible for "maintaining family integration". Moes et al. (1992) interpreted these findings as evidence that mothers are at greatest risk for stress and depression for two reasons. First, they speculate that when family difficulties arise, mothers who cope by maintaining family cooperation may feel solely responsible and blame themselves for their children's and families' unresolved problems (Moes et al., 1992). Second, and in agreement with others (Gray & Holden, 1992; Gray, 1994), Moes et al. (1992) also presume that for fathers, working outside the home may provide a form of daily respite from caregiving stressors.

In summary, a large body of evidence indicates that mothers of children with autism are at risk for clinically high levels of stress, anxiety, and depression related to their caregiving roles (Gray & Holden, 1994; Hastings et al., 2005a; Sharpley et al., 1997). Mothers have reported high stress profiles related to raising a child with autism, regardless of their cultural or geographic location, their child's age or level of functioning

(Koegel et al., 1992). Findings indicate that mothers of children with autism experience higher levels of distress than fathers of children with autism and mothers of children with Down syndrome, cerebral palsy, or those who are typically developing (Bouma & Schweitzer, 1990; Dumas et al., 1991; Gray & Holden, 1992; Gray, 1994; Moes et al., 1992). Collectively, the evidence supports the conclusion that the nature of autism places higher demands on primary caregivers. It is possible that caring for children with autism is more difficult and intense because of the core deficits in communication, socialization and behavioural flexibility, and in particular, because of the high levels of associated disruptive behaviour (Donenberg & Baker, 1993). These findings have lead researchers to focus on social supports that might buffer the negative effects of caring for a child with autism.

Supports

For mothers and families, support has been defined as a coping resource consisting of multiple forms (i.e., instrumental, emotional, and informational), from both informal and formal sources (Bristol, 1979; Dunst, Trivette, & Cross, 1986). Informal support refers to unpaid assistance from immediate and extended family, friends, neighbours and other parents with a child with a disability (Bristol, 1979). Formal support refers to community, education and health services that are government-funded or private fee-for-service arrangements (Bristol, 1979). In one of the early studies on social support, Bristol (1987) found that mothers' perceptions of helpful informal support predicted happier marriages and enhanced their parenting practices, but did not protect them from depression. Unexpectedly, formal support had no effect on any of the outcomes, including maternal depression. Given that mothers, children with autism, and

their families have high needs, it seems unlikely that there is no source of formal support that is helpful to them. Thus, since the publication of Bristol's findings many studies have examined support and its relationship with children's symptom severity and maternal distress.

In a follow-up to Bristol's (1987) early work, Konstantareas and Homatidis (1989) looked specifically at the number of supports that were available and the degree to which supports were either helpful or aggravating for parents of children with autism. Particular attention was paid to spousal support and whether parents desired additional support from their spouse. Support was defined in terms of social and community agents (i.e., spouses, in-laws, friends, neighbours, workplace, church, parent groups, schools, doctors and social agencies). Findings indicated that mothers' higher stress levels were related to having children with greater symptom severity (e.g., non-verbal, self-abusive, and hyper-irritable) and to unhelpful support. Mothers reported high aggravation with all sources of support, especially spousal support. Indeed, 55% of mothers and only 7% of fathers desired additional support from their spouse. Mothers thought that fathers should provide additional support in the form of relief from caregiving, shared disciplining, and more involvement in daily chores. Generally, mothers valued accessible support and, in particular, sharing caregiving responsibilities with others in their homes. Importantly, mothers of children with hyper-irritability were least likely to receive support that they perceived as helpful.

In a conceptually related study, Hastings and Johnson (2001) examined informal and formal support, together with children's behavioral problems, parental coping strategies and perceptions of their children's early intervention program, as predictors of

family problems and depression in the main caregiver (92% were mothers). When all of these factors were examined together, parents who coped by *actively pursuing* support and positively reframing their challenges experienced lower levels of depression. Parents who actually *received* helpful informal support and positively reframed their challenges experienced fewer parenting and family problems. Consistent with Bristol's (1987) findings, formal support had no effect on parent outcomes. Rather, parents' who *sought* support to cope with their stressors had lower levels of depression, whereas parents' who *received* helpful informal support reported fewer marital and family problems.

Similar findings have been reported by Dunn et al. (2001). They examined stressors, supports, locus of control, and coping styles as potential moderators of social isolation, spousal relationship problems and depression in parents of children with autism. Findings indicated that parents who coped by *actively pursuing* social support and positively reframing their challenges, rather than trying to escape or avoid their problems, reported fewer spousal relationship problems. Moreover, *receiving* social support moderated the relationship between parents' life stressors and their experiences of social isolation. Consistent with the findings of Bristol (1987) and Hastings and Johnson (2001), receiving informal or formal support had no relationship with parental depression.

To gain an in-depth understanding of the factors associated with mothers' social support, satisfaction with services and psychological health, Bromley, Hare, Davison, and Emerson (2004) conducted structured interviews with 68 mothers of children with autism. Over half of the mothers screened positive for possible psychiatric "caseness". Mothers with poor psychological health received less informal support and were more

likely to have children with high levels of behavioural disturbance. Despite the relationship of children's disruptive behaviour with maternal health, only mothers of children with greater language delay and aloof behaviour received *helpful* formal support. In contrast, *access* to formal support was not related to any child or family characteristic. Taken together, these findings indicate that mothers of children with disruptive behaviour were least likely to receive either helpful informal or formal support (Bromley et al., 2004).

In summary, there is evidence that informal support has had limited benefit and formal support has had no benefit for mothers' mental health (Bristol, 1987; Bromley et al., 2004; Dunn et al., 2001; Hastings & Johnson, 2001). Findings consistently show that formal support has not been helpful, or has even aggravated mothers' distress (Bristol, 1987; Bromley et al., 2004; Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989). Instead, helpful informal support, as perceived by mothers, is more likely to positively influence maternal stress levels, spousal relationships and family adjustment, but not maternal depression (Hastings & Johnson, 2001; Dunn et al., 2001). Taken together, authors suggest that some mothers may use informal and formal supports to help their children and family, risking their own poor mental health (Bristol, 1979; 1987; Moes et al., 1992). Mothers may be at higher risk for distress if they use their support for their family, perceive their lives as unmanageable, and cope in unhealthy ways. Indeed, mothers' coping strategies may undermine the support efforts of those trying to directly help them, especially if mothers feel solely responsible, overwhelmed and/or blame themselves for their child's condition (Bristol & Schopler, 1983; Moes et al., 1992).

Perceptions of the Stressor and Coping

In conceptualizing the ABCX model of family adjustment, McCubbin and Patterson (1983) argued that in addition to supports, parents' perceptions of crisis and their coping strategies may also play a role in adjustment. Broadly, the ABCX model assumes that family members cope with stressors interdependently to manage child-related and other stressor demands (A), and that support from within and beyond family resources (B) is garnered to understand and manage the child's chronic condition (C) in an attempt to create balance in parents' and family function (X). Applying the ABCX model to study adjustment in families of children with autism, Bristol (1987) was among the first to examine the roles of maternal perceptions of caregiving burden, support, self-blame and coping strategies in protecting maternal health. Bristol found that mothers' support and coping resources had no relationship with their health; instead, mothers' coping strategies appeared to positively relate to their families' adjustment.

Maternal perceptions of stressors, supports, and coping strategies were also examined by Orr et al. (1991). They employed structural equation modeling to test the applicability of the ABCX model in explaining adjustment in families of children with disabilities. Results failed to provide support for the particular linear pattern of the ABCX model (i.e., stressors → resources → perceptions/coping → outcomes) but instead suggested an ACBX pattern of stressors (i.e., stressors → perceptions/coping → resources → outcomes). While these findings indicate that maternal perceptions of the stressor were more predictive of maternal outcomes than the actual stressors, only a few studies have shown that coping is directly related to mothers' distress. Studies have shown that mothers who cope by *actively pursuing* social support and positively

reframing their challenges report lower levels of depression (Dunn et al., 2001; Hastings & Johnson, 2001; Hastings et al., 2005a). Thus, it appears that mothers who cope by positively managing their challenges and resources well may experience better outcomes.

As previously reviewed, for children with the most severe behavioural difficulties, support may be unavailable or insufficient in helping mothers (Bromley et al., 2004). Therefore, instead of relying on support from others, mothers may need to rely on their own strengths – self-efficacy to manage their child’s behaviour and empowerment to garner resources (Hastings & Brown, 2002; Nachshen & Minnes, 2005). While no studies have employed the ABCX model to examine the role of maternal self-efficacy and empowerment, emerging evidence suggests that these strengths may relate to lower levels of distress in mothers with children who have autism (Hastings & Brown, 2002; Nachshen & Minnes, 2005). Of particular interest is which maternal strengths are important for raising a child with autism who has severe behavioural difficulties, and whether these may buffer mothers from stress, anxiety or depression.

Maternal Strengths

In research with families of children with developmental disorders and/or behavioural difficulties, but not autism, parents’ self-efficacy and empowerment have been shown to be related to better family support and adjustment (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006; Graves & Shelton, 2007; Hudson et al., 2003; Jex, Bliese, Buzzell, & Primeau, 2001; Koren et al., 1992; Nachshen & Minnes, 2005; Sofronoff & Farbotko, 2002). Although self-efficacy is a well-established construct in the psychology literature, very few studies have investigated self-efficacy in mothers of children with autism and virtually nothing is known about their empowerment (e.g.,

Hastings & Brown, 2002; Diamond, 2005). The potential value of self-efficacy and empowerment for enhancing health in mothers of children with autism is considered below.

Self-efficacy. Bandura (1982) defines self-efficacy as the expectation that one is able to successfully perform the actions required for particular situations. Bandura (1997) contends that what people do is predicted by their belief and confidence in their skills rather than by their actual abilities. Therefore, applying the construct to the role of parenting a child with autism, mothers with self-efficacy would believe they have the knowledge, skills and confidence to manage their children's behaviour. Given the complexity of these difficult behaviours, most behavioural strategies require "try and try again" approaches and mothers' efforts may have limited or variable effects on the behaviour. Fortunately, a mother's motivation to keep trying may be better predicted by her self-efficacy beliefs than by her prior successes (Pajares, 2002). Thus, parental efficacy may influence mothers' motivation for managing difficult behaviour even when their success is inconsistent, allowing them to feel more positive about their parenting. However, for mothers of children with autism and highly disruptive behaviour, parental self-efficacy for managing difficult behaviour may not have any effect on parenting practices or maternal health in the absence of real skills and knowledge.

In one of the first studies of maternal self-efficacy in mothers of children with autism, Rodrigue et al. (1990) examined the differential impact of parenting a child with autism or Down syndrome or a typically developing child on mothers' marital and family adjustment. Mothers' self-efficacy was measured using Gibaud-Wallston and Wandersman's (1978) Parenting Sense of Competence Scale. This scale defines self-

efficacy as the extent to which parents perceive they have the requisite knowledge and skills to raise their children and the perceived value of their parenting role. Findings indicated that mothers of children with autism believed they had less knowledge and fewer skills for parenting, and placed less value on parenthood than the other groups. They also experienced less family flexibility and marital satisfaction. Further, mothers of children with autism and those with Down syndrome reported more family planning, caretaker, and family burden than mothers of typically developing children. These findings were taken as evidence that mothers have particular difficulty coping with the multiple and complex parenting skills required in raising a child with autism (Rodrigue et al., 1990). Higher rates of information-seeking coupled with lower parenting skills suggested to the authors that mothers of children with autism lack parenting efficacy and are struggling to understand their child's condition.

Hastings and Brown (2002) also examined self-efficacy in mothers and fathers of children with autism to determine whether self-efficacy might mediate the effect of child behaviour problems on parents' anxiety and depression. Self-efficacy, measured by a questionnaire developed by the authors (i.e., The Difficult Behaviour Self-Efficacy Scale), was defined as parents' perceptions of their skills, knowledge, and confidence in managing their children's difficult behaviour problems. The child's classroom teacher provided an independent measure of child behaviour problems. Findings indicate that self-efficacy mediated the effect of child behaviour problems on mothers' anxiety and depression, whereas self-efficacy moderated the effect of child behaviour problems on fathers' anxiety. Thus, parental self-efficacy for managing difficult behaviour may be a critical factor in lowering distress in mothers and fathers of children with autism.

In an attempt to identify critical predictors of self-efficacy in mothers of children with autism, Kuhn and Carter (2006) examined the associations between maternal self-efficacy and potentially related cognitions (i.e., autism knowledge, maternal agency, guilt, stress and depression). Mothers' self-efficacy was measured using the Maternal Efficacy Scale, which assesses perceived efficacy for understanding, communicating with and comforting their children (Teti & Gelfand, 1991). Kuhn and Carter (2006) also proposed the concept of maternal agency. Conceptually distinct from self-efficacy, maternal agency was defined as "the extent to which a mother assumes an active role in her child's development, engages in interactions with her child, and persists in identifying strategies that minimize maladaptive child behaviors and maximize adaptive behaviors" (Kuhn & Carter, 2006, pp. 565). After controlling for time since diagnosis and the presence of a second child with a disability, maternal agency, guilt, stress and depression each explained some variance in maternal self-efficacy. Mothers' knowledge about autism was not associated with their self-efficacy. In the final model, mothers with higher levels of self-efficacy reported having only one child with a disability, a longer time since diagnosis, less parenting stress and guilt about not doing enough and, most critically, higher levels of agency for engaging in activities to *promote* child development (Kuhn & Carter, 2006).

Taken together, these results suggest that parenting efficacy is likely to have a direct and positive effect on mothers' health. Of particular interest is that each study defined parental self-efficacy somewhat differently. For example, Rodrigue et al. (1990) defined self-efficacy as parental knowledge, skills and perceived value of their parenting role. In contrast, Hastings and Brown (2002) defined self-efficacy as parents' beliefs

about their ability to specifically manage difficult child behaviour. Kuhn and Carter (2006) defined parental self-efficacy as a mother's perceived efficacy in understanding, communicating with and comforting their child. While all the definitions have subtle differences, they also have one factor in common, that is, mothers' perceptions of how they effectively interact with their child. However, some children with autism have idiosyncratic communication and/or behaviours that are difficult for parents to interpret. Thus, for some mothers acquiring or sustaining parenting efficacy may depend on their level of empowerment for managing their home environment, accessing resources, and working with available autism services. While very few studies have examined parental self-efficacy, none have attempted to disentangle the relationship between self-efficacy and empowerment. Next, the few studies that have examined empowerment in parents of children with disabilities will be reviewed.

Empowerment. In general, empowerment is "...an intentional, ongoing process ... through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989). For parents of children with disabilities, Nachshen (2005) defines empowerment as having specific knowledge about their children's disability and based on this knowledge, having the ability to confidently act and exert control over their home environment and available resources. While empowerment may involve some aspects of parental self-efficacy (i.e., parents' perceptions of the parent-child relationship), it also has a broader focus on managing family resources and advocating for services. For parents of children with disabilities, empowerment is useful in managing day-to-day family life, in navigating the service system, and in advocating for or advising on services governed by

community/political organizations (Koren et al, 1992). In addition, empowerment is expressed through parents' attitudes, knowledge and behaviours (Koren et al., 1992). However, whether and the extent to which empowerment is related to maternal health and well-being are still largely unknown, particularly in mothers of children with autism.

Although few studies have examined empowerment in parents of children with a disability, evidence from families of children with behavioural disorders (e.g., oppositional defiant disorder and attention deficit / hyperactivity disorder) indicates that parental empowerment predicts better family functioning and lower parental stress (Scheel & Rieckmann, 1998). Moreover, studies with parents of children with autism and other developmental disabilities have shown that mothers with perceived empowerment in their family life and with their child's service providers also report less stress and better family adjustment (Diamond, 2005; Nachshen & Minnes, 2005). These findings suggest that mother's perceptions of their family and service empowerment may be an important predictor of their better health outcomes.

The few studies conducted on parental self-efficacy and empowerment in mothers have focused on the individual effects of these variables. None have examined the relationship between empowerment and parental efficacy or their combined effects on adjustment in mothers of children with autism. Research is needed to empirically disentangle the relationship of parental empowerment with parental self-efficacy. It is also unclear whether maternal empowerment and self-efficacy influence mothers' use of formal or informal support, or whether collectively they change the negative relationship between children's difficult behaviour and mothers' health. While these factors have not been examined together, it is possible that mothers may need a constellation of helpful

supports, parental coping, self-efficacy and empowerment to help them to function well and even thrive -- in spite of their high caregiving demands. Some advocates claim that “thriving” parents become knowledgeable about autism, do not retreat or become intimidated but instead embrace autism as a challenge that needs to be understood (Akerley, 1975). Specifically, thriving parents advocate for their child, for their family, and for themselves. Indeed, thriving parents confidently manage their child’s condition, understand how to access and use support, and negotiate well with professionals (Turnbull & Turnbull, 2006). Parents with these skills and strengths may also have positive perceptions of their parenting roles (Akerley, 1975; Turnbull & Turnbull, 1978).

Positive Perceptions of Parenting

Although mothers of children with autism report a myriad of challenges associated with children’s difficult behaviour, not all report clinically high levels of stress, depression and anxiety (Bristol, 1987; Konstantareas & Homatidis, 1989; Hastings et al., 2005a). Rather, some report that parenting a child with a disability positively transforms their lives (Behr & Murphy, 1993; Hastings et al., 2005b; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & Sobsey, 2004; Turnbull & Turnbull, 1978). To further explore these *positive* parental experiences, Behr, Murphy, and Summers (1992) employed McCubbin and Patterson’s (1983) ABCX model and Taylor’s (1983) Cognitive Adaptation theory to examine *successful* outcomes in 1200 families of children with developmental disability. The ABCX model presupposes that the extent to which families adapt after experiencing a crisis depends on the support or coping resources they have to meet stressor demands, whereas Taylor’s (1983) Cognitive Adaptation theory assumes that positive perceptions arise as an adaptive response to a significant threat. Thus,

parents of children with disabilities may develop positive perceptions when they construe positive meaning, and gain a sense of self-efficacy from their parenting roles. In support of both of these theories, Behr et al. (1992) found that in addition to garnering resources to fend off stress and a sense of burden, parents also reported that raising a child with a disability positively enriched their lives (hereafter, “positive perceptions of parenting”). Parents reported that their children were sources of happiness and family strength, and that they had greater parenting efficacy from overcoming challenges, and a greater sense of life’s purpose. Taken together, these findings suggest that some parents develop positive personal outcomes from parenting children with disability (Behr et al., 1992; Behr & Murphy, 1993).

Although the process of achieving positive perceptions of parenting remains unclear, positive perceptions from caregiving are commonly reported by mothers and other primary caregivers who provide intensely demanding care (e.g., of newborns discharged from intensive care, Affleck, Tennen, & Rowe, 1991; of loved ones with AIDS, Folkman, Moskowitz, Ozer, & Park, 1997; or of family members with cancer, Kim, Schulz, & Carver, 2007). The construct has several labels, including sense-making and benefit-finding (Pakenham, Sofronoff, & Samios, 2004), stress-related growth (Park et al., 1996), post-traumatic growth (Tedeschi et al., 1998) and benefit-reminding (Tennen & Affleck, 2002). For mothers of children with autism, among the outstanding questions are: how do positive perceptions of parenting develop, and what are the factors that underlie their development?

Taylor and Brown (1988) suggest that the development of positive perceptions may be explained by the cognitive adaptation theory of positive illusions, which contends

that individuals mildly and positively distort stressful situations. Similarly, Hastings and Taunt (2002) suggest that mothers of children with autism may develop positive perceptions by mildly and positively distorting their caregiving demands. Interestingly, some findings indicate that mothers' reports of positive perceptions are unrelated to the severity of child-related stressors (e.g., difficult behaviour, poor adaptive skills, and autism symptoms; Hastings et al, 2005b; Lloyd & Hastings, 2008). These findings suggest that reframing the stressor more positively may be a significant pathway to developing positive perceptions, although it remains untested in mothers of children with autism. However, parents managing high disruptive behaviour may not be able to think positively about their caregiving, particularly in the absence of real skills to actively manage their children's disruptive behaviour. These parents may be challenged by feedback from social networks such as family members or teachers who try to negatively shift their perceptions. Although unexamined in mothers of children with autism, a more likely predictor of positive perceptions of parenting may be parenting efficacy rather than positively reframing the experience.

Recent evidence indicates that mothers of children with intellectual disability who believed they could manage their child's difficult behaviour were more likely to report positive perceptions of caregiving (Lloyd & Hastings, 2009). Lloyd and Hastings (2009) contend that mothers who are not able to understand and manage their children's difficult behaviour may view the behaviour as threatening and difficult to overcome. These findings suggest that parental efficacy, specifically self-efficacy for managing difficult behaviour, may be a promising predictor of mothers' positive perceptions of their child with autism and may buffer them from anxiety and depression (Hastings et al., 2005b;

Lloyd & Hastings, 2008). The authors acknowledge that an inherent limitation of all studies that employ correlational designs is that the direction of the effect is unknown. It is also reasonable to assume that mothers with positive perceptions and lower distress are better prepared to manage their children's difficult behaviour than mothers with high distress (Lloyd & Hastings, 2008).

Theoretically, positive perceptions of parenting may develop as part of an adaptive process in response to a significant stressor. This process includes attributing positive meaning to the stressor, achieving control over the stressor, and enhancing one's self-esteem in managing the stressor (Taylor, 1983; Taylor & Armor, 1996). Although the concept of positive perceptions of parenting has been well-documented in developmental and intellectual disability research (e.g., Behr et al., 1992), research on positive perceptions related to raising children with autism is scant. Future research needs to examine whether maternal strengths such as self-efficacy and empowerment are predictive of parental positive perceptions in mothers of children with autism.

Strengths-based ABCX Model of Maternal Adjustment

McCubbin and Patterson (1983) argue that parents and, in particular, mothers require a constellation of factors to adapt to raising a child with a chronic condition. In support of this assumption, Bristol found that several factors in the ABCX model (i.e., stressors, supports, coping, and self-blame) collectively explained 53% of the variance in depression for mothers of children with autism. Further support for a multi-factor approach was found for mothers raising children with various disabilities. Indeed, Saloviita, Itälina, and Leinonen (2003) found that the ABCX model (notably, severity of children's adaptive behaviour, marital relationship, social support, coping strategies, and

appraisal of stressors as a catastrophe) accounted for 70% of the variance in maternal stress. As expected, Pakenham, Samios, and Sofronoff (2005) also found for mothers of children with Asperger syndrome that the ABCX model (notably, severity of children's behaviour, pile-up of stressor demands, social support, coping strategies, and appraisal of stressors) significantly predicted adjustment, accounting for the variance in maternal social adjustment (61%), depression (58%), anxiety (54%), and subjective health status (38%). Collectively, these findings show that despite employing different definitions and measures of the constructs, a multi-factor model (e.g., the ABCX model) accounts for a significant portion of the variance in maternal stress, anxiety, and depression. While it is clear that no single factor can account for mothers' health, little is known about how more positive predictors such as parental self-efficacy and empowerment might influence the ABCX model's utility for predicting parental and family outcomes.

As reviewed above, children's disruptive behaviour, support, appraisal of stressors and coping strategies are known to influence mothers' outcomes. Drawing on the findings of studies that have focused on these constructs individually (vs. collectively, as in a model), children's disruptive behaviour is highly related to maternal distress. There is also evidence that mothers who cope by seeking social support and those who receive informal support are less stressed (Dunn et al., 2002; Bromley et al., 2004). However, all of this research employed cross-sectional and correlational designs. Thus, it is difficult to determine whether mothers who were less stressed were better able to seek and receive support or whether coping and support buffered maternal stress. Regardless, neither coping nor support was sufficiently helpful in reducing maternal anxiety or depression. These disappointing findings have lead authors to claim that external sources

of support alone may be insufficient and that mothers may also need to possess self-efficacy and empowerment to experience better outcomes (Hastings & Brown, 2002; Nachshen & Minnes, 2005). While parental self-efficacy has been shown to buffer mothers of children with autism from anxiety and depression (Hastings & Brown, 2002), there are no comparable data on the effects of parental empowerment. Moreover, self-efficacy and empowerment have not been examined together, or in combination with either informal or formal supports. A better understanding of these strengths may elucidate how mothers experience more positive outcomes.

A major concern that emerges from reviewing the studies on maternal outcomes is the way in which outcomes have been conceptualized. Most of the studies define maternal outcomes in terms of maternal distress (i.e., stress, anxiety or depression), such that higher levels of distress are poor outcomes and lower levels of distress are better outcomes. Some authors suggest that better outcomes may be more than an *absence* of pathology (i.e., lower distress) but also include the presence of parents' positive perceptions (Behr et al., 1992; Hastings & Taunt, 2002; Perry, 2004; Scorgie & Sobsey, 2000). Consistent with this, recent findings indicate that mothers' positive perceptions of parenting are related to mothers' positive affect, unrelated to their perceptions of difficult child behaviour, and negatively related to anxiety and depression (Hastings et al., 2005a; Hastings et al., 2005b). Thus, in addition to examining maternal distress, more research is needed to understand the role of positive perceptions in mothers of children with autism.

In summary, evidence reviewed here suggests that mothers' positive perception of parenting is an important outcome. It is also important to examine whether a relationship exists among maternal supports, mothers' abilities to manage children's difficult

behavior, and their positive perceptions of parenting. There is a need for research designed to consider the contribution of strengths-based predictors, both individually and collectively, for their effects on both mothers' positive perceptions of raising their children with autism and on their own mental health. These outstanding questions herald the need for a paradigm shift when examining predictors of better maternal outcomes. Proponents of positive psychology principles argue for a conceptual shift to more positive predictors -- from a focus on perceptions of crisis to a focus on parental self-efficacy and empowerment -- *and* for a shift to more positive outcomes -- from a focus on maternal distress and burden to a focus on maternal well-being and parents' positive perceptions (King et al., 2005; Scorgie & Sobsey, 2000).

Present Study

The present research addresses the knowledge gaps found in the reviewed research literature, in an attempt to better understand supports and strengths that optimize positive outcomes and minimize negative outcomes in mothers of children with autism. To date, very little of the research in autism has adopted positive psychology principles, which assume that maternal adaptation is more than coping with stressors and garnering support, and includes parenting efficacy and empowerment to manage the stressors. While evidence suggests that good maternal health is important for families, most of the studies conducted thus far have defined better outcomes as lesser degrees of pathology rather than higher degrees of well-being (Bayat, 2007; Hastings et al., 2005b; Walsh, 2003). Thus, the present study extends previous research by examining the associations among stressors *and* strength-based predictors and their relationships with maternal distress *and* well-being. For this purpose, the *Strengths-based ABCX model of maternal*

adjustment was used as a framework in which children's disruptive behaviour, informal and formal supports, parental self-efficacy and empowerment were included as predictors of mothers' positive perceptions of parenting and maternal distress (i.e., anxiety and depression). Of particular interest were the potential roles of self-efficacy and empowerment in mediating the relationship between children's disruptive behavior and maternal outcomes. The three main objectives of the study were to examine:

1. Whether demographic characteristics (i.e., mothers' or children's age) are related to maternal distress and positive perceptions of parenting.
2. The relationships among the predictor variables (i.e., children's disruptive behavior, supports, empowerment and self-efficacy) and the outcome variables (i.e., maternal distress and positive perceptions of parenting).
3. The potential mediating effects of mothers' strengths (i.e., self-efficacy and empowerment) on the relationship between child disruptive behavior and mothers' outcomes (i.e., maternal distress and positive perceptions of parenting).

These objectives were achieved by employing a postal survey design. Mothers (n = 114) of children with autism (aged 4-21 years) provided demographic information and completed various questionnaires. The following specific hypotheses were postulated.

For Objective 1, it was predicted that younger mothers would report higher distress and lower positive perceptions of parenting than older mothers.

For Objective 2, it was predicted that when examined sequentially, children's disruptive behavior, informal and formal support, parental self-efficacy, family and service empowerment would all contribute significantly to the prediction of maternal distress. In addition, it was predicted that when examined sequentially, children's

disruptive behavior, informal and formal support, parental self-efficacy, family and service empowerment would all contribute significantly to the prediction of mothers' positive perceptions of parenting.

For Objective 3, the primary prediction was that the relationship between ratings of children's disruptive behaviour and maternal distress would be mediated by maternal reports of parental efficacy. It was also expected that the relationship between ratings of children's disruptive behaviour and positive perceptions of parenting would be mediated by maternal reports of parental efficacy. The secondary prediction was that the relationship between ratings of children's disruptive behaviour and maternal distress would be mediated by maternal reports of family empowerment. It was also expected that the relationship between ratings of children's disruptive behaviour and positive perceptions of parenting would be mediated by maternal reports of service empowerment.

Chapter 2 Method

Participants

Responding to invitations that were sent out through local autism societies (see Appendix A), 246 families contacted the principal investigator and expressed interest in the study (please see the procedure section below for more detail on the recruitment method). Of these interested participants, 204 met the criteria for participating in the study (i.e., had a child aged 4 - 21 years with an Autistic Spectrum Disorder who lived in the family home), and they were mailed survey packages. Of the 204 who met criteria, 137 participants returned the survey package, for a response rate of 67%. Of the 137 responders, 15 were removed because they were fathers (vs. mothers), and 8 mothers were removed due to incomplete data ($n = 3$), their children were outside the criterion age range for the study ($n = 4$), or their questionnaire scores were extreme outliers ($n = 1$), yielding a final sample of 114 mothers.

Demographic descriptions of the 114 mothers who participated in this study are presented in Table 1. The mothers' mean age was 41.9 years, ranging from 28 to 67 years. Most of the mothers were married (86.8%) and Caucasian (98.2%). A majority of the participants reported having a college diploma (47.3%) or a university degree (39.5%), while 13.2% had a high school diploma. Mothers' employment status ranged from stay-at-home caregivers (33.4%) to part-time (21%) and full-time work (45.6%). For the total sample, 23.7% had a family income of less than \$40,000, 26.3% between \$40,001 and \$70,000, and 47.4% greater than \$70,000. Based on the Hollingshead Index (1975), all families were of middle to upper-middle socioeconomic status (SES). Based

on the data collected from the Hollingshead Index, it was also confirmed that the sample in this study conformed to what is typically found in survey research (Fowler, 2009).

The demographic descriptions of the children are presented in Table 2. The children's mean age was 10.9 years, ranging from 3 to 21 years (i.e., 10.5% were 3- to 4-year-olds; 78.9% were 5- to 18-year-olds; 10.5% were 19- to 21-year-olds). As expected, most of the children were male (84.2%), resulting in a male-to-female ratio of 5.3:1 (APA, 2000). The demographic questionnaire included all of the possible Autistic Spectrum Disorder (ASD) diagnoses. Mothers reported that 77.2% of the children had a diagnosis of autism/ASD, 4.4% had Pervasive Developmental Disorder (PDD), 3.5% had Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and 14.9% had a diagnosis of Asperger syndrome. The main purpose of this study was to examine the outcomes of mothers of children with any form of autism, thus these diagnoses were combined to test the hypotheses.

Table 1

Mother Demographics (N = 114)

Variable	N	%	<i>M (SD; Range)</i>
Age	113		41.9 years (7.4; 28 – 67 years)
Marital Status			
Single	15	13.2	
Spouse/Partner	99	86.8	
Ethnicity			
White/Caucasian	112	98.2	
South Asian	1	.9	
African Canadian	1	.9	
Education			
High School	15	13.2	
College	54	47.3	
University	45	39.5	
Employment			
At-home	34	33.4	
Part-time	24	21.0	
Full-time	52	45.6	
Family Income			
< \$40,000	27	23.7	
\$40,001 - \$70,000	30	26.3	
> \$70,000	54	47.4	

Table 2

Child Demographics (N = 114)

Variable	N	%	<i>M (SD; Range)</i>
Age	114		10.9 years (5.1; 3 - 21 years)
Gender			
Male	96	84.2	
Female	18	15.8	
Diagnosis			
Autism/ASD	114	100	

Procedure

Mothers listed in the databases of regional ASD Societies in Nova Scotia, New Brunswick, and Prince Edward Island were sent letters and emails informing them of the study with an invitation to contact the researcher (see Appendix A). Mothers who chose to participate in the study contacted the researcher by email or, in two cases, by telephone. They were informed that participation would take approximately 35 minutes of their time and that assistance was available for filling out the questionnaires. One mother requested assistance but later declined to participate in the study because her child was home sick. Interested mothers were mailed a survey package. To maintain participants' confidentiality, a code was assigned to each survey questionnaire. The packages also included detailed instructions regarding participation. For example, mothers were asked to complete a series of questionnaires (for an outline of survey measures and key variables, see Table 3). Mothers were encouraged to complete the survey in one sitting and to answer with their initial reaction. When the survey was

completed, the mothers were asked to mail back the questionnaires in a postage-paid envelope. In accordance with current ethical guidelines for research in which questionnaires are mailed, participants were not required to sign and return an informed consent form. Employing Dillman's (2000) tailored design method for increasing survey response rates, non-responders were sent an email reminder after two weeks and 4 weeks, and a reminder in the mail after 6 weeks.

Table 3

Strengths-based ABCX Model Variables and Survey Measures

<i>Variables</i>	<i>Measures</i>
Demographics	Demographic questionnaire
Stressor: A	
Child disruptive behavior	Developmental Behaviour Checklist ^a
Resources: B	
Helpful informal support	Family Support Scale (includes subscales for Informal and Formal Support) ^b
Helpful formal support	
Perception of strengths: C	
Self-efficacy	Difficult Behaviour Self-Efficacy Scale ^c
Family empowerment	Family Empowerment Scale (included subscales for Family and Service) ^d
Service empowerment	
Adjustment outcome: X	
Maternal distress	Hospital Anxiety and Depression Scale ^e
Positive perceptions of parenting	Positive Contribution Scale ^f

^aEinfeld & Tonge (1995); ^bDunst, Jenkins, & Trivette (1994); ^cHastings & Brown (2002); ^dKoren, DeChillo, & Friesen (1992); ^eZigmond & Snaith (1983); ^fBehr, Murphy, & Summers, (1992).

Measures of the Strengths-based ABCX Model

Demographics. A survey demographic questionnaire was used to collect data on mothers' age, marital status, level of education and income, as well as children's age, gender, diagnosis or description of disability (Corkum, 2008; see Appendix B). For the purposes of analyses, the Hollingshead Four Factor Index was used to calculate socioeconomic status (SES) by weighting education and occupation scores to obtain a single score for each participant and spouse (range 8 to 66) that reflected one of five levels of social status (1 representing unskilled service workers through to 5 representing professionals).

Stressor (A)

Children's Difficult Behaviour. The Developmental Behaviour Checklist – Primary Carer Version (DBC-P; Einfeld & Tonge, 1995; 2002) was developed specifically for children with intellectual disabilities. Item selection was based on behavioral and emotional symptoms described in case files of children and adolescents with developmental disabilities. The DBC-P has 96-items and includes six subscales for disruptive, self-absorbed (i.e., aloof), communication disturbance, anxiety, autistic and antisocial behavior. The DBC-P has good internal consistency ($\alpha = .94$), good to high inter-rater reliability ($r = 0.60 - 0.83$; Einfeld & Tonge, 2002; Hastings, Brown, Mount, & Cormack, 2001) and test-retest reliability ($r = 0.73 - 0.83$; Einfeld & Tonge, 2002). Based on evidence that disruptive behaviour is the most predictive factor for mothers' stress, depression and anxiety (Bebko et al., 1987; Donenberg & Baker, 1993; Konstantareas & Homatidis, 1989; Sharpley et al., 1997), the DBC-P disruptive

behaviour subscale score was used in this study. Due to copyright restrictions the DBC-P questionnaire is not included in the appendices.

Resources (B)

Informal and Formal support. The Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984; 1994) assesses the helpfulness of various supports in raising children with disabilities (see Appendix C). The FSS has 18 items and five subscales for support received from partner/spouse, informal relationships, formal relationships, social organizations, and professional services. Ratings are made on a five-point Likert scale ranging from Not at All Helpful to Extremely Helpful. The FSS has good internal consistency ($\alpha = 0.77$) and test-retest reliability ($r = 0.91$). This study used McConachie and Waring's (1997) revised scoring procedure, which employs a mean score for the helpfulness of both informal support and professional services (hereafter, formal support), rather than a combined total.

Perception of Strengths (C)

Self-Efficacy. Difficult Behaviour Self-Efficacy Scale (Hastings & Brown, 2002). This scale was developed to measure self-efficacy for managing difficult behaviour in children with ASD (Hastings & Brown, 2002; see Appendix D). The measure is based on the assumption that child variables, including child behavior problems and caregiving demands, are related to parental self-efficacy and predictive of parental health (e.g., Heller, 1993). Thus the scale measures parents' perceptions of their ability to manage problematic child behavior. The questionnaire has five items and each item is rated on a 7-point scale. A total score is derived by summing the ratings on the five items. In a study of 46 parents the scale demonstrated acceptable internal consistency, with a Cronbach's

alpha of 0.94 for mothers and 0.92 for fathers (Hastings & Brown, 2002). The total score of the five items was used in this study.

Empowerment. The Family Empowerment Scale (FES; Koren et al., 1992) is a questionnaire that measures parents' sense of empowerment, defined as confidence in their knowledge and/or actions within the family, service system and community/political domains (see Appendix E). The questionnaire measures attitudes, knowledge, and behaviours in three subscales: (i) Family, (ii) Service System, and (iii) Community/Political. The FES has 34 items, each rated on a five-point Likert scale ranging from "not true at all" to "very true". Scoring involves summing responses from items within the Family (12 items), Service System (12 items), and Community/Political (10 items) categories to yield three sub-scores. In 440 parents of children with emotional and behavioral disorders, each of the three subscales were found to have adequate internal consistency (Family: $\alpha = 0.88$; Service system: $\alpha = 0.87$; Community/Political: $\alpha = 0.88$) and test-retest reliability ($n = 107$ over 3-4 weeks) was adequate for each of the three subscales (Family, $r = 0.83$; Service System, $r = 0.77$; Community/Political, $r = 0.85$; Koren et al., 1992). In the present study the Family empowerment and Service System empowerment sub-scale scores were used. This decision was based on the results from studies with parents of children with autism and other developmental disabilities which showed that maternal perceptions of Family empowerment and Service empowerment (vs. Community/Political empowerment) were significantly related to their stress or well-being (Diamond, 2005; Nachshen & Minnes, 2005).

Adjustment Outcome (X)

Maternal Distress. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to measure mothers' distress (i.e., anxiety and depression). The HADS has 14 items, with seven items assessing depression and seven items assessing anxiety. Each item is rated on a four-point scale (0-3), with scores ranging from 0 to 21 for anxiety and 0 to 21 for depression. An analysis of scores on the two subscales has indicated that a score of 0 to 7 on either subscale is within the normal range, and that a score of 11 or higher indicates probable presence ('caseness') of either depression or anxiety disorder (Zigmond & Snaith, 1983). The two subscales were found to have adequate internal consistency (depression: $\alpha = 0.89$; anxiety: $\alpha = 0.86$) in a study of mothers of children with autism (Hastings & Brown, 2002). Hastings and Brown also reported that the depression and anxiety subscales were moderately and positively related ($r = .62$). Although evidence suggests that the HADS conveys two clinically meaningful subscales for anxiety and depression, Herrman (1997) in his review of 200 studies, reported the subscales had a mean correlation of .63 from 18 separate studies ($n = 8160$). These findings suggest that it would be reasonable to combine the scores from the Anxiety and Depression subscales to obtain a total score as a measure of general psychological distress (Crawford, Henry, Crombie, & Taylor, 2001; Herrman, 1997). For the purpose of this study, the total HADS score was used as a global measure of maternal distress. Due to copyright restrictions the HADS questionnaire was not included in the appendices.

Positive Perceptions of Parenting. Kansas Inventory of Parental Perceptions Positive Contributions Scale (KIPP-PC; Behr et al., 1992; see Appendix F). This scale

measures parents' beliefs that their child with a disability has positive characteristics (e.g., kind and loving, provides unexpected pleasures), has had a positive impact on their lives (e.g., has enhanced their social network, provided a different perspective on life) and on the other family members (e.g., brings the family together, improves family members' understanding of other people). The questionnaire has 50 items and nine subscales derived from a large-scale study of parents ($n = 1262$) of children with disabilities (Behr et al., 1992). The KIPP-PC was found to have adequate internal consistency ($\alpha = 0.77$) and test-retest reliability ($r = 0.56$; Behr et al., 1992). In a study of 200 parents of children with disabilities, Hastings, Beck and Hill (2005) reported that the total score for this scale had a high level of internal consistency, with Cronbach's alpha of 0.92 for mothers and 0.94 for fathers. The KIPP-PC total score (summed ratings across all 50 items) was used in this study to measure mothers' positive perceptions of parenting.

Data Analyses

Power Analysis. Estimation of the power needed to detect the hypothesized effects for this study was based on Cohen's (1988) formula for determining adequate sample size when employing multiple regression analysis. With 6 predictor variables, assuming a medium effect size of .15 and an alpha level of .05, it was determined that a minimum sample of 97 participants was required for sufficient power to detect the hypothesized effects (Algina & Olejnik, 2003). With a sample of 114 participants and 6 predictor variables, this study had sufficient power to test the hypotheses.

Data Analyses Overview. Preliminary exploratory analyses were conducted prior to testing the hypotheses (note: all analyses were conducted using SPSS 15, SPSS Inc.,

Chicago, IL). The variables were systematically examined for data entry errors, missing values, and violations of assumptions for conducting multivariate analysis (i.e., outliers, non-normality, non-linearity, multicollinearity and heteroskedasticity; Tabachnick & Fidell, 2007). Bivariate correlation analyses among predictor variables were conducted to identify associations and collinearity. This was followed by descriptive analyses of predictor and outcome variables. Bivariate correlation analyses of demographic and outcome variables were conducted to identify demographic covariates for subsequent analyses. Finally, Pearson's product-moment correlations, multiple regression, and mediator analyses were employed to test the main hypotheses.

Chapter 3 Results

Preliminary Exploratory Analysis

Missing Data Analysis. Frequency and descriptive analyses were conducted to detect missing and erroneous data points. All scores were within the expected range and no data entry errors were detected in the data set. A missing value analysis was conducted to determine the amount and pattern of missing data (i.e., non-random vs. random; McKnight, McKnight, Sidani, & Figueredo, 2007; Rubin, 1976). A pattern of non-random missing data was found for three participants (i.e., 2 participants did not complete one full page of the Positive Contribution scale and 1 participant did not complete one full page of the HADS). These three participants were removed based on McKnight et al.'s recommendations for managing non-random missing data. A random pattern for missing data were found in 3.5% of the participants, ranging from 1 item to 3 items per scale, which represented less than 10% of the total items on any given scale. Because these missing data had a random pattern they were managed by substituting the sample's mean score for that missing scale item (Rubin, 1976).

Exploratory Descriptive, Correlation and Regression Analysis. Data were examined for violations of assumptions for conducting multivariate analysis (i.e., outliers, non-normality, non-linearity, multicollinearity and heteroskedasticity; Tabachnick & Fidell, 2007). Normality was assessed for each variable. Three variables (i.e., child disruptive behaviour, formal support, and family empowerment) had significant Kolmogorov-Smirnov tests and visual inspection revealed skewed histograms and boxplot distributions. To confirm the nature of the non-normality, the means and standard deviations for each of these variables were converted into z-scores and compared with the

critical values on the z distribution (Field, 2005). Child disruptive behaviour and formal support had moderate positive skewness and a square root transformation improved the normality of these variables. Family empowerment had a mild negative skew without transformation and a positive skew with transformation. In cases like these, Tabachnick and Fidell (2007) recommend that the variable is not suitable for transformation and thus family empowerment was not transformed.

Correlations among the predictor variables were examined for collinearity (see Table 4). None of the correlations among the variables exceeded Tabachnick and Fidell's (2007) criterion for excluding variables in multivariate analysis (bivariate correlations greater than .90). Multicollinearity was examined for each of the multiple regressions and none of the variance inflation factors (VIF), condition indices and variance proportions indicated multicollinearity. Using Mahalanobis distances, no cases were identified as unduly influential on the regression parameters (Tabachnick & Fidell). Cook's distance scores indicated that no cases were influential outliers (Cook's distance < 1). A visual examination of the residual scatterplots for the two dependent variables (i.e., maternal distress and mothers' positive perceptions of parenting) also confirmed that the assumptions for multivariate analyses were met (i.e., normality, linearity, and homoscedasticity between the predicted dependent variable scores and errors of prediction). However, after conducting the multivariate analysis for maternal distress, a suppression effect was found for service empowerment. A visual inspection of the partial regression plot revealed one case was a multivariate outlier and had high leverage, low discrepancy, and moderate influence. Thus, this case was only removed for the multivariate analyses of maternal distress.

Table 4

Correlations among Predictor Variables (N = 114)

Predictor Variables	2	3	4	5	6
1. Disruptive behaviour	-.12	.03	-.29**	-.17	-.05
2. Helpful informal support		.37**	.34**	.35**	.22*
3. Helpful formal support			.10	.24*	.26**
4. Self-efficacy				.63*	.30**
5. Family empowerment					.54**
6. Service empowerment					

* $p < .05$. ** $p < .01$.*Main Analyses*

Descriptive Analyses. The Strengths-based ABCX model was used as a conceptual framework for reporting the variables of interest. Thus, the stressor (*A*) was child disruptive behaviour, resources (*B*) were informal and formal supports, perceptions of strengths (*C*) were self-efficacy and empowerment, and adjustment outcomes (*X*) were maternal distress and positive perceptions of parenting. Means, standard deviations, range of scores and Cronbach's alpha values for the variables are presented in Table 5.

The stressor (*A*) variable of children's disruptive behaviour (Developmental Behaviour Checklist, disruptive behaviour subscale; Einfeld & Tonge, 2002) had a mean score of 16.44 (SD = 8.89). Without data on children's intellectual level, the percentiles for the severity of disruptive behaviour could not be precisely interpreted. However compared to normative data, an average score of 16.44 would place individuals with a mild intellectual disability above the 54th percentile for severity of disruptive behaviour, with moderate intellectual disability above the 60th percentile for severity, and with

severe intellectual disability above the 72th percentile for severity of disruptive behaviour, all of which are above the clinical cut-off for psychiatric caseness (Einfeld & Tonge, 2002).

Resources (*B*) such as helpful informal support and helpful formal support (Family Support Scale, Dunst, Jenkins, & Trivette, 1994) had mean scores of 1.91 (*SD* = .74) and 1.77 (*SD* = .99), respectively. Cronbach's alpha values were acceptable for both helpful informal and formal support (i.e., .79 and .85, respectively). Thus on average mothers reported informal and formal supports ranged from "not at all helpful" to "sometimes helpful".

Perception of parental strengths (*C*) included self-efficacy (Difficult Behaviour Self-efficacy Scale; Hastings & Brown, 2002) and empowerment (Family Empowerment Scale; Koren et al., 1992). Self-efficacy for managing disruptive behaviour had an acceptable Cronbach's alpha value of .88 and a mean score of 21.73 (*SD* = 4.92) indicating on average a mid-range sense of self-efficacy. Family empowerment had an acceptable Cronbach's alpha value of .91 and a mean score of 46.13 (*SD* = 7.32), which indicated that on average mothers felt empowered to manage her family-life "sometimes" to "often". Service empowerment had an acceptable Cronbach's alpha value of .87 and a mean score of 48.30 (*SD* = 7.12), indicating that on average mothers "often" felt empowered while case managing services for their child with ASD.

Adjustment (*X*) included maternal distress and positive perceptions of parenting, which were measured by the *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983) and the *Kansas Inventory of Positive Contribution Scale* (Behr et al., 1992), respectively. The total score for maternal distress had an acceptable Cronbach's alpha

value of .87 and a mean score of 16.38 ($SD = 7.31$). Using the cut-off score of 11 for caseness, the anxiety and depression subscales of the HADS indicated that 70.2% of mothers were in the clinical range for anxiety and 36% of mothers were in the clinical range for depression. Positive perceptions of parenting had an acceptable Cronbach's alpha value of .93 and the mean score was 140.39 ($SD = 18.78$) out of a possible range of 0 to 200.

Table 5

Variable Means (SD) and Range (N = 114)

Variable	<i>M (SD)</i>	Range	
		Potential	Actual
Disruptive behaviour	16.44 (8.89)	0-47	3-44
Helpful informal support	1.91 (.74)	0-5	.36-3.89
Helpful formal support	1.77 (.99)	0-5	0-4.5
Parenting self-efficacy	21.73 (4.92)	0-35	9-33
Family empowerment	46.13 (7.32)	0-60	30-60
Service empowerment	48.30 (7.12)	0-60	31-60
Maternal distress	16.38 (7.31)	0-42	3-36
Positive perceptions	140.39 (18.78)	0-200	98-190

Correlation Analyses of Demographics with Predictor and Outcome Variables.

Correlation analyses were conducted to identify significant associations between the demographic variables and the predictor and outcome variables (see Tables 6 and 7).

Pearson's product-moment correlations were used for continuous demographic variables (i.e., maternal and child age). Pearson's chi-square tests for independence were used for ordinal demographic variables (i.e., education, occupation, and family income).

Only two significant correlations were found between maternal demographics and predictor/outcome variables. Mothers' level of education was negatively associated with children's disruptive behaviour ($r = -.27, p < .01$) and mothers' age was negatively associated with distress ($r = -.24, p < .05$). Thus, mothers with higher levels of education reported lower levels of disruptive child behaviour, and older mothers reported lower levels of anxiety and depression. Only one significant correlation was found between child demographics and predictor/outcome variables. Children's age was negatively associated with the helpfulness of formal support ($r = -.20, p < .05$). Thus, mothers of younger children received more helpful formal support.

Table 6

Correlations between Demographic and Predictor Variables (N = 114)

	Disruptive Behaviour	Helpful		Self-efficacy	Empowerment	
		Informal Support	Formal Support		Family	Service
Maternal Age	-.03	-.01	-.05	.05	.15	.1
Education	-.27**	.17	.09	.11	.13	.18
Occupation	.13	-.07	-.01	.16	.09	-.09
Family Income	-.13	.13	.14	.01	-.03	.04
Child Age	-.00	-.07	-.20*	.04	.14	.12

* $p < .05$. ** $p < .01$

Table 7

Correlations between Demographic and Outcome Variables (N = 114)

	Maternal Distress	Positive Perceptions of Parenting
Maternal Age	-.24*	-.07
Maternal Education	-.07	-.04
Maternal Occupation	-.07	-.01
Family Income	-.14	-.13
Child Age	-.17	-.04

* $p < .05$. ** $p < .01$.

Correlations of Predictor and Outcome Variables. Pearson's product-moment correlation analyses were conducted to examine the zero order associations between the predictor and outcome variables (see Table 8). The stressor, disruptive child behaviour had a significant and positive association with distress ($r = .35, p < .001$) and a negative association with positive perceptions of parenting that approached significance ($r = -.16, p < .09$).

Three of the six strengths-based predictors (i.e., informal supports, self-efficacy, and empowerment) were associated with both maternal distress and positive perceptions of parenting. For mothers, helpfulness of informal support, self-efficacy for managing disruptive behaviour, and empowerment were negatively associated with maternal distress ($r = -.27, p < .01$; $r = -.46, p < .01$; and $r = -.38, p < .01$, respectively) and positively associated with positive perceptions of parenting ($r = .28, p < .01$; $r = .37, p < .01$; and $r = .38, p < .01$, respectively). Thus, when the predictors were examined individually, higher levels of disruptive child behaviour were related to higher maternal

distress. In contrast, mothers with higher levels of helpful informal support, self-efficacy, and family empowerment had lower levels of maternal distress and higher levels of parental positive perceptions.

Table 8

Correlations for Predictor and Outcome Variables (N = 114)

	Maternal Distress	Positive Perceptions of Parenting
Disruptive behaviour	.35***	-.16*
Helpful informal support	-.27**	.28**
Helpful formal support	-.15	.11
Self-efficacy	-.46**	.37**
Family empowerment	-.38**	.38**
Service empowerment	-.04	.17

* $p < .09$. ** $p < .01$. *** $p < .001$.

Hierarchical Multiple Regression Analyses: Overview. To examine the applicability of a strengths-based ABCX model for explaining adjustment in mothers of children with autism, two separate analyses were conducted, one for each of the criterion variables: maternal distress and positive perceptions of parenting. Adhering to the strengths-based ABCX model, the predictor variables were entered into the regression equation in 4 blocks in the following order: 1) disruptive child behaviour (stressor), 2) informal support and formal support (support/resources), 3) self-efficacy for managing child behaviour (maternal strength) and 4) family empowerment and service empowerment (maternal strength).

Hierarchical Multiple Regression Analysis: Maternal Distress. Maternal age was entered into the model first because it was identified as a demographic covariate with

distress (see Table 5 above). When entered, maternal age made a significant contribution to predicting distress ($\beta = -.24, p < .001$), accounting for 6.6% of the variance ($F(1, 110) = 7.78, p < .05$) indicating that older mothers report lower levels of distress. After controlling for the effects of maternal age, disruptive child behaviour was entered into the second block of the model and made a significant unique contribution to predicting maternal distress ($\beta = .34, p < .0001$), accounting for an additional 11.8% of the variance ($F(2, 109) = 7.78, p < .0001$). Specifically, higher levels of disruptive child behaviour were related to higher levels of maternal distress.

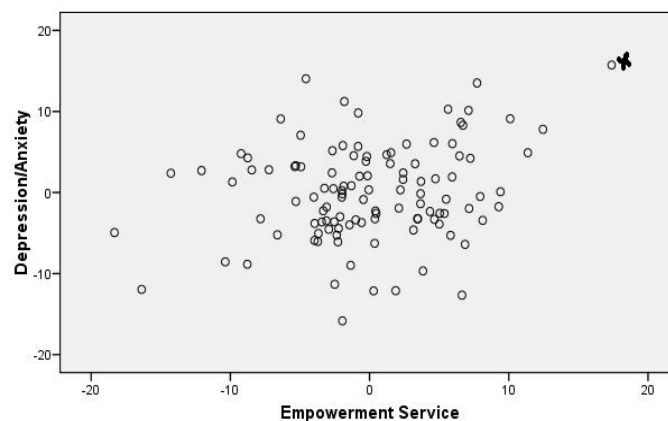
Informal and formal supports were entered into the third block of the model. Informal support alone made a significant unique contribution to predicting maternal distress ($\beta = -.19, p = .03$) and formal support made a non-significant contribution ($\beta = -.09, p > .05$), while both forms of support accounted for an additional 6.3% of the variance ($F(4, 107) = 8.77, p < .0001$). Thus, helpful informal support was related to lower levels of maternal distress.

Self-efficacy was entered into the fourth block of the model and made a significant unique contribution to predicting maternal distress ($\beta = -.37, < .0001$), accounting for an additional 9.6% of the variance ($F(5, 106) = 11.03, p < .0001$). Specifically, higher levels of self-efficacy were related to lower levels of maternal distress.

Family empowerment and service empowerment were entered in the final and fifth block of the model. Service empowerment alone made a significant unique contribution to predicting maternal distress ($\beta = .24, p = .01$) and family empowerment made a nonsignificant contribution ($\beta = -.12, p > .05$), while both forms of empowerment

accounted for an additional 4% of the variance ($F(7, 104) = 9.19, p < .0001$). Notably and in contrast to expectations, higher levels of service empowerment were related to higher levels of maternal distress. Supplementary analyses were conducted to investigate this unexpected result. A partial regression plot was constructed which showed the effect of adding service empowerment to the model when all of the other predictors were in the model (see Figure 1). As indicated by the X in Figure 1, the data point (i.e., case) in the far upper right side represented an outlying case that had high leverage, low discrepancy, and moderate influence on the model. Once this case was removed from the model, service empowerment was only marginally significant ($p = .053$).

Figure 1. *Partial Regression Plot*



With the multivariate outlier removed, the final model accounted for 35% of the variance in maternal distress (see Table 9). Significant predictors were Maternal Age ($\beta = -.24, p = .01$), Disruptive Child Behaviour ($\beta = .23, p = .01$), and Self-efficacy ($\beta = -.37, p = .001$). In summary, supports and empowerment did not significantly contribute to the final model; instead higher levels of maternal distress were predicted by maternal age and disruptive child behaviour while lower levels of maternal distress were predicted by maternal self-efficacy for managing children's disruptive behaviour.

Table 9.

Summary of Hierarchical Regression Analysis for Variables Predicting Maternal Distress ($N = 113$)

Variable	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Constant	17.38	4.19		23.88	4.73		35.05	5.11		31.62	5.64	
Mothers age	-.23	.08	-.24**	-.24	.08	-.25**	-.22	.07	-.24**	-.23	.08	-.24**
Child Disruptive Behaviour	2.18	.55	.34***	2.06	.54	.32***	1.46	.54	.23**	1.45	.52	.23**
Informal Support				-1.86	.88	-.19*	-.76	.88	-.08	-.78	.86	-.08
Formal Support				-1.65	1.68	-.09	-1.65	1.68	-.09	-2.10	1.59	-.11
Self-efficacy							-.53	.13	-.37***	-.49	.16	-.34**
Family Empmt										-.12	.12	-.12
Service Empmt										-.19	.08	.19
R^2		.18			.24			.35			.37	
<i>F</i> for change in R^2		15.66***			4.07*			18.08***			1.92	

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

Hierarchical Multiple Regression Analysis: Positive Perceptions of Parenting. No demographic variables were related to mothers' positive perceptions, thus disruptive child behaviour was entered into the model first; its contribution was not significant ($p = .10$) and accounted for 2.4% of the variance in positive perceptions of parenting ($F(1, 111) = 2.7, p = .10$). Next, informal and formal supports were entered into the second block of the model. Informal support alone made a significant unique contribution to predicting positive perceptions of parenting ($\beta = .25, p = .01$), accounting for 6.4% of the variance ($F(4, 107) = 8.77, p < .05$). Thus, helpful informal support was related to higher levels of positive perceptions of parenting. Self-efficacy was entered into the third block of the model and made a significant unique contribution to predicting positive perceptions of parenting ($\beta = .32, p = .01$), accounting for an additional 8.5% of the variance ($F(4, 108) = 5.64, p < .0001$). Specifically, higher levels of self-efficacy were related to higher levels of positive perceptions of parenting. Family and service empowerment entered in the fourth block of the model. Neither made a significant contribution to predicting positive perceptions of parenting.

The final model accounted for a total of 17% of the variance in positive perceptions of parenting (see Table 10). Once all of the predictors had entered the model, only self-efficacy ($\beta = .32, p < .05$) significantly contributed to positive perceptions of parenting. In summary, disruptive child behaviour, support, and empowerment did not contribute to the model instead, mothers with higher levels of self-efficacy for managing their children's behaviour reported more positive perceptions of parenting.

Table 10.

Summary of Hierarchical Regression Analysis for Variables Predicting Mothers' Positive Perceptions (N = 114)

Variable	Model 1			Model 2			Model 3			Model 4		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Constant	150.66	6.26		136.47	8.76		109.90	11.59		99.83	14.39	
Child Disruptive Behaviour	-2.54	1.55	-0.15	-2.07	1.52	-0.13	-0.71	1.51	-0.04	-0.77	1.51	-0.05
Informal Support				6.33	2.47	0.25*	3.84	2.48	0.15	3.49	2.50	.14
Formal Support				0.18	4.71	.00	0.20	4.51	.00	-1.00	4.63	-.02
Self-efficacy							1.20	0.36	0.32**	0.87	0.45	0.23
Family Empmt										0.33	0.34	0.13
Service Empmt										0.10	0.28	0.04
R^2		.02			.09			.17			.19	
<i>F</i> for change in R^2		2.70			3.85*			11.04**			.88	

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

Mediation Analyses: Maternal Distress. A mediator variable can explain how or why a predictor variable affects the outcome. Thus, Baron and Kenny's (1986) criteria for testing mediation requires that a mediating variable is related to both the predictor and outcome variables and also accounts, either fully or partially, for the relationship between them. First employing hierarchical regression, a significant relationship was established between the predictor, disruptive child behavior, and the outcome variable, maternal distress ($\beta = .35, p < .001$). Second, a relationship was established between the mediator, self-efficacy, and the outcome, maternal distress ($\beta = -.46, p < .001$). Third, a relationship was established between the predictor, disruptive child behavior, and the mediator, self-efficacy ($\beta = -.29, p < .001$). In the fourth regression analysis, the mediator (i.e., self-efficacy) reduced the strength of the relationship between the predictor, child disruptive behavior, and the outcome, maternal distress (i.e., from $\beta = .35, p < .001$ to $\beta = .24, p < .01$; see Table 11).

The Sobel test was conducted to test whether the mediating effect of self-efficacy on the relationship between disruptive child behaviour and maternal distress was significant (Preacher & Hayes, 2004). Self-efficacy was found to partially mediate the effect of child disruptive behaviour on mothers' distress, as shown by the significant reduction in the strength of the relationship between child disruptive behaviour and maternal distress (i.e., self-efficacy had an estimated indirect effect of $\beta = .11, z = 2.62, p < .01$; see Figure 2).

Table 11

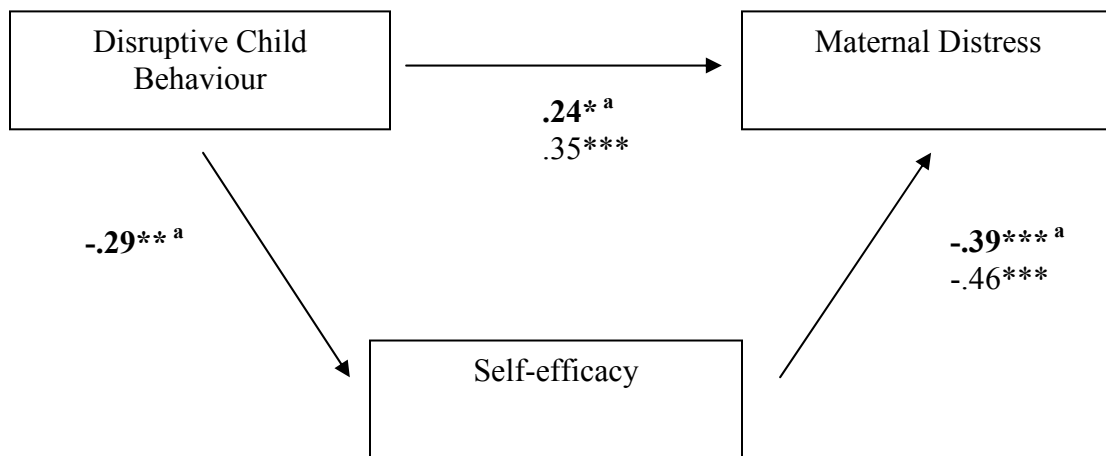
Summary of Hierarchical Regression for the Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Maternal Distress

Model	Predictor	B	SE B	β	R ²	ΔR^2	Sobel (z)
1	Disruptive Behaviour	2.29	.58	.35***	.12	.12	
2	Disruptive Behaviour	1.55	.56	.24**			
	Self-efficacy	-.58	.13	-.39***	.26	.14	2.62**

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

Figure 2.

Partial Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Maternal Distress



Notes: ^a Sobel result: $\beta = .11$, $z = 2.62$, $p < .01$.
* $p < .05$. ** $p < .01$. *** $p < .001$.

Mediation Analyses: Positive Perceptions of Parenting. Unlike maternal distress, there is very little research on the factors that predict positive perceptions of parenting. With limited evidence for formulating hypotheses, an exploratory approach was adopted to examine whether self-efficacy had a mediating effect on the relationship between disruptive child behaviour and positive perceptions of parenting. Self-efficacy did not fully meet the criteria outlined by Baron and Kenny (1986) for conducting mediation analysis, but because there was a trend, it was decided to proceed with an exploratory analysis (see Table 4). Employing hierarchical regression analyses, disruptive child behavior was related to self-efficacy ($\beta = -.29, p < .001$) and positive perceptions of parenting ($\beta = -.16, p = .09$). Self-efficacy was also related to positive perceptions of parenting ($\beta = .37, p < .0001$). Next, to test for mediation, the variable disruptive child behaviour was entered into the first block, and self-efficacy was entered into the second block along with disruptive child behaviour as predictors of positive perceptions of parenting. Self-efficacy was found to mediate the small effect of child disruptive behaviour on mothers' sense of positive perceptions of parenting (i.e., from $\beta = -.16, p < .09$ to $\beta = -.06, p > .05$; see Table 12).

The Sobel test was conducted and self-efficacy was found to fully mediate the small effect of child disruptive behaviour on positive parental perceptions, as shown by the significant reduction in the strength of the relationship between child disruptive behaviour and mothers' positive perceptions of parenting (i.e., self-efficacy had an estimated indirect effect of $\beta = -.10, z = -2.48, p < .01$; see Figure 3).

Table 12.

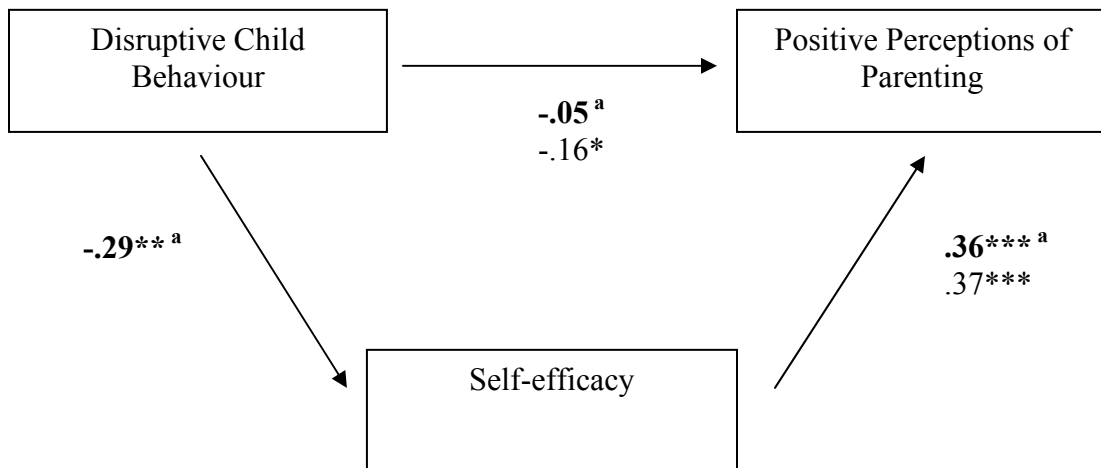
Summary of Hierarchical Regression for the Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Positive Perceptions of Parenting

Model	Predictor	B	SE B	β	R ²	ΔR^2	Sobel (z)
1	Disruptive Behaviour	-2.68	1.57	-.16*	.02	.02	
2	Disruptive Behaviour	-.93	1.55	-.06			
	Self-efficacy	1.36	.35	.36***	.14	.12	-2.48**

* $p < .09$. ** $p < .01$. *** $p < .001$.

Figure 3.

Mediating Effect of Self-efficacy on the Relationship between Disruptive Child Behaviour and Positive Perceptions of Parenting



Notes: ^a Sobel result: $\beta = -.10$, $z = -2.48$, $p < .01$.
* $p < .09$. ** $p < .01$. *** $p < .001$.

Summary of Findings. Consistent with predictions for Objective 1, younger mothers did report higher distress. Contrary to predictions, mothers' age was not related to positive perceptions of parenting.

As predicted for Objective 2, the strengths-based ABCX model explained 35% of the variance in maternal distress. After controlling for the effect of mothers' age and the significant contribution of higher levels of disruptive child behaviour (*A* stressor), the contribution of supports (*B* resources) were secondary to the effects of higher levels of self-efficacy for managing disruptive behaviour (*C* perception of maternal strengths) in predicting lower levels of distress (*X* outcome) in mothers. Contrary to expectations, family and service empowerment (*C* perception of maternal strengths) did not contribute significantly to the final model for maternal distress.

Also predicted for Objective 2, the strengths-based ABCX model explained 17% of the variance in positive perceptions of parenting. Among all of the predictors and contrary to predictions, only self-efficacy (*C* perception of maternal strengths) significantly contributed in the final model. Thus, the contribution of disruptive child behaviour (*A* stressor), support (*B* resources) and empowerment (*C* perception of maternal strengths) were secondary to the effects of higher levels of self-efficacy for managing disruptive behaviour (*C* perception of maternal strengths) in predicting higher levels of positive perceptions of parenting (*X* outcome) in mothers.

Consistent with the first hypothesis for Objective 3, self-efficacy was found to partially mediate the effect of child disruptive behaviour on mothers' distress. Prior to entering self-efficacy into the model, disruptive child behaviour explained 35% of the variance in maternal distress. After entering the model, self-efficacy explained 14% of the variance between disruptive child behaviour and maternal distress, leaving 23% unexplained. Thus, self-efficacy (*C* perception of maternal strengths) does partially

mediate the relationship between disruptive child behaviour (*A* stressor) and distress (*X* outcome) in mothers.

Consistent with the second hypotheses for Objective 3, self-efficacy was found to mediate the very small effect of child disruptive behaviour on mothers' positive perceptions of parenting. Prior to entering self-efficacy into the model, disruptive child behaviour explained 16% of the variance in positive perceptions of parenting. After entering the model, self-efficacy explained 11% of the variance between disruptive child behaviour and positive perceptions of parenting, leaving 5% unexplained. Thus, self-efficacy (*C* perception of maternal strengths) fully mediates the relationship between disruptive child behaviour (*A* stressor) and positive perceptions of parenting (*X* outcome) in mothers.

Contrary to the third prediction for Objective 3, family and service empowerment failed to mediate the relationship between disruptive child behaviour (*A* stressor) and distress (*X* outcome) in mothers. Family and service empowerment also failed to mediate the relationship between disruptive child behaviour (*A* stressor) and positive perceptions of parenting (*X* outcome) in mothers.

Chapter 4 Discussion

The present study is the first to examine a strengths-based framework for predicting better outcomes in mothers of children with autism. Specifically, the ABCX model of family adjustment to stress and crises (McCubbin & Patterson, 1983) was adapted to include both maternal strengths and positive outcomes. Employing a survey design, 114 mothers of school-age children with autism provided the details of their children's difficult behaviour, family and formal supports, their own self-efficacy, empowerment, distress and positive perceptions of parenting. The primary purpose of this study was to discover whether there were individual factors or patterns of factors that would predict better outcomes in mothers of children with autism. After accounting for all of the predictors (see details below), mothers with higher perceived self-efficacy experienced less maternal distress and more positive perceptions of parenting. In addition, maternal self-efficacy weakened the strong relationship between children's disruptive behaviour and mothers' perceptions of distress. Finally, mothers' perceptions of parental self-efficacy reduced the small but negative effect of children's disruptive behaviour on mothers' positive perceptions of parenting. Taken together, these findings indicate that the main predictor of better outcomes in mothers of children with autism was their self-confidence and self-reliance (i.e., perceived self-efficacy) rather than relying on external supports alone.

In the present study, questions were addressed first for the outcome of maternal distress and, secondly for the outcome of positive parental perceptions. For each of these outcomes, I will discuss the direct and unique influences that child disruptive behaviour, supports, self-efficacy and empowerment have on maternal health. This will be followed

by a discussion of the mediating effects of parental self-efficacy on maternal outcomes. Finally, the limitations of the study and the possible clinical implications and directions for future research will be outlined.

Before examining the main predictors of maternal outcomes, the influences of demographic characteristics were considered for their possible effects on mothers' outcome. As expected, and in agreement with others (Bebko et al., 1987; Dumas et al., 1991), younger mothers were more likely to experience higher levels of maternal distress. Evidence of higher levels of distress in younger mothers is inconsistent with claims that mothers may burn out from their caregiving over time (Gray, 2006; Holmes & Carr, 1991). Rather, these findings provide support for McCubbin and Patterson's (1983) ABCX Model for Family Adaptation which suggests instead that mothers adjust over time. Higher maternal distress may also be related to a more recent diagnosis of autism. A new diagnosis of autism represents a difficult period of adjustment for mothers and all members of the family (Nissenbaum, Tollefson, & Reese, 2002). Therefore, it is possible that higher distress in younger mothers may be explained by their grief and inexperience with parenting a child with autism.

Family theorists also propose that mothers who are distressed may not feel positive about their parenting and may view their children as the source of their distress (McCubbin & Patterson, 1984). However, in the present study, while younger mothers were likely to be more distressed, there was no age difference for mothers' positive perceptions of parenting. These findings indicate that mothers may have positive perceptions about their parenting even if they are vulnerable to distress. Each of these adjustment outcomes, first maternal distress and second positive perceptions, will be

discussed in relationship to factors that are thought to influence better health in mothers of children with autism.

Outcome: Maternal Distress

The present study examined several questions that were premised on the assumption that children with autism have highly difficult behaviours which strongly relate to mothers' distress. The mothers who participated in this study indicated that their children's behaviours were highly disruptive and as such, were comparable to other studies conducted with children with autism (e.g., Brereton, Tonge, & Einfeld, 2006; Tonge & Einfeld, 2003). Brereton and colleagues suggest that these levels of highly disruptive behaviour are "well-above the clinical cut-off point for psychiatric caseness" and significantly higher than those found in children with intellectual disability. Certainly, difficult behaviour is challenging for everyone in the child's life, but has shown to be especially stressful for mothers (Hastings et al., 2005).

Indeed, the majority of mothers in the present study had clinically high levels of distress. These distress levels were comparable to levels found in other mothers raising children with autism (Hastings et al., 2005) and to clinical populations (Snaith & Zigmond, 1994), placing them at the 84th percentile for distress in the general population (Crawford, Henry, Crombie, & Taylor, 2001). As predicted, mothers' distress was strongly related to their children's difficult behaviour. Also hypothesized and found was that younger mothers were more distressed than older mothers, thus providing some evidence for maternal adjustment over time and raising the question of what factors might contribute to this adjustment.

One of the main contributions of this study was the evaluation of a strengths-based model to examine mothers' stressors, supports, and strengths in relationship to maternal outcomes. Building on the ABCX model which proposes that families garner resources to cope with stressors associated with raising a child with a disability, the strengths-based model proposes that mothers experience better outcomes when they garner resources, gain self-efficacy, and become empowered to raise their child with autism. It was hypothesized that these factors would individually influence maternal health. All of the factors were related with the exception of mothers' formal supports and service empowerment. Findings suggested that mothers with higher distress were more likely to be younger and have children with more difficult behaviour. Mothers with less distress had helpful family support, an average understanding of how to manage their child's difficult behaviour, and believed they could manage their families' needs. In the present study these factors were also examined together to determine their unique contributions to maternal distress.

The main correlates of maternal distress were mothers' age, children's difficult behaviour, informal support, self-efficacy and empowerment. Although unrelated to maternal distress, formal support and service empowerment were also entered into the model to account for their relationships with these main correlates (see Table 4 above). Most of the factors contributed to maternal distress, accounting for 35% of the variance, with the exception of family and service empowerment. After controlling for mothers' age, only children's disruptive behaviour, a negative predictor, and parental self-efficacy, a positive predictor, explained a significant, moderate amount of the variance in mothers' distress. Contrary to expectations, support and empowerment were subsumed by parental

self-efficacy. Thus when considering a strengths-based approach for understanding maternal distress, the present findings suggest that enhancing mothers' ability to manage their children's condition may be more health-promoting than relying on external supports alone.

Support. Consistent with expectations, formal services were not helpful for maternal distress and informal supports were only somewhat helpful. While the average mother described both informal and formal support as only "somewhat helpful", the range of helpfulness differed for informal supports and formal supports. Indeed, mothers' perceptions of informal supports ranged from "not at all helpful" to "generally helpful", while their perceptions of formal supports ranged from "not available" to "very helpful". As discussed above, the benefits of both forms of support were secondary to maternal self-efficacy. Considered together, these findings may point to the conditions under which supports are truly helpful.

In a recent study focusing on respite support, mothers indicated that support must benefit their children before it could be of benefit to them (Hutchinson et al., 2010). Moreover, mothers believe that support providers must be competent in managing their child's condition to be truly helpful (Sharpley et al., 1997). Mothers may perceive support as helpful when it is provided by those who understand their children's needs and when they perceive it as beneficial for their child. Perhaps when these two conditions are met mothers might also benefit from support. In contrast, mothers who perceive their supports as incompetent or not in-line their children's needs may jeopardize their own health to meet their children's needs. Thus, informal support may be available to mothers but it may not be perceived as helpful when family and other community members lack

the expertise to properly care for or enrich the lives of children with autism. This may indicate that support from those with expertise should be more helpful.

Consistent with the findings of others (e.g., Bromley et al., 2004), all types of formal support played a minor role in buffering maternal distress, even though mothers of younger children reported receiving more helpful formal support. A common assumption is that formal service providers possess the expertise that could be helpful to families. But the helpfulness of these formal services was unrelated to children's difficult behaviour and failed to impact maternal distress. So although it was expected that formal support would not affect maternal distress based on the findings of others (e.g., Bromley et al., 2004; Hastings & Johnson, 2001) it bears some discussion, particularly since the children in this study had highly difficult behaviour and mothers were highly distressed. These circumstances would suggest that these mothers and their children needed helpful formal services but received none that were sufficiently effective. This raises several concerns about the effectiveness of service delivery for mothers and their children with autism. For example, Hutchinson et al. (2010) found that services were not available when mothers needed them (i.e., timing of service) or that the available formal supports did not target children's difficult behaviour or maternal distress (i.e., nature of service). In clinical, educational, and social systems of care, practitioners often suggest that parents need to be empowered to access services and support (Naschen & Minnes, 2005). However in the present study, despite younger children receiving more *helpful* formal support than older children, the helpfulness of formal supports had no relationship with children's disruptive behaviour or maternal distress even when mothers were empowered for garnering formal support.

Empowerment. Given that this study was among the first to examine empowerment in families of children with autism, there were no specific hypotheses related to this construct. Consistent with Diamond's (2005) findings, mothers in the present study often felt empowered in managing their families' daily life and in their ability to garner services. Although empowerment was related to maternal distress it became nonsignificant when it was collectively examined with other buffering strengths (e.g., support and self-efficacy). However, it is important to note that both family and service empowerment shared variance with these other strengths. Indeed, mothers' sense of empowerment in their family and service environment shared a positive relationship with both informal and formal support and self-efficacy for managing behaviour. As noted in the Introduction, of particular interest was the relationship between family empowerment and self-efficacy. As proposed, they were strongly related ($r = .63$), suggesting that they are overlapping constructs. While related, they both buffered maternal distress at the univariate level (family empowerment, $r = -.38$; self-efficacy, $r = -.46$) but only self-efficacy emerged as a buffer of maternal distress when this shared relationship was accounted for. This finding may reflect the way in which family empowerment and maternal self-efficacy were defined in this study.

In the present study, family empowerment was broadly defined as mothers' perceptions of their ability to manage daily family life and parenting responsibilities. Maternal self-efficacy was more narrowly defined than family empowerment and as such focused exclusively on mothers' perceptions of their skills, knowledge, and confidence for managing their children's difficult behaviour. The results indicate that the main difference between these constructs is that family empowerment shares no relationship

with children's difficult behaviour while self-efficacy was moderately related. As defined in the present study, family empowerment only relates to maternal distress, while parental self-efficacy relates to both children's difficult behaviour and maternal distress.

Finally, although mothers believed they were empowered to access services, they reported very low rates of helpful formal support. In this situation, mothers may feel distress when they believe that they know how to access services but find none that are helpful. Indeed, mothers reported that the helpfulness of formal services ranged from "not available" to "very helpful". This finding raises an important question that requires further exploration. Is it possible when services are not available that mothers with higher levels of service empowerment experience increased levels of maternal distress?

Self-efficacy. In the present study, mothers had, on average, a mid-range sense of self-efficacy. These findings were comparable to those found in the first study of parental self-efficacy in mothers of children with autism (Hastings & Brown, 2002). At the univariate level, parental self-efficacy for managing children's difficult behaviour positively influenced most aspects of mothers' lives. For example, mothers' self-efficacy was negatively related to their children's difficult behaviour, positively related to their helpful informal support and perceptions of family and service empowerment, and most importantly predictive of lower levels of maternal distress. The only factor with which maternal self-efficacy had no relationship was mothers' helpful formal support. This finding was surprising but it may be a reflection of the formal service system in which this study was conducted. Indeed, there was no relationship between the availability or helpfulness of formal services and the severity of children's difficult behaviour. Thus it makes sense that a formal service system that is either unavailable or does not

specifically address children's difficult behaviour would also be unrelated to mothers' self-efficacy for managing children's difficult behaviour.

When examined collectively with children's difficult behaviour, maternal support and empowerment, self-efficacy was the predominant predictor of lower maternal distress. As hypothesized, and consistent with the finding of Hastings and Brown (2002), self-efficacy was the only factor that mediated the relationship between disruptive child behaviour and mothers' distress. Taken together, the findings support the main assumption in this study, that children's disruptive behaviour is very stressful for mothers but self-efficacy in the form of knowledge, skills, and confidence to manage children's behaviour (vs. empowerment for managing families' resources) buffers maternal distress.

Outcome: Positive Parental Perceptions

With so little known about mothers' positive parental perceptions, the present study tested several hypotheses but employed an exploratory approach to examining its relationship with children's difficult behaviour, mothers' supports, self-efficacy, and empowerment. The findings indicate that some mothers in this study experienced positive perceptions of their parenting role. These levels of positive perceptions were consistent with those found in other studies of mothers with autism (Hastings, Beck, & Hill, 2005). Hastings et al. (2005) found that levels as high as these were strongly and positively related to mothers' positive affect. Consistent with Hastings et al. (2005) mothers' positive parental perceptions had no relationship with maternal anxiety and only a modest relationship with maternal depression. Moreover, children's mean level of difficult behaviour was high and comparable to other studies (e.g., Tonge & Einfeld, 2003) but

only a modest relationship was found with mothers' positive parental perceptions. Taken together, these findings suggest that positive parental perceptions are present in spite of child difficulties and are relatively independent of maternal distress, thus supporting the views of previous scholars (Behr et al., 1992; Hastings & Taunt, 2002; Hastings et al., 2005; Perry, 2004).

The present study attempted to examine the factors that might explain mothers' positive parental perceptions. While individually helpful informal support, self-efficacy, and family empowerment were related to mothers' positive perceptions, in the final model family empowerment did not significantly add to the prediction. Moreover, the final model for mothers' positive parental perceptions included informal and formal support but neither was significant when mothers' self-efficacy was present. In addition, there was a small relationship between children's disruptive behaviour and mothers' positive perceptions, which was mediated by maternal self-efficacy. Given the novelty of these findings, each factor will be briefly discussed in the context of this study and the current literature.

Support. Similar to maternal distress, it was anticipated that informal services would contribute to mothers' positive perceptions. However, it was hypothesized that formal support would not. Consistent with the findings for maternal distress, mothers' perceptions of helpful informal supports were related to their positive perceptions of parenting, but again the benefit of support was subsumed by maternal self-efficacy. These findings suggest that supportive external sources may not be as important for mothers' positive perceptions, as their sense of self-efficacy for managing their child's behaviour. Many suggest that helpful support from family and friends buffers mothers from distress

and convey an underlying assumption that support promotes well-being (e.g., Boyd, 2002; Dunst et al., 1994). However, in the present study, no source of support was sufficiently helpful, while mothers' own self-efficacy (e.g., confidence, knowledge, and skills) was helpful. For mothers, this may suggest that a lack of confidence in the ability of support providers may also reduce its perceived helpfulness (Sharpley et al., 1997). Although it was not examined in this study, the perceived competence of support providers may influence more positive perceptions rather than the perceived helpfulness of support. For example, support providers who blend into families' routines and mirror families' values may promote positive perceptions in mothers. In addition, support that is sufficiently competent to normalize families' lives, by blending into families' routines and mirroring the families' values, may also influence mothers' positive perceptions of parenting. This suggests that if available, home-based care delivered by competent paraprofessionals may be very helpful to families. However, in the present study no formal supports were sufficiently available or helpful to influence mothers' positive perceptions of parenting.

Based on the literature, it was anticipated and found that formal supports did not influence mothers' positive perceptions of parenting (see Scorgie, Wilgosh, & Sobsey, 2004; Turnbull & Turnbull, 1978). These findings may point to the conditions under which formal supports are received and found to be helpful. In a recent study, mothers identified several systemic reasons why formal supports were not perceived as helpful (e.g., out-dated service delivery models and service delivery ideologies, and insufficient access; Hutchinson et al., 2010). Consistent with Dunst et al. (1994) and King et al. (2005), Hutchinson et al. (2010) suggest that children's formal services should be family-

centered (i.e., consider and include all family members) rather than child-centered (i.e., focusing on the child's needs in isolation of the families' needs). However, adopting a family-centered approach may complicate service delivery by exponentially increasing clinicians' caseload (e.g., considering the well-being of one individual vs. all family members). In addition, practitioners trained for pediatrics may not be trained for addressing adult depression. Further, when resources are finite, family-centered care may not seem feasible, particularly for those providers who have not been trained to deliver service in this way. Family-centered care requires professionals to change their focus from treating the individual with autism to include the family living with autism. Thus targets for treatment would explicitly include both child and parent outcomes.

Armstrong and Shevellar (2002) also have suggested that the guiding ideologies of formal services may influence whether they are helpful for promoting well-being. Applying these ideologies to services for children with autism and their mothers, it is important to reflect on the requirements for medical, social, and education models that deliver such services. For example, assessment and treatment services may be based on the medical model of disease which requires families to demonstrate their child's severity to gain access. Respite and community services may be based on the charity model of neediness where families must demonstrate poverty. While all children are entitled to an education, this model of service focuses on the learning needs of the majority rather than on the unique needs of children with autism. Thus, parents must highlight their children's cognitive deficits to access specialized educational services. To access services in any of these models of formal support, parents must be aware of the criteria for each service and must be willing to outline their deficiencies to receive services. After parents determine

which services they need, what the criteria are for access, and expose their deficiencies to gain access, they are likely to be placed on a wait list (Law et al., 2003). Thus services may not be available when children or mothers need them because of finite public resources (Hutchinson et al., 2010). In these circumstances, families must meet the criterion of being in crisis – that is having the highest needs, enduring these needs for a long period of time, showing that they have exhausted all of their personal resources, and demonstrating that they cannot function one more day in their current situation (Hutchinson et al., 2010). All of these experiences may be detrimental to mothers' positive perceptions of parenting, especially if they believe their child is the only reason for their stressors, rather than understanding that it is the fractured system of care that creates these experiences (Turnbull & Turnbull, 2006). In the present study, the helpfulness of formal supports had no relationship with mothers' positive perceptions of raising a child with autism.

Empowerment. It was expected that family and service empowerment would be related to mothers' positive perceptions of parenting. Family empowerment did influence mothers' positive perceptions of parenting; however, service empowerment had no influence. This finding was not surprising given the low helpfulness of formal support. In contrast, mothers' empowerment for helping their families contributed to positive perceptions of parenting, although it was subsumed by their perceptions of parental self-efficacy. Thus mothers' confidence in their ability to manage family resources does influence their well-being but it is their confidence in managing their children's behaviour that relates to their positive perceptions of parenting.

Self-efficacy. When examining parental self-efficacy in the strengths-based model, with child behaviour, support and empowerment, only self-efficacy was significant in the final model. Moreover, only parental self-efficacy accounted for the small relationship between mothers' reports of their child's difficult behaviour and positive perceptions of their parenting. Together, these findings were consistent with those of Lloyd and Hastings (2009) in mothers of children with intellectual disability. Lloyd and Hastings (2009) suggest that mothers with low self-efficacy may feel threatened and overwhelmed by their children's difficult behaviour, and may therefore experience negative perceptions of parenting. Indeed, mothers with higher self-efficacy may feel confident when managing difficult behaviour and the experience of overcoming these challenges contributes to a sense of competence, allowing them to perceive parenting more positively. These arguments concur with Taylor's (1983) Cognitive Adaptation theory. This theory proposes that facing and overcoming a challenging life event inspires individuals to construe positive meaning from the experience. Thus, applying this theory to mothers of children with autism would suggest that mothers who believe they can successfully manage highly disruptive behaviour (i.e., self-efficacy) may also construe positive meaning from their parenting and experience positive perceptions of parenting.

Summary of Findings

In summary, when examining the impact of children's difficult behaviour on mothers' distress and positive perceptions of parenting, mothers' informal support from family and community members, and perceived empowerment for managing their family resources are important for enhancing their well-being. However, empowerment and support were subsumed by mothers' self-efficacy for managing their child's disruptive

behaviour. The final strengths-based model predicted both lower distress and positive perceptions of parenting including the stressor (i.e., disruptive child behaviour), support (i.e., mainly informal) and the strength of parental self-efficacy. Therefore, if service providers want to help children with autism and their mothers they should focus on enhancing parental self-efficacy. Based on the findings from this study – service providers should offer support but most importantly they should do so by teaching mothers how to manage their children’s difficult behaviour. Finally, these findings will be discussed in the context of the limitations of the study and directions for future research, and ending with conclusions and implications for practice.

Limitations

The current study has a few limitations that warrant discussion. First, the participants in this study may represent a biased sample. Adhering to Dillman’s (2000) protocol for reducing bias in survey research, the sample was drawn from the membership lists of autism societies and their support groups. Although untested, it is possible that mothers who are members of autism societies may require more support than those who are not, or they may have poorer mental health. However it is also possible that mothers who belong to autism societies may feel more empowered or hold similar values for understanding autism. Thus, given the possible range of maternal profiles, no conclusions can be drawn as to whether inviting participants from autism societies is a legitimate source of bias.

Another potential source for sample bias may arise from employing a pen and paper survey design. The choice to use a questionnaire survey may have excluded parents who are less literate or those who have less time due to parenting children with higher

needs. To mitigate this effect, mothers were offered the choice of completing their survey by phone. Only one parent requested this option but later declined. This study also suffered from a limitation common to studies conducted with families of individuals with autism, that is, under-representation of single mothers and racially/culturally diverse families. Future researchers may want to broaden sampling procedures, by inviting participants from autism societies, clinical settings and/or schools and by considering ways to engage under-studied groups.

Second, the study relied exclusively on mothers' self-reports and as such, the limitations and strengths inherent in self-report data. All of the measures depended on mothers reporting their children's behaviour and diagnosis, their helpful support, self-efficacy, and empowerment, as well as their mental health. It is possible that mothers may have under-reported their situations, either because they coped by reframing their situation or because they had a need to portray a more well-adapted child. It is also possible that mothers who were highly distressed might over-report their children's behaviour. While multiple informants (i.e., parent, teacher, or clinician) may provide disparate ratings about child behaviour, this may not suggest that mothers' reports are inaccurate. Indeed, reports from multiple informants may only suggest that children's behaviour is different across settings (Achenbach, McConaughy, & Howell, 1987). In addition, cross-informant ratings of children's disruptive behaviour may only reflect the different roles each informant has in the child's life. Thus, engaging multiple informants may provide a more complete picture of children's behaviour rather than discounting the validity of parents' reports (Achenbach et al., 1987). Moreover, subjective reports are the only way of gaining mothers' *perceptions* of their circumstances. Rather than striving for

an objective measure, Achenbach, Krukowski, Dumenci, and Ivanova (2005) argue that subjective reports are useful when examining participants' perceptions and are more accurate for measuring global psycho-social functioning than using objective measures. Future research might compare and/or use both participant self-report and clinical observation measures to determine whether they provide complementary or additional findings.

Third, an inherent limitation in all cross-sectional survey research is that the data are correlational and drawn from one point in time thus precluding conclusions about the direction of effects or causality more generally. For example, it is not known whether child behaviour causes distress in parents or whether distress would be evident regardless of their parenting roles. Moreover, it was not clear how mothers used their supports. Instead of using their supports for themselves, mothers may have used their support for their children's benefit and as an effect, jeopardized their own health. In contrast, mothers might use their supports to develop a sense of parental self-efficacy. Therefore, future research might be conducted longitudinally to provide a clearer picture of directionality, the adaptation process and development of self-efficacy in mothers.

Directions for Future Research

Future research might build on the current research in several ways, some of which have been noted above. Suggestions include employing different research methods and analyses as well as adding or enhancing constructs within the strengths-based model. As reviewed above, a common limitation in research with families of children with autism and in other types of family research is an under-representation of fathers, single parents and parents from diverse socio-economic backgrounds and cultures (Bromley et

al., 2004). In subsequent studies, researchers might diversify their recruitment strategies by inviting participants from a variety of settings to broaden the representation of the sample. Moreover, additional efforts should be made to recruit fathers, single mothers and parents from racially diverse families. Both quantitative and qualitative methods might be employed to combine mothers' self-report with personal interviews to understand the complex nature of parenting children with autism. A longitudinal design might strengthen our understanding of how mothers adapt over time (Gray, 2006). Further, the questions asked in this research are well-suited to structural equation modeling (SEM) analysis. SEM allows the examination of theoretically predicted relationships between the variables of interest and the latent variables underlying the constructs. Such analyses could be used to test the direction of effects and examine the relationships among the constructs to test the strengths-based model proposed in the present study.

Conceptually, future research might extend the strengths-based model to include other stressors or mothers' coping. Life stressors other than child-related stressors have been shown to account for a portion of the variance in maternal outcomes (e.g., Bristol, 1987). Positive coping in the form of reframing, seeking social support, and problem-focused coping have all been shown to be helpful for maternal adjustment (Hastings et al., 2005; Hutchinson & Bryson, in preparation). While the present study found that parental self-efficacy in managing difficult behaviour contributed to maternal well-being, an extension of this construct might include parental self-efficacy for teaching new behaviour. Drawing from positive behavioural support principles, a natural extension of the current construct would be to include parents' beliefs about their ability to teach their

children new skills that might serve as a functional replacement for disruptive behaviour. Lastly, given that empowerment is commonly thought of as an important part of successfully parenting a child with autism, it may be fruitful to examine this construct in various systems of care. In the present study, the helpfulness of formal services was low. A comparison of parental empowerment from different regions that receive less and more helpful formal services might shed more light on the benefit of empowerment.

Finally, based on the present finding that self-efficacy enhances maternal outcomes, future research might focus on the development and evaluation of educational programs designed to enhance self-efficacy in mothers of children with autism. Educational programs might enhance parental self-efficacy by teaching parents how to manage their children's difficult behaviour (cf. Coolican, 2009). Evidence provided here of a positive relationship between maternal self-efficacy and helpful support also raises the possibility that it will be important to provide direct programming to children affected by autism.

Such programming would ideally be family and community-centered, including mothers, fathers, and paraprofessionals, to optimize the generalization of child skills to home and community settings. The intervention would target parents' skill development for both managing disruptive behaviour and teaching replacement behaviours. Of particular interest is whether such a service would be perceived as helpful for families and enhance self-efficacy in parents? Thus, a more applied extension of the present research would be to use an experimental design to examine whether a causal relationship exists between self-efficacy and better maternal outcomes.

Conclusions and Implications for Practice

The present study extends the research literature on mothers of children with autism in a number of ways. First, the current study has provided preliminary evidence for a strengths-based model for predicting better maternal outcomes. Second, this was the first study to examine and an attempt to disentangle parental self-efficacy and empowerment in the context of other factors known to influence maternal outcomes (i.e., children's disruptive behaviour and informal support). Building on previous research (e.g., Hastings & Brown, 2002; Hastings et al., 2005), these findings provide professionals with a specific focus (e.g., positive behavioural strategies and parental self-efficacy) for parent training programs and for others involved in the care and education of children with autism. Indeed, providing parents of children with autism, or other types of behavioural or developmental disorders, with education and training might enhance parents' confidence and self-efficacy for improving their parenting practices and their child's development. Moreover, teaching parents skills to manage their child's behaviour early on may prevent disruptive behaviour from occurring or if disruptive behaviour does occur, parents will feel less threatened and more confident to meet the challenge of disruptive behaviour in their child. Finally, the findings suggest that increasing mothers' self-efficacy may be very promising for preserving and promoting mothers' health. This is a critical finding, given that our families are often competing with the aging population, for health and long-term care services. Supporting parents of children and adults with autism to provide care longer will be a primary concern for policy-makers in the next decades. Thus, the present findings point to a key area of strength for parents of children with autism, self-efficacy for managing the difficult behaviour associated with

autism. In a climate of finite resources, parental self-efficacy is a construct that deserves serious attention and further consideration in future research.

References

- Abrahams, B. S., & Geschwind, D. H. (2008). In autism genetics: On the threshold of a new neurobiology. *Nature Review Genetics*, *9*, 341-55.
- Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin*, *101*, 213-232.
- Achenbach, T. M., Krukowski, R. A., Dumenci, L., & Ivanova, M. Y. (2005). Assessment of adult psychopathology: Meta-analyses and implications of cross-informant correlations. *Psychological Bulletin*, *131*, 361-382.
- Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park, CA: Sage.
- Akerley, M. (1975). The invulnerable parent. *Journal of Autism and Childhood Schizophrenia*, *5*, 275-281.
- Affleck, G., Tennen, H., & Rowe, J. (1991). *Infants in crisis: How parents cope with newborn intensive care and its aftermath*. New York: Springer-Verlag.
- Algina, J., & Olejnik, S. (2003). Sample size tables for correlation analysis with applications in partial correlation and multiple regression analysis. *Multivariate Behavioral Research*, *38* (3), 309-323.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Armstrong, J., & Shevellar, L. (2006). Re-thinking respite. *The SRV Journal*, *1*, 14-25.
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*, 122-147.
- Bandura, A. (1997). *Self-Efficacy. The exercise of control*. New York, NY: W.H. Freeman and Company.
- Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2006). Sensory experiences questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*, *47*, 591-601.
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.

- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714.
- Bebko, J. M., Konstantareas, M. M., & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism & Developmental Disorders, 4*, 565-576.
- Behr, S. K., Murphy, D. L., & Summers, J. A. (1992). *User's manual: Kansas inventory of parental perceptions (KIPP)*. Lawrence, KS: Beach Center on Families and Disability.
- Behr, S. K., & Murphy, D. L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A. P. Turnbull, J. A. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 151-163). Baltimore: Brookes.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*, 722-730.
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*, 208-215.
- Bristol, M. M. (1979). Mothers coping with autistic children: Adequacy of interpersonal support and effects of child characteristics. Unpublished doctoral dissertation, University of North Carolina.
- Bristol, M. M. (1987). Mothers of children with autism and communication disorders: Successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders, 17*, 469-486.
- Bristol, M. M., & Schopler, E. (1983). Stress and coping in families of autistic adolescents. In E. Schopler & G. B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 251-276). New York: Plenum Press.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*, 409-423.
- Brookman-Frazer, L., Stahmer, A., Baker-Ericzen, M. J., & Tsai, K. (2006). Parenting interventions for children with autism spectrum and disruptive behavior disorders: Opportunities for cross-fertilization. *Clinical Child and Family Psychology Review, 9*, 181-200.

- Centers for Disease Control (2010). *Autism and developmental disabilities monitoring (ADDM) network*. Retrieved January 19, 2010 from <http://www.cdc.gov/ncbddd/features/counting-autism.html>
- Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 3, 289-306.
- Cohen, J. W. (1988). *Statistical power analysis for the behavior sciences* (2nd edition). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Coolican, J. (2009). *Brief parent training in pivotal response treatment for preschoolers with autism* (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 1872523741)
- Cornell Empowerment Group (1989). Empowerment and family support. *Networking Bulletin*, 1, 1 – 23.
- Crawford, J. R., Henry, J. D., Crombie, C. & Taylor, E. P. (2001). Brief report normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40, 429–434.
- Corkum, P. (2008). *Demographic Questionnaire*. Unpublished questionnaire, Department of Psychology, Dalhousie University, Halifax, Nova Scotia, Canada.
- Diamond, T. (2005). *Positive and negative impacts of raising a child with autism: An examination of the direct and moderating effects of various coping resources* (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 1079657691)
- Dillman, D. A. (2000). *Mail and internet surveys: The tailored design method* (2nd edition). New York: Wiley.
- Donenberg, G., & Baker, B. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, 21 (2), 179-198.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2, 97-110.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.

- Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family support scale: Reliability and validity. *Journal of Individual, Family and Community Wellness, 1*, 45–52.
- Dunst, C. J., Jenkins, V., & Trivette, C. M. (1994). Family support scale. In C. J. Dunst, C. M. Trivette & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies, and practices* (pp. 152–160). Cambridge, MA: Brookline Books.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency, 90*, 403–417.
- Dunst, C. J., Trivette, C. M. & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA Brookline Books.
- Einfeld, S. L., & Tonge, B. J. (1995). The developmental behavior checklist: The development and validation of an instrument for the assessment of behavioral and emotional disturbance in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 25*, 81–104.
- Einfeld, S. L., & Tonge, B. J. (2002). *Manual for the developmental behaviour checklist (Primary Carer Version)*. Melbourne, Australia: Monash University Centre for Developmental Psychiatry.
- Field, A. (2005). *Discovering statistics using SPSS*. Sage Publications Ltd.
- Folkman, S., Moskowitz, J. T., Ozer, E. M., & Park, C. L. (1997). Positive meaningful events and coping in the context of HIV/AIDS. In B. H. Gottlieb (Ed.), *Coping with Chronic Stress* (pp. 293–314). New York: Plenum.
- Fowler, F. (2009). *Survey research methods: Applied social research methods* (4th edition). Sage Publications.
- Gibaud-Wallson, J., & Wandersman, L.P. (1978). *Development and utility of the parenting sense of competence scale*. Paper presented at the meeting of the American Psychological Association, Toronto.
- Gray, D. E. (1994). Coping with autism: stresses and strategies. *Sociology of Health & Illness, 16*, 275-300.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research, 50*, 970-976.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18*, 83–93.

- Graves, K. N., & Shelton, T. L. (2007). Family empowerment as a mediator between family-centered systems of care and changes in child functioning: Identifying an important mechanism of change. *Journal of Child and Family Studies, 16*, 556-566.
- Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in parents of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 269-275.
- Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*, 1338-1349.
- Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities, 9*, 155-165.
- Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107*, 222-232.
- Hastings, R. P., Brown, T., Mount, R. H., & Cormack, K. F. M. (2001). Exploration of psychometric properties of the developmental behavior checklist. *Journal of Autism and Developmental Disorders, 31*, 423-431.
- 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.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Degli Espinosa, F., & Remington, B. (2005a). Coping strategies in mothers and fathers of pre-school and school age children with autism. *Autism, 9*, 377-391.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Degli Espinosa, F., Brown, T., & Remington, B. (2005b). 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. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.
- Heller, T. (1993). Self-efficacy coping, active involvement and caregiver well-being throughout the life course among families of persons with mental retardation. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J.

- Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 195–206). Baltimore: Brookes.
- Herrmann, C. (1997). International experiences with the hospital anxiety and depression scale – A review of validation data and clinical results. *Journal of Psychosomatic Research*, 42, 17–41.
- Hollingshead, A. B. (1975). *Four factor index of social status*. Author, New Haven, CT.
- Holroyd, J., Brown, N., Wikler, L., & Simmons, J. Q. (1975). Stress in families of institutionalized and noninstitutionalized autistic children. *Journal of Community Psychology*, 3, 26-31.
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down’s syndrome and childhood autism. *American Journal on Mental Deficiency*, 80, 431–436.
- Holmes, N., & Carr, J. (1991). The pattern of care in families of adults with a mental handicap: A comparison between families of autistic adults and Down syndrome adults. *Journal of Autism and Developmental Disorders*, 21(2), 159-175.
- Howlin, P. (1998). Practitioner review: Psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry*, 39, 307–22.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 parents. *Autism: The International Journal of Research and Practice*, 1, 135-162.
- Hudson, A. M., Matthews, J. M., Gavidia-Payne, S. T., Cameron, C. A., Mildon, R. L., Radler, G. A., & Nankervis, K. L. (2003). Evaluation of an intervention system for parents of children with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 47, 238-249.
- Hutchinson, P. S. & Bryson, S. E. (in preparation). *A critical review of coping in mothers of children with autism*. Dalhousie University, Halifax, Nova Scotia, Canada.
- Hutchinson, P. S., Bryson, S. E., Leblanc, D., McFadyen, S., MacRae, A., & Amit, H. (2010). *Creating respite solutions for families of children with chronically high needs in Nova Scotia*. Dalhousie University, Halifax, Nova Scotia, Canada. Prepared for the Minister of the Nova Scotia Department of Community Services.
- Jex, S. M., Bliese, P. D., Buzzell, S., & Primeau, J. (2001). The impact of self-efficacy on stressor-strain relations: Coping style as an explanatory mechanism. *Journal of Applied Psychology*, 86, 401-409.

- Kielinen, M., Rantala, H., Timonen, E., Linna, S., & Moilanen, I. (2004). Associated medical disorders and disabilities in children with autistic disorder: A population-based study. *Autism, 8*, 49–60.
- Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69*, 283-291.
- King, G. A., Zwaigenbaum, L., King, S., Baxter, P., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development, 32*, 353-369.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., & Plien, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 2*, 205-216.
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., Singh, G. K., Strickland, B. B., Trevathan, E., & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics* (doi:10.1542/peds.2009-1522)
- Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 30*, 459–70.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321.
- Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*, 329–339.
- Kuhn, J., & Carter, A. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*, 564-575.
- Landa, R., & Garrett-Mayer, E. (2006). Development in infants with autism spectrum disorders: A prospective study. *Journal of Child Psychology and Psychiatry, 47*, 629–638.
- Lavee, Y., McCubbin, H. I., & Patterson, J. M. (1985). The double ABCX model of family stress and adaptation: an empirical test by analysis of structural equations with latent variables. *Journal of Marriage and the Family, 47*, 811-825.

- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development, 29*, 357-366.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*, 172-183.
- Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: Cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research, 52*, 37-48.
- Lloyd, T., & Hastings, R. P. (2009). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual & Developmental Disability, 34*, 104-115.
- Loucas, T., Charman, T., Pickles, A., Simonoff, E., Chandler, S., Meldrum, D., & Baird, G. (2008). Autistic symptomatology and language ability in autism spectrum disorder and specific language impairment. *Journal of Child Psychology and Psychiatry, 49*, 1184-92.
- McConachie, H., & Waring, M. (1997). *Child psychology portfolio: Parental coping and support*. Windsor: NFER-Nelson.
- McCubbin, H. I., & Patterson, J. (1983). The family stress process: The double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman, & J. M. Patterson (Eds.), *Social stress and the family: Advances and developments in family's stress theory and research*. New York: Haworth Press.
- McKnight, P. E., McKnight, K. M., Sidani, S., & Figuredo, A. J. (2007). *Missing data: A gentle introduction*. New York: Guilford Press.
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism: The International Journal of Research & Practice, 3*, 273-286.
- Moes, D., Koegel, R. L., Schreibman, L., & Loos, L. M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71*, 1272-1274.
- Nachshen, J. S. (2005). Empowerment and families: Building bridges between parents and professionals, theory and research. *Journal of Developmental Disabilities, 11*, 67-75.

- Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*, 889-904.
- Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities, 17*, 30-43.
- Orr, R. R., Cameron, S. J., & Day, D. M. (1991). Coping with stress in families with children who have mental retardation: An evaluation of the double ABCX model. *American Journal of Mental Retardation, 95*, 444-50.
- Pakenham, K. I., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding. *Research in Developmental Disabilities, 25*, 245-264.
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism: The International Journal of Research & Practice, 9*, 191-211.
- Park, C. L., Cohen, L. H., & Murch, R. L. (1996). Assessment and prediction of stress-related growth. *Journal of Personality, 64*, 71-105.
- Pajares, F. (2002). "Overview of social cognitive theory and of self-efficacy", available at: www.emory.edu/EDUCATION/MFP/eff.html (accessed 24 July 2009).
- Perry, A. (2004). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on Developmental Disabilities, Special Issue: Families, 11*, 1-16.
- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, and Computers, 36*, 717-731.
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology, 1*, 57-90.
- Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371-379.
- Rubin, D. (1976). Inference and missing data. *Biometrika, 63*, 581 - 592.
- Rutter, M. (2005). Aetiology of autism: Findings and questions. *Journal of Intellectual Disability Research, 49*, 231-238.

- Saloviita, T., Itälina, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research, 47*, 300-312.
- Scheel, M. J., & Rieckmann, T. (1998). An empirically derived description of self-efficacy and empowerment for parents of children identified as psychologically disordered. *American Journal of Family Therapy, 26*, 15-28.
- Scorgie, K., & Sobsey, D. (2002). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*, 195-206.
- Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). Transformational outcomes and effective life management strategies in parents of children with Autism. *Exceptionality Education Canada, 1*, 43-61.
- Sharpley, C. E., 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 and Developmental Disability, 22*, 19-28.
- Snaith, R. P. (2003). The hospital anxiety and depression scale. *Health and Quality of Life Outcomes, 1*, 1-4.
- Tabachnick, B.G., & Fidell, L.S. (2007). *Using multivariate statistics*. (5th ed.) Boston: Pearson Education.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaption. *American Psychologist, 38*, 1161-1173.
- Taylor, S. E., & Brown, J. D. (1988). Illusion and well-being: A social psychological perspective on mental health. *Psychological Bulletin, 103*, 193-210.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (Eds.). (1998). *Posttraumatic growth: Positive change in the aftermath of crisis*. Mahwah, NJ: Erlbaum.
- Tennen, H., & Affleck, G. (1999). Finding benefits in adversity. C. R. Snyder (Eds.). *Coping: The psychology of what works*. New York: Oxford University Press.
- Tennen, H., & Affleck, G. (2002). Benefit-finding and benefit-reminding. In C. R. Snyder & S. J. Lopez (Eds), *Handbook of Positive Psychology*. London: Oxford University Press.
- Tonge, B. J., & Einfeld, S. L. (2003). Psychopathology and intellectual disability: The Australian child to adult longitudinal study. *International Review of Research in Mental Retardation, 26*, 61-91.

- Turnbull, A. P., & Turnbull, H. R., III (1978). *Parents speak out: Views from the other side of the two-way mirror*. Columbus, Ohio: Charles E. Merrill Publishing Company.
- Turnbull, A. P., & Turnbull, H. R., III (2006). *Families, professionals, and exceptionality: A special partnership*. Upper Saddle River, NJ. Pearson/Merrill-Prentice Hall.
- Walsh, F. (2003). Changing families in a changing world: Reconstructing family normality. In F. Walsh (Ed), *Normal family processes: Growing diversity and complexity*, 3rd ed., (pp. 3–26). Guilford, New York; London.
- Wilgosh, L., & Scorgie, K. (2000). Family life management when a child has severe developmental disabilities: A subgroup examination. *Developmental Disabilities Bulletin*, 28, 15-18.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361–70.

Appendix A. Recruitment Letter to Parents

Re: Creating Solutions for Families of Children and Youth with Autism Spectrum Disorder

Dear Parent/Caregiver:

My name is Paula Hutchinson and I am a PhD student at Dalhousie University working with Dr. Susan Bryson at the IWK Health Centre. As a parent of a child with autism and as a researcher, I have been working in partnership with other parents, community groups, and government agencies to look closely at the issue of support and respite for families of children and adults with Autism Spectrum Disorder. We would like to know more about children's needs, parents' coping strategies, and the kinds of supports that families use and need. We intend to use this research to provide information that is relevant for service providers and other decision-makers about these important issues.

I invite you and your partner to assist me by filling out the enclosed questionnaires. This will take about 35 minutes. Please know that you do not have to provide this information and that it is your personal choice to fill out the questionnaires. I would like to reassure you that your information will be kept confidential. The information will be stored using identification numbers on a secure computer at the IWK Health Centre. The results from this research will form the basis of my doctoral work and will be published in newsletters and journals, presented at conferences, and used for educational purposes. Neither you nor your child will be identified in any publication or presentation.

If you need assistance or have any questions, please contact Paula Hutchinson at 470-7275, paula.hutchinson@iwk.nshealth.ca. If you have any questions at any time during or after the study about research in general, you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday between 9 a.m. and 5 p.m.

On behalf of the Autism Research Centre, we would like to thank you for your time and participation.

Paula Hutchinson, MA, PhD Candidate
Autism Research Centre
IWK Health Centre/Dalhousie University

Dr. Susan Bryson
Autism Research Centre
IWK Health Centre/
Dalhousie University

Appendix B. Demographic Questionnaire

Child's Date of Birth: ____ / ____ / ____ Gender of Child: Male Female
 Day Month Year

Child's Diagnosis:

- Autism or Autistic Disorder (ASD)
- Asperger Syndrome
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Cerebral Palsy
- Developmental Delay
- Down Syndrome
- Fetal Alcohol Spectrum Disorder (FASD)
- Fragile X
- Muscular Dystrophy
- Neurodevelopmental Disorder/Syndrome
- Pervasive Developmental Disorder (PDD)
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
- Spina Bifida
- Other (Please Specify) _____

What is **your** relationship to this child?

- Biological Mother
- Adoptive Mother
- Step Mother
- Foster Mother
- Other (please specify): _____

What is **your current spouse or partner's** relationship to your child?

- I am a single parent (No spouse or partner)
- Biological Father
- Adoptive Father
- Step Father
- Foster Father
- Other (please specify): _____

What is **your** age? _____

What is **your spouse or partner's** age? _____

Which Statistics Canada category best describes your ethnic or cultural heritage?

- White/Caucasian
- Chinese
- South Asian (e.g., East Indian, Pakistani, Punjabi, Sri Lankan)
- Black (e.g., African, Haitian, Jamaican, Somali)
- Native/Aboriginal People (North American Indian, Metis or Inuit/Eskimo)
- Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
- Filipino
- South East Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese)
- Latin-American
- Japanese
- Korean
- Other (Please Specify) _____

What is **your** level of education? Check all that apply.

- Less than High School (Highest grade completed: _____)
- High School Diploma
- Some Community College
- Community College Diploma
- Some University
- University Degree

What is **your spouse or partner's** level of education? Not applicable

- Less than High School
- High School Diploma
- Some Community College
- Community College Diploma
- Some University
- University Degree

What is **your** occupation? Check all that apply.

- I work outside the home: Part-time Full-time
- Stay at home parent
- Student
- Not Employed outside the Home

What is **your spouse or partner's** occupation? Check all that apply. Not applicable

- He/she works outside the home: Part-time Full-time
- Stay at home parent
- Student
- Not Employed outside the Home

What is **your family's** approximate total annual income (before taxes). *Please check only one box.*

- up to \$20,000
- \$20,001 to \$30,000
- \$30,001 to \$40,000
- \$40,001 to \$50,000
- \$50,001 to \$60,000
- \$60,001 to \$70,000
- more than \$70,000

Please describe the children currently living in your home. What are their ages and do they have any difficulties?

Sex	Date of Birth	Diagnosis	Learning Problem?	Behaviour Problem?	Speech Problem?	Medical Problem?
	/ /					
	/ /					
	/ /					
	/ /					
	/ /					

12. If you would like to have a copy of the collective results from this research, please provide your address below so that we can mail the results to you.

Thank you very much for your time!

Appendix C. Family Support Scale

Listed below are people and groups that often times are helpful to families raising a child with special needs. This questionnaire asks you to indicate how helpful each source is to your family. Please circle the response that best describes how helpful the sources have been to your family during the **past 3 to 6 months**. If a source of help has not been available to your family during this period of time, circle the NA response (Not Available).

How helpful each of the following has been to you in the past 6 months ?	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. Our Parents	NA	1	2	3	4	5
2. Our Relatives	NA	1	2	3	4	5
3. Partner/Spouse	NA	1	2	3	4	5
4. Our other children	NA	1	2	3	4	5
5. Friends	NA	1	2	3	4	5
6. Neighbours	NA	1	2	3	4	5
7. Other parents	NA	1	2	3	4	5
8. Co-workers	NA	1	2	3	4	5
9. Parent Groups	NA	1	2	3	4	5
10. Social Groups	NA	1	2	3	4	5
11. Faith Based Organization	NA	1	2	3	4	5
12. Early Intervention	NA	1	2	3	4	5
13. School/day program	NA	1	2	3	4	5
14. After-school program	NA	1	2	3	4	5
15. Respite workers	NA	1	2	3	4	5
16. Physician	NA	1	2	3	4	5
17. Psychologist	NA	1	2	3	4	5
18. Speech Language Pathologist	NA	1	2	3	4	5
19. Social Workers	NA	1	2	3	4	5
20. Occupational therapist	NA	1	2	3	4	5

Adapted From: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA Brookline Books.

Appendix E. Family Empowerment Scale (Koren, DeChillo, & Friesen, 1993)

These questions ask about several areas of your life: your family, your child’s services, and your community. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer “Never”. Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking of your own situation. Feel free to write any additional comments at the end.

<i>ABOUT YOUR FAMILY</i>	Never	Seldom	Some- times	Often	Very Often
1. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. I believe I can solve problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child’s disorder.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5

© 1993 Family Empowerment Scale, Koren, DeChillo, & Friesen, Regional Research Institute, Portland State University, P.O. Box 751, Portland, OR 97207-0751 (I:\Staff\GSSW\RRIR&T\Dissemination\FES Empowerment\Current FES Documents\A COMPLETE VERSION -df.doc)

<i>ABOUT YOUR CHILD'S SERVICES</i>	Never	Seldom	Some- times	Often	Very Often
13. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
14. I know the steps to take when I am concerned by child is receiving poor services.	1	2	3	4	5
15. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
16. I am able to make good decisions about what services my child needs.	1	2	3	4	5
17. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
18. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
19. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
20. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
21. I know what services my child needs.	1	2	3	4	5
22. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
23. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
24. Professionals should ask me what services I want for my child.	1	2	3	4	5

© 1993 Family Empowerment Scale, Koren, DeChillo, & Friesen, Regional Research Institute, Portland State University, P.O. Box 751, Portland, OR 97207-0751 (I:\Staff\GSSW\RRIR&T\Dissemination\FES Empowerment\Current FES Documents\A COMPLETE VERSION -df.doc)

Appendix F. Kansas Inventory of Parental Perceptions

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

Directions: There are four sections: A, B, C, and D. Each section begins with a sentence. The sentence at the top of **Part A** is: **MY CHILD _____ IS:** All the statements in Part A complete this sentence. The blank space after the word “child” is there to remind you to think only of your child with special needs when you answer each statement. **Read each statement carefully and circle the one response** that best describes how much you agree or disagree with each statement.

Part A. Circle only one response for each statement.				
MY CHILD _____ IS:	Strongly Disagree	Disagree	Agree	Strongly Agree
1. the reason I attend religious services more frequently.	SD	D	A	SA
2. why I met some of my best friends.	SD	D	A	SA
3. the reason my life has better structure.	SD	D	A	SA
4. why I am a more responsible person.	SD	D	A	SA
5. the reason I've learned to control my temper.	SD	D	A	SA
6. responsible for my learning patience.	SD	D	A	SA
7. responsible for my increased awareness of people with special needs.	SD	D	A	SA
8. fun to be around.	SD	D	A	SA
9. the reason I am more realistic about my job.	SD	D	A	SA
10. responsible for my being more aware and concerned for the future of mankind.	SD	D	A	SA
11. kind and loving.	SD	D	A	SA
12. helpful to other family members, which saves time and energy for me.	SD	D	A	SA
13. a source of pride because of his/her artistic accomplishments.	SD	D	A	SA
Part B. Circle only one response for each statement.				
I CONSIDER MY CHILD _____ TO BE:	Strongly Disagree	Disagree	Agree	Strongly Agree
14. what gives me common ground with other parents.	SD	D	A	SA
15. helpful without having to be asked.	SD	D	A	SA
16. responsible for my increased sensitivity to people.	SD	D	A	SA
17. what gives our family a sense of continuity - a sense of history	SD	D	A	SA
18. the reason I am more productive.	SD	D	A	SA
19. an advantage to my career.	SD	D	A	SA
20. the reason I budget my time better.	SD	D	A	SA
21. the reason I am able to cope better with stress and problems.	SD	D	A	SA
22. very affectionate.	SD	D	A	SA
23. what makes me realize the importance of planning for my family's future.	SD	D	A	SA
24. able to use good judgment.	SD	D	A	SA
25. a great help around the house.	SD	D	A	SA

Part C. Circle only one response for each statement.

THE PRESENCE OF MY CHILD _____ :

	Strongly Disagree	Disagree	Agree	Strongly Agree
26. is an inspiration to improve my job skills.	SD	D	A	SA
27. helps me understand people who are different.	SD	D	A	SA
28. is a source of pride because of his/her achievements.	SD	D	A	SA
29. cheers me up.	SD	D	A	SA
30. confirms my faith in God.	SD	D	A	SA
31. gives a new perspective to my job.	SD	D	A	SA
32. renews my interest in participating in different activities.	SD	D	A	SA
33. is very uplifting.	SD	D	A	SA
34. is a reminder that all children, including those with special needs, need to be loved.	SD	D	A	SA
35. is a reminder that everyone has a purpose in life.	SD	D	A	SA
36. makes us more in charge of ourselves as a family.	SD	D	A	SA
37. helps me take things as they come.	SD	D	A	SA

Part D. Circle only one response for each statement.

BECAUSE OF MY CHILD _____ :

	Strongly Disagree	Disagree	Agree	Strongly Agree
38. my circle of friends has grown larger.	SD	D	A	SA
39. I have someone who shares responsibility for doing several tasks around the house.	SD	D	A	SA
40. my social life has expanded by bringing me into contact with other parents.	SD	D	A	SA
41. I am more compassionate.	SD	D	A	SA
42. I learned about mental retardation.	SD	D	A	SA
43. my family is more understanding about special problems.	SD	D	A	SA
44. I am grateful for each day.	SD	D	A	SA
45. our family has become closer.	SD	D	A	SA
46. I am more sensitive to family issues.	SD	D	A	SA
47. I have learned to adjust to things I cannot change.	SD	D	A	SA
48. my other children have learned to be aware of people's needs and their feelings.	SD	D	A	SA
49. I have many unexpected pleasures.	SD	D	A	SA
50. I am more accepting of things.	SD	D	A	SA