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Psychological Well-Being in Parents of Children with Autism and Down Syndrome

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December 2009

A thesis submitted to McGill University in partial fulfilment of the requirements of the

degree of Doctor of Philosophy in Educational Psychology, Human Development

Acknowledgements

This dissertation is the culmination of a long and meaningful journey that could not have been achieved alone. To begin, I extend my sincere gratitude to my supervisor, Dr. Ingrid Sladeczek, for her constant support, encouragement, and guidance, and for fostering such a positive experience throughout my entire studies. It has truly been a pleasure working with you. Also, thank you to Daniel Amar, the Max Bell team, and the volunteers who made the EI project a success. I am also indebted to Drs. Jake Burack and Lucy Lach, Dr. Bob Hodapp and Dr. Shelley Watson, Jessica Toste and Kerri Staples for their thoughtful and timely feedback on the manuscript. This research would have never been possible without the families, children, and countless school personnel. Crossing paths with them has been enlightening and inspiring. On a more personal note, I have been truly blessed with the greatest friends and family a girl could ever ask for! To friends, old and new. You have been my 'rocks' in so many special ways. Thank you for your unfailing sisterhood – it has meant the world to me. Next, this work and in fact, my *entire* educational pursuit is dedicated to my wonderful parents Dragica and Milan (a.k.a. faza) Miodrag for believing in me and loving me unconditionally. A very special shout-out goes to Majka and Baba Gina, and of course Nemanja, whose sweet face motivated me to persevere when it felt never-ending. To the Bozic, Filipovic, Korovesi, Miodrag-Matovic, and Francis families–your cheers from the sidelines kept me going! I love you all. Finally, this journey would not be nearly as sweet or triumphant without the unwavering love and support of my bff and partner in life, Dean. I would not have succeeded without your understanding, laughter, and above all, patience. Thanks babe, for taking this adventure with me and making it worthwhile. We did it! *Thank you to the FQRSC granting agency and McGill for their financial support for this research.*

Contributions of Authors

The three manuscripts presented in this dissertation were conceptualized, researched, written, and edited by me. All drafts of the manuscripts were also edited by my doctoral supervisor and co-author, Dr. Ingrid E. Sladeczek, who provided editorial advice and suggested feedback through revisions and in formulating ideas. Dr. Sladeczek also served in an advisory capacity during the conceptualization phase of this dissertation. The data drawn from the National Early Intervention Research Initiative (NEIRI) that are reported in this dissertation were collected collaboratively, which included myself, research assistants and associates from the Max Bell team, volunteers from Dr. Sladeczek's Early Intervention Research laboratory at McGill University, and educators from the Donald Berman Yaldei Developmental Center in Montréal. The second round of data collection described in this dissertation was conducted solely by me.

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Abstract

This dissertation examined how various child and parent factors relate to psychological well-being in parents of children with autism and Down syndrome. In Article 1, parent-related stressors, social support, negative appraisals, diagnosis, and behaviours of health professionals predicted 40 to 41% of the variance of maternal depressive symptoms. As well, 60% of mothers met the clinical threshold for depressive symptoms. Mothers with fewer depressive symptoms had better overall coping and informal social support than mothers with greater depressive symptoms. The groups did not differ on positive appraisals, behaviours of health professionals and children's distractibility/hyperactivity, adaptability, and demanding behaviour. In Article 2, the effect of child diagnosis on maternal and paternal stress was examined. Clinically significant child-related stress was reported by 67% of mothers and 60% of fathers and clinically significant parent-related stress was reported by 49% of mothers and 28% of fathers. Mothers felt more depressed, restricted in the parenting role, and unsupported by spouses than fathers. When maternal and paternal stress was differentiated by autism and Down syndrome, significant differences emerged for parent depression and role restriction and children's demanding behaviour, positive reinforcement to parent, and mood. Mothers of children with autism fared the worst in all domains of stress. In Article 3, children's social competence and parent stress were explored. Children with Down syndrome had better emotional regulation, social participation, and peer initiations than children with autism. Greater maternal stress related to parenting competence, depression, and isolation was linked to poorer pretend play, peer initiations, play and leisure time, and coping in children with autism. For mothers of children with Down syndrome, greater stress associated with parenting competence and role restriction was linked to children's poorer emotional

regulation. Likewise, stress associated with parenting competence, isolation, physical health, role restriction, and lack of spousal support were implicated in children's poorer coping. Finally, restriction in the parenting role and lack of spousal support were related to poorer interpersonal relations and play and leisure skills. The collective findings and their implications for professionals and families of children with autism and Down syndrome are discussed.

Résumé

Cette thèse explique comment divers facteurs de la relation parents-enfants influencent le bien-être psychologique de parents d'enfants atteints d'autisme ou du syndrome de Down. À l'article 1, les facteurs relatifs au stress parental, c'est-à-dire, le soutien social, les évaluations négatives, le diagnostic et les comportements des professionnels de la santé prévoient une variation de 40 à 41 pour cent de mères atteintes de troubles dépressifs. Soixante pour cent de ces mères atteignent le seuil clinique. Les mères aux symptômes dépressifs plus légers s'adaptent avec plus de facilité à la situation et s'appuient davantage sur un réseau de soutien informel que celles ayant des symptômes dépressifs plus profonds. Aucune différence n'apparaît entre les groupes quant aux évaluations positives, aux comportements des professionnels de la santé et à ceux des enfants liés à l'inattention, à l'hyperactivité, à l'adaptabilité et à leurs exigences comportementales. L'article 2 examine les conséquences de ce diagnostic chez les enfants sur le stress éprouvé par les mères et les pères. Le stress éprouvé par les enfants est cliniquement significatif puisqu'il a été signalé par soixante-sept pour cent des mères et 60 pour cent des pères, ainsi quarante-neuf pour cent des mères et 28 pour cent des pères rapportent éprouver eux-mêmes ce stress. À l'instar des pères, les mères se sentent davantage dépressives, restreintes dans leurs responsabilités parentales et non soutenues par leurs conjoints. Entre le stress maternel et le stress paternel de parents d'enfants atteints d'autisme ou du syndrome de Down, des différences majeures apparaissent entre leurs états dépressifs, la restriction des rôles, les comportements liés aux exigences des enfants, le renforcement positif offert aux parents et leurs humeurs. Les mères d'enfants atteints d'autisme présentent les plus grands dommages face à l'ensemble des domaines liés au stress. L'article 3 examine les aptitudes sociales des enfants et le stress des parents.

Les enfants atteints du syndrome de Down présentent un meilleur équilibre affectif, une activité sociale supérieure et participent plus facilement aux activités d'apprentissage entre pairs, que les enfants atteints d'autisme. Les habiletés parentales, la dépression et l'isolement sont une source de stress accru pour les mères, sont liés aux jeux consistant à faire semblant, aux activités d'apprentissage entre pairs, aux périodes de jeux et de loisirs, et aux mécanismes de débrouillardise des enfants atteints d'autisme. Pour les mères d'enfants atteints du syndrome de Down, les habiletés parentales et la restriction des rôles sont une source de stress accru en rapport au déséquilibre affectif de ces enfants. En outre, le stress lié aux habiletés parentales, l'isolement, la santé physique, la restriction des rôles et le manque de soutien aux conjoints sont associés au faible degré de débrouillardise chez ces enfants. Enfin, les restrictions relatives au rôle parental et le manque de soutien aux conjoints sont associés à la mauvaise qualité des relations interpersonnelles et des habiletés d'apprentissage par le jeu et les loisirs. Prises dans leur ensemble, les conclusions et leurs conséquences, pour les professionnels, les familles d'enfants atteints d'autisme et du syndrome de Down, sont analysées.

Introduction

Psychological stress and depression are real and persistent aspects of life for parents of children with developmental disabilities (DD) affecting both mental and physical health (Bourke et al., 2008) and making this a major public health concern (Perry, 2004). Understanding what factors influence psychological well-being is a multifaceted phenomenon on account of copious child and parent factors. Parents of children with autism and Down syndrome in particular, exhibit a range of psychological reactions given their unique strengths, vulnerabilities, and experiences (Hutton & Caron, 2005) and are thus, the focus of this research.

One framework that helps facilitate our understanding of the psychological well-being of families of children with autism and Down syndrome is the double ABCX model of adjustment and adaptation (McCubbin & Patterson, 1983). The double ABCX model is a multivariate model that identifies stressors and strains (*A*), coping resources (*B*), and the meaning that parents give to their life situation (*C*) to understand a family crisis or outcome (*X*; McCubbin & Patterson, 1983). In this research program, I use McCubbin and Patterson's double ABCX model as a guide to elucidate how particular child and parent factors can affect psychological well-being in families of children with autism and Down syndrome. Knowing what variables, play what role, in what context, and for what families can benefit health care professionals who are there to ensure the provision of family-centered services and in turn, family well-being.

This dissertation is written in accordance with the guidelines established by the Faculty of Graduate Studies and Research at McGill University. In chapter 1, I present a comprehensive literature review delineating factors that aid in understanding psychological well-being in parents of children with autism and Down syndrome. In chapters 2, 3, and 4, I present three inter-related

manuscripts using the same sample of parents and their children with autism and Down syndrome.

In Article 1, entitled *Depressive Symptoms in Mothers of Children with Autism and Down Syndrome*, I use a multidimensional approach to examine how a set of child and parent predictors account for the variance of maternal depressive symptoms and identify to what degree the variables are related to maternal depression. A multivariate inquiry is essential because depression does not manifest in isolation, but instead is the corollary of child, parent, and contextual factors that are mutually influential. In fact, single-factor changes are uncommon in the real world (Raina et al., 2005).

In Article 2, entitled *Psychological Stress in Parents of Children with Developmental Disabilities: Do Parent Gender and Child Diagnosis Matter?* I examine whether there are child- and parent-related stress differences across mothers and fathers and autism and Down syndrome. Such comparisons are central to understanding why fathers feel the stress they do and in part, because researchers have largely focused on maternal well-being, despite emerging reports that fathers also experience significant strain (e.g., McNeill, 2004).

As well, rooted in the research on behavioural phenotypes in intellectual disabilities (Hodapp & Burack, 2006), behaviours inherent within a specific disability can spawn diverse psychological reactions by parents (e.g., Abbeduto et al., 2004). For example, some parents of children with Down syndrome show a Down syndrome advantage and experience less stress and better well-being because of their children's relative easy and positive personalities (Hodapp, Ly, Fidler, & Ricci, 2001). Conversely, for mothers of children with autism, symptoms of anxiety have been associated with child behaviour problems (e.g., Hastings, 2003) and psychological stress has been linked to specific externalizing behaviours (Lecavalier, Leone, & Wiltz, 2006).

Children with autism and Down syndrome have other distinct behavioural, social, and communicative traits (e.g., Dykens, Hodapp, & Finucane, 2000) that can influence parent well-being, and understanding the role of disability-specific traits to parent well-being can lead to suitable provision of family services.

In the third and final Article entitled *Peer-Related Social Competence in Children with Autism and Down Syndrome: Relations to Maternal Stress*, I explore the agreement between children's peer-related social competence and maternal stress. Children's peer-related social competence is a fundamental life skill required to navigate oneself in a social world (Guralnick, 2003). Demonstrating social competence is a significant challenge for children with autism and Down syndrome. Identifying whether, and to what extent there is a connection between social competence and maternal stress is vital to the ongoing parent-child relationship in early life (Iarocci, Yager, Rombough, & McLaughlin, 2008), and to interventions where social competence and parent stress are often amenable to change.

While the three manuscripts are independent papers, each with a focused literature and independent inquiries, they do not stand alone for the purposes of the dissertation, but rather are integrated and show progression from one paper to the next. Readers will encounter slight overlap and repetition in the methodologies because the same procedure was used for each study. Likewise, there is some repetition in the literature reviews because articles that were deemed seminal to the field were cited. Readers will also notice slight variation in the number of participants reported in each study due to partial missing parent and/or child data. In conclusion, chapter 5 highlights the original contributions to knowledge, practical implications, and future research directions of this collection of work.

CHAPTER 1

Overall Review of Literature

The family is with unprecedented certainty, the cornerstone in the lives of children with developmental disabilities (DD; Fidler, Hodapp, & Dykens, 2000; Shonkoff & Phillips, 2000). Thus, when there are disruptions to a parent's psychological well-being, the entire family can be affected (Glidden & Schoolcraft, 2003; Perry, 2004). Psychological stress and deleterious mental health issues can considerably jeopardize one's social, professional, and physical health (Singer, 2006), compromise the parent-child relationship (Abidin, 1995; Magill-Evans & Harrison, 2001), and impact the child's functioning (Crnic, Gaze, & Hoffman, 2005).

There is much variability in the psychological well-being of parents raising children with DD, showing greater levels of stress for some (e.g., Olsson & Hwang, 2001), yet little to no stress for others (e.g., Montes & Halterman, 2007). Such variability can be accounted for by various child and parent factors that when identified, are revealing for research and practice. In this review, key child and parent factors are described to elucidate their role to psychological well-being experienced by parents of children with autism and Down syndrome.

To begin, I introduce McCubbin and Patterson's (1983) double ABCX model of adjustment and adaptation because it is a multivariate approach to understanding family adaptation and can be applied to parents of children with DD. The double ABCX model is in line with the seminal stress and coping model (e.g., Lazarus, 1999; Lazarus & Folkman, 1984) and as such, deserves brief attention as well in this review. The components within McCubbin and Patterson's model are applied to this program of research to investigate the psychological well-being of parents of children with autism and Down syndrome.

Theoretical Guide: Double ABCX Model

The double ABCX model theorized by McCubbin and Patterson (1983) was originally

modeled after Hill's ABCX family crisis model (Hill, 1949, 1958), but expanded to apply to

families of children with DD, and has been used widely in familial research (Blacher & Hatton,

2007). The model moves beyond the notion that the situation itself of having a child with DD,

determines outcome. Instead, multiple components jointly determine how a family reacts, which

can be adaptive or maladaptive. According to McCubbin and Patterson (1983), the family

outcome (*X*) is affected by the pile-up of stressors and strains such as the child's personal

characteristics including their diagnosis and other qualities (*A*), the internal and external

resources used by the family such as coping strategies (*B*), and the meaning parents give to the

situation (*C*). The 'double' highlights that the child characteristics, parent resources, and family

perceptions of the stress event will all change across time (Blacher & Hatton, 2007; McCubbin &

Patterson, 1983).

McCubbin and Patterson's (1983) model is in line with other models where stress, coping,

and cognitive appraisals are intricately connected such that, experiencing psychological

difficulties while facing adversity can be mediated by one's appraisal of the situation and

evaluation of coping resources (Lazarus & Folkman, 1984). When a person views a situation as

threatening or challenging, and when there are no adequate coping strategies intact, stressful

emotions can emerge. Stress then, can be viewed as a particular relationship between the person

and the environment that is perceived as taxing to one's well-being (Lazarus & Folkman, 1984).

Lazarus and Folkman describe two types of appraisals. A primary appraisal is an evaluation of

whether a situation is stressful because it harms, threatens, or challenges the individual. A

secondary appraisal is the individual's evaluation of what can be done to cope, specifically, of

available coping resources (Lazarus, 1999; Lazarus & Folkman, 1984). Hodapp et al. (2001)

contend that stress in families of children with DD is "felt or experienced tension that disrupts

family routines and norms" (p. 321), and is a reality for many families at one time or another.

The double ABCX model helps guide the current research program by examining the

following child and parent variables that can aid in understanding psychological well-being (e.g.,

depression; *X*) in parents of children with autism and Down syndrome: child- and parent-related

stressors, child diagnosis, child behaviour problems, peer-related social competence (*A*); family

coping, acquiring informal social support, and behaviours of health care professionals (*B*); and

negative and positive appraisals of the childhood disability and its impact on the family (*C*).

Maternal and Paternal Stress

Mothers have garnered the greatest interest concerning psychological well-being in parenting

children with DD given the longstanding role of 'mother as primary caregiver' (e.g., Abbeduto et

al., 2004; Glidden & Schoolcraft, 2003; Hassall, Rose, & McDonald, 2005). The interest also

stems from mothers' reports of psychiatric difficulties such as depression (Bailey, Golden,

Roberts, & Ford, 2007; Feldman et al., 2007). These difficulties are detrimental, compromising

not only their own life (Singer, 2006), but that of their child (Crnic et al., 2005). The restricted

attention on maternal well-being however, is a considerable limitation because fathers also

contribute greatly to their parenting role. To examine their well-being speaks volumes about the

importance of their role as fathers (Ricci & Hodapp, 2003) and the value of their opinions.

There is some evidence to suggest that mothers and father respond to stress differently. Gray

(2003) argues that fathers generally take on a more traditional parenting role and thereby

experience less stress and need for different coping mechanisms. In contrast, mothers bare most

of the responsibility in dealing with ongoing medical, educational, and behavioural challenges

associated with their child (Hastings et al., 2005). These caretaking tasks can become burdensome and demanding and take a toll on one's psychological well-being (Saloviita, Itälinna, & Leinonen, 2003). Despite using diverse coping strategies such as religion, informal social support, and expressing their feelings to others, mothers continue to report higher levels of emotional distress compared to fathers (Gray, 2003).

Fathers' needs are reportedly different from mothers' (Hodapp & Ly, 2005), particularly in their adjustment to stress and coping. Fathers tend to be concerned with the financial costs of rearing a child with special needs whereas mothers' tend to be concerned about childcare, receiving proper resources, and having a support network (Bailey, Blasco, & Simeonsson, 1992). Hodapp and Ly (2005) also found gender differences on two dimensions of coping as mothers used active avoidance coping more frequently than fathers. Active avoidance coping strategies are maladaptive in nature and can set in motion stress and other psychological problems.

Mothers' and fathers' stress reactions may vary as a function of various factors (Baker, Blacher, & Olsson, 2005). Hastings et al. (2005) found that mothers and fathers experience stress equally, but predicted by different factors. Specifically, maternal stress was positively predicted by their child's behaviour problems and their partner's depression whereas paternal stress was positively predicted only by their partner's depression, which might have been explained by the diverse coping strategies used by each gender. Davis and Carter (2008) found that mothers and fathers were equally affected by the child's behaviour problems, but by different aspects of it. Specifically, mothers were stressed by their child's regulatory problems such as feeding and sleeping, whereas fathers were stressed by their child's externalizing behaviours such as aggression.

Conversely, Dyson (1997) found no significant differences when stress levels, family functioning, and social support was compared in mothers and fathers of children with DD, despite higher levels of stress in families of children with DD compared to families of children without DD. Further research examining maternal and paternal differences must continue to thrive, so that fathers, like mothers can be recognized as critical members of the family unit (Blacher & Hatton, 2007), who may also experience stress that can significantly compromise their well-being.

Child Diagnosis, Behaviour Problems, Peer-Related Social Competence

An etiological approach to behavioural research in DD (e.g., Burack, 1990; Hodapp, 2002) considers that individuals with different genetic etiologies, syndromes, and disorders display characteristics or 'behavioural phenotypes' that are specific to their own disability (Hodapp, 2002; Hodapp & Ly, 2005). In turn, syndrome-specific characteristics can indirectly affect other family members. Sometimes these indirect effects are of benefit to parents. For example, parents of children with Down syndrome show a Down syndrome advantage (Hodapp et al., 2001), wherein they report less stress and better coping in comparison to parents of children with other DD. The advantage exists because children are more positive, sociable, and easy-going and have fewer maladaptive behaviours and less psychopathology proportionate to children with other intellectual disabilities (Dykens & Hodapp, 2001; Dykens & Kasari, 1997; Hodapp, Ricci, Ly, & Fidler, 2003; Ricci & Hodapp, 2003).

In addition, Down syndrome is a widely studied genetic disorder (Ricci & Hodapp, 2003) where parents receive a clear diagnosis at birth and have certainty surrounding its cause, genetic origin, and outcome (Abbeduto et al., 2004; Lovering & Percy, 2007). Moreover, there are established support groups and organizations that parents can access. Collectively, the

behaviours, attitudes, and supports surrounding the disorder appear to contribute to parenting that is less stressful than parenting children with nonspecific or other DD (e.g., Hodapp et al., 2001).

The Down syndrome advantage however, seems to be particularly apparent during the first year of life, but may not be sustained as children get older. Most, Fidler, Booth-Laforce, and Kelly (2006) investigated the early development and trajectories of stress over time for mothers of children with Down syndrome. They examined if the patterns of change in maternal stress were associated with characteristics of the child (e.g., IQ, behaviour problems, language), and the family (e.g., income, maternal age and education) across three times when children were 12 to 15, 30, and 45 months old. Compared to children with various DD, mothers of children with Down syndrome showed a distinct trajectory of stress during the early years reporting lower stress when children were 12 to 15 months old. However, their stress levels were similar to mothers of children with DD when children were 45 months old. Delays related to cognition and language as well as problem behaviours become more obvious in children with Down syndrome as they develop, which can negatively impact maternal stress. Poehlmann, Clements, Abbeduto, and Farsad (2005) found that a third of mothers reported their child's stubbornness, impulsivity, aggression, moodiness, and anxiety to be a source of family stress.

Characteristics of the child can also indirectly affect family members in a negative way. For example, children with autism exhibit marked behaviours as a function of their diagnosis. Autism is a severe pervasive developmental disorder characterized by distinct and qualitative impairments in social interactions, communication, and restricted or repetitive interests and behaviours (American Psychiatric Association, 2000). Often there are demonstrable behaviour problems and many parents feel especially burdened by them (Bromley, Hare, & Emerson, 2004). Bromley et al. found that 59% of mothers of children with autism experienced high levels

of distress that were directly associated with the child's aberrant behaviours. Lecavalier et al.

(2006) examined behaviour problems in children and adolescents with autism spectrum disorders

and found that externalizing behaviours specific to conduct problems as well as poor prosocial

behaviours were strong correlates of caregiver stress. Severe behaviour disturbances, challenging

temperament styles, and increased severity of symptoms have also been associated with

symptoms of depression in mothers of children with autism (Olsson & Hwang, 2001). An autism

diagnosis is made years after birth through an observation and parent interview, which can

contribute to more uncertainty about the diagnosis and future expectations (Lord & Rissi, 2002),

unlike a Down syndrome diagnosis, which is given at birth or shortly thereafter.

Other aspects of children's behaviours such as their relationship with peers may also help in

understanding how parents react psychologically. Early development of social competence has

clear and substantial implications in children's social (play), emotional, linguistic, adaptive,

motoric/physical, and cognitive functioning (Guralnick, 1990, 2005) and is fundamental for

interacting with others, social reciprocity, resolving conflicts, and having friends (Odom,

McConnell, & Evoy, 1992; Shonkoff & Phillips, 2000).

However, the skills that one must coordinate to execute successful social interactions are

countless and complex. Many children with DD have significant deficits in social functioning.

For example, children with autism make less eye contact and exhibit less turn taking, have

poorer face and emotion regulation (Sigman, Spence, & Wang, 2006), and show limited sharing

of affect and enjoyment with others (Volkmar & Wiesner, 2009). Despite their characterized

sociable, positive moods, and few maladaptive behaviours (Hodapp, 2002), children with Down

syndrome also have difficulties that may substantially impede their social interactions and

motivation to succeed with peers. In particular, they have expressive language difficulties,

trouble processing emotions (Wishart & Pitcairn, 2000), and fail to persist on tasks when tasks are arduous (Dykens et al., 2000). Some children show comorbid aggression, attention-deficit/hyperactivity, oppositional defiant disorder, or conduct disorder. Freeman and Kasari (2002) found that a third of children with Down syndrome failed to meet the threshold for having a true friend (i.e., reciprocity and stability). All of these behaviours are likely to have indirect effects on parents.

Informal and Formal Social Support

Coping includes resources that individuals use to deal with psychological stress (Lazarus, 1999; Lazarus & Folkman, 1984). According to Hastings and Johnson (2001), social support is a type of coping that can predict how parents adjust. Social support can be either informal or formal. Informal social support is typically provided by family, friends, and neighbours and can facilitate personal well-being, more positive perceptions of the child's behaviour, increased family functioning, and better parenting actions (Dunst, Trivette, & Jodry, 1997). Being able to depend on others when it is needed most has been documented to have great utility in helping alleviate stress and adapt to psychological stress (Duvdevany & Abboud, 2003). Formal social support is often first delivered through integrated early intervention (EI) services and for many parents, a vital resource during the child's formative years (Guralnick, 2005). Parents who utilize available physical, psychological, and social resources are able to short-circuit the stress response (Trute & Hiebert-Murphy, 2002). Without the requisite resources, families find themselves coping poorly with their stressors.

Both types of support can be favourable to families however informal support appears to temper the effects of psychological difficulties more effectively than formal social support (Duvdevany & Abboud, 2003). Boyd (2002) reported that informal social support from extended

family members was more useful in lessening psychological problems in parents than formal

social support. Luther, Canham, and Young-Cureton (2005), found that 83% of families agreed

or strongly agreed that close friends were an important source of support whereas only 50% felt

they could rely on their community in times of need. Similarly, Hastings and Johnson (2001)

found that mothers with greater social support from extended family members, neighbours, and

friends reported lower levels of stress, higher levels of well-being, and better coping. Formal

social supports however, did not decrease maternal stress.

To understand how formal social support relates to families, researchers have begun to ask

how caregivers feel about their formal care. Typically, families have ongoing relations with the

health care system because of their children's health needs (King, Teplicky, King, &

Rosenbaum, 2004). Thus, the perception of the extent to which the behaviours of health care

professionals are family-centered, is informative and can help or hinder well-being (King et al.,

2004). Researchers have found that perceiving services as family-centered leads to better

psychological outcomes in parents of children with chronic health conditions (Dunst, Boyd,

Trivette, & Hamby, 2002; King, King, Rosenbaum, & Goffin, 1999). King et al. (1999)

examined family-centered caregiving and its association to parent well-being in 164 families of

children with nonprogressive neurodevelopmental disorders including cerebral palsy, spina

bifida, and hydrocephalus. They found significant pathways between family-centeredness and

more satisfaction with services, less stress, and better emotional health. On a smaller scale, there

was an inverse relationship between poorer family-centeredness and greater distress/depression.

Dealing with the service sector can intensify feelings of psychological stress, especially when

services are lacking or disjointed (Baron, Groden, Groden, & Lipsitt, 2006). Due to the

increasing prevalence rate of autism (Fombonne, 2005) and the direct health care these children

often require (Volkmar & Wiesner, 2009), the ongoing medical needs of children with Down syndrome (Boulet, Molinari, Grosse, Honein, & Correa-Villaseno, 2008), and the stressors that families experience, evaluating the degree to which services are family-centered needs to be underscored. Family-centered practice also ensures that families are respected, informed, and part of a partnership that leads to optimal outcomes (Bailey & Powell, 2005).

Cognitive Appraisals of Childhood Disability

Simply put, "…the ways in which individuals think about the situation and themselves will influence their responses and subjective experiences" (Thompson & Gustafson, 1996, p. 199). Much of the variation in psychological well-being is in part, explained by how parents judge the situation and the control they have with coping resources (Lazarus, 1999; Lazarus & Folkman, 1984; Thompson & Gustafson, 1996). Often parent experience increased caregiving demands such as attending numerous medical appointments and ongoing treatment sessions (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006), which can impact their beliefs about their life situation of parenting a child with DD. Mothers especially, report feeling restricted in their social life and time (Olsson & Hwang, 2003). Parents may also experience stress because of the uncertainties surrounding the diagnosis (Spiker, Hebbeler, & Mallik, 2005). When a parent perceives the situation as threatening and when they are not equipped with sufficient coping mechanisms to accomplish the demands, stressful emotions arise.

While parents of children with DD have repeatedly described their lives to include stress, isolation, helplessness, lack of confidence, a disconnect from others, denial, and self-blame (e.g., McNeill, 2004; Poehlmann et al., 2005), they also describe their lives to be positively impacted (Dykens, 2005; Hastings & Taunt, 2002). In fact, mothers and fathers have been found to attribute negative and positive meanings to having a child with DD in the family (Trute, Hiebert-

Murphy, & Levine, 2007), with both experiences occurring simultaneously (Hastings & Taunt,

2002). Thus, parenting a child with a DD is not all about disruptions and crises. To understand

the range of emotions, researchers are adopting a more *balanced* view of the family (Blacher &

Baker, 2007).

Summary

In this program of research, McCubbin and Patterson's (1984) double ABCX framework is

used as a guide to understand how key child and parent factors play a role in psychological well-

being of parents rearing children with autism and Down syndrome. Child and parent factors are

investigated via three empirical studies that comprise the research. In Article 1, perceptions of

psychological stress, child behaviour problems, family coping, behaviours of health care

professionals, negative and positive appraisals of the child's disability on the family, as well as

the child's diagnostic status were evaluated to help predict maternal depression. In Article 2,

differences in the sources of child- and parent-related stress based on child diagnosis were

examined in mothers and fathers. Finally, in Article 3, the relationship between maternal stress

and children's social competence was explored.

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CHAPTER 2

ARTICLE 1

Depressive Symptoms in Mothers of Children with Autism and Down Syndrome

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Abstract

Child and parent variables were examined to predict depressive symptoms in 70 mothers of children with autism or Down syndrome. Approximately 40 and 41% of the variance of depressive symptoms was predicted by parent-related stress, the availability of informal social support, negative appraisals of the child, child diagnosis, child behaviour problems, and behaviours of health care professionals. Parent-related stress and informal social support were the only significant variables that accounted for 21 and 9.1% of the variance, respectively. As well, 60% of mothers met the criteria for showing clinical levels of depressive symptoms. As such, mothers were categorized according to depression status (low or high) and the effect of five family coping strategies, six child-related stressors, and positive appraisals of the child with a disability and its impact on the family were investigated between the low and high depression groups. The low symptoms group showed more adaptive overall family coping with the acquisition of informal social support as the only significant mechanism to differentiate the groups. Despite significant positive relationships between maternal depression and children's distractibility/hyperactivity, adaptability, and demandingness, the high and low symptoms groups did not differ on these characteristics. Likewise, no significant group differences emerged for positive appraisals of the child. Implications for professionals working with families of children with autism or Down syndrome are discussed.

Key words: Depression; developmental disabilities; stress; social support; negative and positive appraisals of the child; and behaviours of health care professionals.

Depressive Symptoms in Mothers of Children with Autism and Down Syndrome

Depression can be detrimental to one's overall well-being. Singer (2006) contends that, "even mild depression is a cause for concern" (p. 156). Because of their unique demands and challenges, mothers of children with developmental disabilities (DD) are especially vulnerable to maladaptive functioning reporting greater depressive symptoms than mothers of children without DD (Montes & Halterman 2007; Olsson & Hwang, 2001; Weiss, 2002). Prevalence rates of clinical depression and depressive symptoms in mothers of children with DD show that a third to half exceed cut-off scores (Bailey, Golden, Roberts, & Ford, 2007; Benson, 2006; Olsson & Hwang, 2001; Singer, 2006; Veisson, 1999). Symptoms related to depression can significantly compromise the mother's functioning, the child's functioning (Crnic, Gaze, & Hoffman, 2005), and the parent-child relationship (Abidin, 1995; Magill-Evans & Harrison, 2001).

Deleterious mental health problems such as depression are often associated with high stress in raising children with DD (Tobing & Glenwick, 2006). In a qualitative exploration of coping, mothers of children with high functioning autism reported that the stress in caring for their child was significant enough to warrant psychiatric treatment in the form of psychotherapy and medication (Gray, 2003). Yet the stressors of having a child with DD alone do not encapsulate a complete understanding of maternal depression. In fact, other key factors related to the child and the parent must be identified if the provision of family services is to be appropriate, timely, and individualized.

General components of the double ABCX model of adjustment and adaptation (McCubbin & Patterson, 1983) were used to guide an understanding of maternal depression whereby the outcome of depression (X) is suggested to be influenced by the child's diagnostic status and

behaviour problems (*A*), family coping resources and strategies (*B*), and the meaning mothers give to the situation (*C*). A review of the model elements follows.

Child Diagnosis and Behaviour Problems

Behavioural phenotypes are behaviours that are particular to individuals within a given syndrome (Hodapp, 2002; Hodapp & Ly, 2005). Syndrome-specific characteristics can be adaptive or maladaptive, and strengths or weaknesses that in turn, can have indirect effects on parents (Dykens & Hodapp, 2001). The child's diagnostic grouping is often used to evaluate psychological well-being in parents because "…it is likely that the physical and behavioral challenges posed by the child will be critical, and to the extent that those challenges vary across diagnoses, differences in parental reactions are possible" (Abbeduto et al., 2004, p. 238).

Take children with autism for example. They show qualitative impairments in their social interaction and communication, and behaviours that are restricting, repetitive, or stereotyped. The associated characteristics and behaviour problems that children with autism exhibit may lead parents to feel overwhelmed in their parenting role (Tomanik, Harris, & Hawkins, 2004). Pisula (2007) found that overprotection/dependency and difficult personality characteristics predicted differences in mothers of children with autism and Down syndrome. Specifically, mothers of children with autism had higher stress levels because of their child's dependence on others and problem behaviours such as self-stimulatory behaviour, tantrums, and aggression, compared to mothers of children with Down syndrome. Bromley, Hare, and Emerson (2004) reported that 59% of mothers of children with autism had elevated levels of psychological distress as a direct result of the child's behaviour problems. Olsson and Hwang (2001) also found that the added distress of severe behaviour disturbances along with more difficult temperament and higher

symptom severity in children with autism might have contributed to the significantly higher symptoms of maternal depression.

Children with Down syndrome for example, tend to be sociable, charming, and friendly (Dykens, Hodapp, & Finucane, 2001). Some researchers support a Down syndrome advantage, which considers that parents of children with Down syndrome are less stressed and cope better on account of their child's positive characteristics. Fidler, Hodapp, and Dykens (2000) examined the association between children's maladaptive behaviour on parent stress levels comparing parents of children with Down syndrome, William's syndrome, and Smith-Magenis syndrome. Children with Down syndrome, who have less maladaptive behaviours, had parents who showed less pessimism overall than parents in both comparison groups, and less parent and family problems than parents of children with Smith-Magenis syndrome. In essence, children with Down syndrome are easier to take care of and in turn, their families adjust better to stress (Hodapp & Burack, 2006).

Stoneman (2007) found a Down syndrome advantage with respect to lower maternal and paternal depression and increased self-reported warmth, and observed warmth in mothers when parents of children with Down syndrome were compared to parents of children with intellectual disabilities (without considering demographic variables as confounds). However, the advantage disappeared when the variance of income was accounted for. Similarly, Corrice and Glidden (2009) found a Down syndrome advantage in mothers of children with Down syndrome compared to mothers of children with other DD, but the differences disappeared when the age of the mother and the adaptive functioning of the child were controlled. The magnitude of the advantage was also small compared to more substantial ones found by previous investigators (e.g., Abbeduto et al., 2004). Others assert that children's traits are not always favourable.

Anecdotally, approximately one third of mothers of children with Down syndrome reported their children's stubborn, impulsive, aggressive, moody, and anxious behaviour to be the source of their family stress (Poehlmann, Clements, Abbeduto, & Farsad, 2005). In short, children's challenging behaviours can be largely troubling to parents (Tomanik et al., 2004). Fortunately, coping resources can act as mediating variables.

Coping Resources

Formal and informal social supports are vital coping resources that can buffer the effects of psychological difficulties (Luther, Canham, & Young-Cureton, 2005). Social support is a resource that has shown to predict parent adjustment (e.g., Hastings & Johnson, 2001). Feldman et al. (2007) found that social support mediated and moderated the relationship between caregiver (primarily mothers) depressive symptoms and children's behaviour problems. Social support is often identified as either informal or formal. Informal social support includes drawing on friends, a partner, and other close allies in times of need, and has been found to reduce stress, increase positive parental perception of the child's behaviour, and produce better functioning of the family, better parenting actions, and better coping (Dunst, Trivette, & Jodry, 1997; Hastings & Johnson, 2001).

Formal social support includes a variety of services provided by health care authorities that help parents cope with the demands of their child's early years. Early intervention (EI) is one example. Early intervention is typically an inclusive, family-centered system (Dunst, 2000; Guralnick, 2005) in which families and children are provided with an extensive constellation of informal and formal services to foster early human development (Dunst, 2000). Increasingly, ideas of what traditional EI constitutes are being replaced by any number of experiences, opportunities, and exchanges that include the entire family (Bailey & Powell, 2005; Dunst,

2000). There has been a shift from child- and professional-centered models to family-centered ones (Brehaut et al., 2004), which is considered best practice in EI (e.g., King, Teplicky, King, & Rosenbaum, 2004).

Family-centered services is a set of philosophies and practices that characterize service delivery and support and respect parents as primary decision-makers in their children's lives (King, King, & Rosenbaum, 2004). A core principle is that parents and providers share an equal partnership (Dunst, 2002; King, Teplicky et al., 2004). In the model, there is a supportive, mutually respectful, and collaborative partnership between families and providers (Dunst, 2002). Parents are deemed 'experts' about their child (King, Rosenbaum, & King, 1997; King, Teplicky et al., 2004), and know their developmental strengths and needs best (King et al., 2004). The balance of power between family and service provider shifts to the family and ultimately, parents are in control of decision-making; professionals ensure that this shift happens (King, King, Rosenbaum, & Goffin, 1999). Parents receive adequate support and resources and participate in exchanging and sharing information with professionals so their competencies are strengthened to improve family functioning (Dunst, 2002; Dunst, Boyd, Trivette, & Hamby, 2002). Professionals in family-centered services are cognizant of the unique strengths and needs of families so that services are individualized and effective (Rosenbaum, King, Law, King, & Evans, 1998).

Family-centeredness. Evaluating the extent to which formal services are family-centered is imperative because families of children with DD have an ongoing and important relationship with their health care providers (King et al., 2004). King et al. (2004) state that knowing how parents perceive the caregiving process, more explicitly, the extent to which health care professionals perform specific behaviours can improve how services are delivered and ultimately how families function. There is evidence to suggest that perceiving services as family-centered

leads to better psychological outcomes for parents of children with chronic health conditions and disabilities (Dunst et al., 2002; King et al., 1999; King, Teplicky, et al., 2004). Van Riper (1999) found that when mothers of children with Down syndrome had a positive relationship and experience with services, and when services were perceived to be family-centered, they perceived higher levels of their own well-being and that of their family. Virji-Babul, Kisly, Eichman, and Duffield (2004) found that negative attitudes and expectations for successful child outcomes projected by health care professionals, along with lack of service provision and funding for services were identified as prime concerns by parents of children with Down syndrome. Virji-Babul et al. (2004) contend that health care issues can significantly influence quality of life. In fact, professional caregiving that positions parents as the central force in their child's life has been shown to initiate more satisfaction with services and better psychological health (King et al., 2004; King, Teplicky, et al., 2004).

Cognitive Appraisals of the Child's Disability

The subjective interpretation of childhood disability and its impact on the family is an important consideration to the well-being of parents of children with DD (Trute & Hiebert-Murphy, 2002; Trute, Hiebert-Murphy, & Levine, 2007). Typically, researchers focus on negative appraisals of the child and potential links to parent well-being (e.g., Bishop, Richler, Cain, & Lord, 2007). Recently, parents have reported negative and positive feelings to occur simultaneously (Trute et al., 2007). In fact, families of children with DD have been found to thrive in unique and changed ways with respect to sibling well-being and personal family growth (Dykens, 2005). Despite elevated stress often found in families of children with DD, there is no evidence to suggest fewer positive feelings or perceptions compared to other families (Gupta & Singhal, 2004; Hastings & Taunt, 2002).

McNeill (2004) found that positive cognitive perceptions about a situation are important to

adaptation and that fathers of children with juvenile rheumatoid arthritis had a more positive

outlook about their child's chronic disability when their partners remained positive. Fathers also

tried to find meaning behind their life situation and to think more optimistically. Reframing a

situation in a more positive light and finding solutions (Folkman & Moskowitz, 2000)

"…encourages people to focus on the value of their efforts and is especially important in helping

people sustain efforts such as those associated with caregiving, over long periods of time"

(Gupta & Singhal, 2004, p. 26). Exploring both positive and negative appraisals shifts our

thinking about the family in a more balanced way (Blacher & Baker, 2007) and recognizes that

parents can and often do, feel good and bad about their life circumstances (Dykens, 2005).

Summary

Taking child and parent factors into consideration reinforces the seminal theories of family

adjustment, which recognize that multiple child and parent characteristics must be factored in

when evaluating psychological outcomes of parents of children with DD (Crnic, Friedrich, &

Greenberg, 1983; McCubbin & Patterson, 1983). As such, I set out to accomplish two objectives

in this study. The first was to examine the potential for relevant child and parent characteristics to

predict maternal symptoms of depression. The relationships between maternal symptoms of

depression and parent-related stress, informal social support, the extent to which parents perceive

the behaviours of health care professionals to occur, negative and positive appraisals of childhood

disability on the family (hereon in referred to as negative and positive appraisals), child diagnosis,

and child behaviour problems were examined. By taking a multivariate approach, the field moves

beyond looking simply at independent effects, recognizing that symptoms of depression do not

emerge in isolation rather in consideration of key stress, coping, and appraisals factors.

Given the significant proportion of mothers of children with DD who report clinical levels of depressive symptoms (Singer, 2006), the second objective was to examine differences between mothers who met criteria for clinical levels of depressive symptoms and those who did not on their coping, child-related stressors, and positive appraisals. Comparing mothers in these two groups can shed light on how these factors may be a risk for, or protection from depression. If differences are found, better facilitation of how to intervene can be made for mothers who are at risk. It was hypothesized that

(a) mothers who report greater depressive symptoms and parent-related stress (i.e., where the source of stress is related to one's own functioning) will have poorer perceptions of their health care providers' abilities to show enabling and partnership, provide general and specific information about the child, coordinate and provide comprehensive care, and be respectful and supportive;

(b) mothers with greater depressive symptoms will report greater parent-related stress, negative appraisals, child behaviour problems, poorer informal social support, and fewer positive appraisals;

(c) parent-related stress, informal social support, negative appraisals, child diagnosis, child behaviour problems, and coordinated and comprehensive care will predict maternal depressive symptoms; and

(d) there will be a significant difference between mothers who show high levels of depressive symptoms and low levels of depressive symptoms in their family coping, such that mothers with greater symptoms will report poorer family coping strategies, greater levels of child-related stress (i.e., distractibility/hyperactivity, adaptability, demandingness, and mood), and fewer positive appraisals.

Method

Participants

Eighty-one Canadian mothers and their children with autism and Down syndrome initially consented to participate. Mothers and children were included if children were between birth and 9 years of age and diagnosed with autism or Down syndrome, and if mothers read at a grade six level and were proficient in English. Children with Asperger's Disorder and Rett's Disorder were excluded because the disorders are significantly different from Autistic Disorder. However, children with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), while a distinct diagnosis, were included because their impairments were comparable to children with Autistic Disorder.

Of the 81 mothers, two mothers did not complete several measures and could not be reached, hence their responses were not included in the analyses. Data for two other mothers were excluded after confirming the children had a diagnosis of Asperger's Disorder. Data for one child were excluded because the diagnosis changed from Autistic Disorder to Rett's Disorder. One mother withdrew for undisclosed reasons. Finally, participants were eliminated from the analyses because fathers were the ones to complete the measures and the sample was restricted to mothers. A final group of 70 mothers remained.

Participant data for 31 mothers and their children were drawn from the larger National Early Intervention Initiative (NEIRI) project. An additional 39 families who met criteria for the study were recruited from the community via flyers and websites. The final sample included 36 families of children with autism (25 males, 11 females) and 34 families of children with Down syndrome (18 males, 16 females). Child diagnoses were identified from a demographics questionnaire completed by each family. Based on DSM-IV criteria (American Psychiatric

Association, 2000), 37 children were diagnosed with Autistic Disorder and four with PDD-NOS. The etiology of children with Down syndrome was Trisomy 21 except for two children who had Down syndrome from another genetic source.

Children ranged in age from 8 months to 11.6 years (autism $M = 5.69$, $SD = 1.95$; Down syndrome $M = 5.17$, $SD = 2.86$). All children entered the study before they turned 10 years of age, but a few children were not assessed until after 10, hence the upper range reaching 11.6 years. Mothers were between the ages of 26 and 48 ($M = 39.06$, $SD = 4.99$) and all were the biological mothers.

Mothers reported receiving private, government-based, or both types of services. Services were *therapy-based* (e.g., applied behavioural analysis, speech-language, occupational, physical, play, horseback riding, creative arts); *parent-based* (e.g., social work, respite, counseling); *health-based* (e.g., nutrition services, medical/acute care, home-based nursing); and *education-based* (e.g., EI, assistive technology). Mothers reported accessing multiple services at one time. See Table 1 for complete demographic information.

Table 1

Child and Mother Demographics	
Child age in years (*M*, *SD*)	
Autism	5.69 (1.95)
Down syndrome	5.17 (2.86)
Diagnostic Group (*no.*)	
Autism/PDD-NOS	32/4
Down syndrome	34
Gender by Diagnosis (*no.*)	
Autism – males	25
Autism – females	11
Down syndrome – males	18
Down syndrome – female	16
Mother's age (*M*, *SD*)	39.06 (4.99)
Mother's education in years (*M, SD*)	14.99 (1.01)
Mother's level of education (*no*. and %)	
High school	3 (4.3%)
Some college	18 (25.7%)
College graduate	22 (31.4%)
Graduate/Professional	27 (38.6%)
Mother's ethnicity (*no*. and %)	
European-Canadian	51 (72.9%)

Middle-Eastern (non-Jewish)	2 (2.9%)
Jewish	12 (17.1%)
Asian	1 (1.4%)
African-Canadian	1 (1.4%)
East Indian	3 (4.3%)
Marital Status (*no.* and %)	
Married	60 (85.7%)
Divorced/Remarried	1 (1.4%)
Divorced/Single	4 (5.7%)
Separated	1 (1.4%)
Single	2 (2.9%)
Common-law	2 (2.9%)
Residence by province (*no.* and %)	
Québec	37 (33.6%)
Ontario	26 (23.6%)
British Columbia	6 (5.5%)
Nova Scotia	1 (0.9%)

Measures

Parenting Stress Index (PSI, long version; Abidin, 1995). The PSI was used to examine levels of perceived stress in the parent-child system. The PSI is a standardized self-report measure that consists of 101 likert-scale items where respondents read a statement and circle a response: strongly agree, agree, not sure, disagree, or strongly disagree (Abidin, 1995). Two subscales are formed, the Child Domain and the Parent Domain, wherein the sources of stress are

based on specific child and parent behaviours. The Child Domain represents the actual and perceived stressors related to child characteristics and include the subscales, Distractibility/Hyperactivity (9 items); Adaptability (11 items); Reinforces parent (6 items); Demandingness (9 items); Mood (5 items); and Acceptability (7 items). The Parent Domain represents specific traits of the parent and family context and includes the subscales, Competence (13 items); Isolation (6 items); Attachment to child (7 items); Health (5 items); Role restriction (7 items); Depression (9 items); and Spouse (7 items). The two domains create a composite Total Stress Domain. High levels of defensive responding were not identified in the sample (i.e., raw score of 24 or less).

Total raw scores correspond to percentile scores for each subscale. Higher scores signify greater levels of perceived stress. A Total Stress raw score at or above 260 falls in the critical range and identifies individuals who should be considered for psychological services (Abidin, 1995). A critical range is considered above or below normal, with normal being between the 15th and 80th percentile. Total Stress can be within normal limits even as a domain score falls in the critical range. In the present study, the Child and Parent Domain scales were examined separately. The depression subscale (9 items) from the Parent Domain was omitted before any analyses were conducted because the items would have likely overlapped with the items on the Depression subscale of the Symptoms Checklist-90-Revised.

The PSI has been normed on 2,633 mothers and 200 fathers and used extensively in research on parents of children with various DD (e.g., Hanson & Hanline, 1990; Smith, Oliver, & Innocenti, 2001). The alpha coefficients for internal consistency reliability were computed for each subscale and domain. The coefficients ranged from .70 to .83 for the Child Domain and from .70 to .84 for the Parent Domain. Child and Parent Domain alpha coefficients were .90 and

.93 respectively, showing a high degree of internal consistency. Test-retest reliability was calculated for a clinical sample of 30 mothers at two time points and correlation coefficients between Time 1 and 2 were .63 (Child Domain) and .91 (Parent Domain). A two-factor model was used to assess the factorial validity of the Child Domain and the Parent Domain and to show the items have a good fit as indicated by the Child Domain subscale: Adaptability (.63); Acceptability (.74); Demandingness (.70); Mood (.76); Distractibility/Hyperactivity (.52); and Reinforces Parents (.60) and the Parent Domain subscale: Depression (.73); Attachment (.52); Role Restriction (.72); Competence (.60); Isolation (.73); Spouse (.65); and Health (.62).

Symptoms Checklist-90-Revised (SCL-90-R; Derogatis, 1994). Mothers completed a 90-item self-report inventory that measures a range of psychological symptoms. Items are rated on a 5-point scale ranging from 0 (not at all) to 4 (extremely). Current psychological symptom status is assessed within "the past 7 days including today" (Derogatis, 1994, p. 6). Nine primary symptom dimensions are generated: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Only the Depression dimension was used in the current study because it is a public health concern for mothers of children with DD (e.g., Glidden & Schoolcraft, 2003; Khamis, 2007; Olsson & Hwang, 2001). A *t* score of 60 is considered clinical.

The SCL-R-90 has been normed on adult nonpatients ($N = 1002$), nonpatient normals ($N = 974$), psychiatric inpatients ($N = 423$), and adolescent nonpatients ($N = 806$). The normed mean score for the SCL-R-90 GSI is a *t* score of 50, and a standard deviation of 10. Internal consistency reliability for the Depression dimension was .90 (Derogatis, Rickels, & Rock, 1976; Horowitz, Rosenberg, Baer, Ureno, & Villasenor, 1988). Test-re-test reliabilities have shown to be superior. More than 1,000 studies have been conducted demonstrating its reliability, validity, and utility.

Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin, Olson, & Larsen, 1981). The F-COPES was used to measure reported coping strategies families use to adjust to life stressors. The instrument comprises 29 coping behaviours rated on a 5-point likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). Responses indicate the extent to which each statement describes the individual's attitudes and behaviours in response to family difficulties. Higher scores represent more adaptive coping. There are five subscales: Acquiring social support (9 items), Reframing (8 items), Seeking spiritual support (4 items), Mobilizing family to acquire and accept help (4 items), and Passive appraisal (4 items).

Parents answered the word stem: *When we face problems or difficulties in our family, we respond by…* Sample items include *...sharing our difficulties with relatives; seeking encouragement and support from friends;* and *seeking advice from relatives such as grandparents*. Alpha reliability for acquiring social support is .83; Reframing, .82; seeking spiritual support, .80; Mobilizing family to acquire and accept help, .71; Passive appraisal, .63; and Total Scale reliability, .86. Test-retest reliability with a sample of 116 was .78; .61; .95; .78; .75; and .81, respectively (McCubbin et al., 1981).

Family Impact of Childhood Disabilities Scale, Second Edition (FICD-2; Trute & Hiebert-Murphy, 2002). The FICD-2 was used to measure cognitive appraisals of the influence that childhood disability has on the positive and negative aspects of family life. Ten negative items make up the negative subscale and 10 positive items make up the positive subscale. Mothers were asked to rate each item on the family consequences of having a child with a DD in the family. Response categories are 1 (not at all), 2 (mild degree), 3 (moderate degree), and 4 (substantial degree). A sample negative item is *There has been unwelcome disruption to "normal" family routines* and a sample positive item is *The experience has made us more*

spiritual. The FICD-2 is a useful predictor of parental adjustment and provides an understanding of negative and positive appraisals for parents of children with various DD. The scale has also shown good internal consistency with Cronbach's alpha reliability of .88 for the negative subscale and .71 for the positive subscale (Trute & Hiebert-Murphy, 2002).

Measure of Processes of Care (MPOC-20; King et al., 2004). The MPOC-20 was used to measure mother's perceptions of the extent to which specific behaviours of health care professionals actually occur within a 12-month period. The MPOC-20 is a 20-item self-report questionnaire and a shorter version of the MPOC-56, used to examine the degree to which there is an association between how care is delivered and the psychosocial well-being of parents who have children with chronic illness and disabilities (King et al., 2004). The measure has five factor analytical scales: enabling and partnership (4 items), providing general information (4 items), providing specific information about the child (3 items), coordinated and comprehensive care for the child and family (4 items), and respectful and supportive care (5 items). Items 1 through 15 are introduced with the following word stem: *In the past year, to what extent do the people who work with your child...* Items 16 through 20 use the same word stem, but the word 'people' is replaced with 'organization'. Each item describes a specific behaviour or action. Respondents indicate how much the event or situation happens to them. For example, *...help you feel competent as a parent* and *...provide opportunities for the entire family to obtain information.* Responses are on a 7-point likert scale ranging from 1 (not at all) to 7 (to a very great extent). A zero denotes a situation that is not applicable. Respondent data yield 5 scores, one for each scale. There is no total score as the scales are examined individually. To compute a scale score, the average of the items' ratings are taken.

Using pre-existing data sets as well as a new sample from a province-wide survey, King et al.

(2004) suggest good internal consistency, reliability, and validity for the MPOC-20. Cronbach's

alphas reliabilities ranged from .83 to .90 using the new independent sample. The values are

similar to the values found with the MPOC-56 and MPOC-20 in existing data sets. With respect

to the construct validity, "intercorrelations between the five scale scores ranged from .56

(moderate) to .87 (high) and indicate the interrelatedness of the scales" (King et al., 2004, p. 50).

The MPOC-20 appears to retain the critical aspects of family-centeredness from the MPOC-56,

has solid psychometric properties, and has utility to evaluate intervention programs.

Behavior Assessment System for Children, Parent Rating Scales (BASC-2 PRS, Reynolds &

Kamphaus, 2004). Mothers completed either the PRS-C (child), or PRS-P (preschool) rating

scales to measure children's problem behaviours. A number of dimensions make up the

following composites: Externalizing Problems (Aggression, Hyperactivity, Conduct Problems);

Internalizing Problems (Anxiety, Depression, Somatization); School Problems (Attention

Problems); Adaptive Skills (Adaptability, Leadership, Social Skills, Study Skills); and the

Behavioral Symptoms Index (BSI; Aggression, Hyperactivity, Anxiety, Depression, Attention

Problems, Atypicality, Withdrawal; Kamphaus, Reynolds, Hatcher, & Kim, 2004; Reynolds &

Kamphaus, 2004). Only the BSI was used in this study. The PRS-C contains 160 items and the

PRS-P contains 134 items. Both use a 4-choice response format. Standardized scores were used

with ranges classified as average (41 to 59); at-risk (60 to 69); and clinical (70 and above;

McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006).

The BASC-2 has been normed on recent U.S. Census population characteristics. Norms are

based on large, representative samples and differentiated according to age, sex, and clinical

status of the child. T scores and percentiles are available for general and clinical populations.

Internal consistencies for the PRS are very high for the general norm samples: "in the low to middle .90s for Adaptive Skills and the Behavioral Symptoms Index (BSI), and in the middle 80s to middle 90s for Externalizing Problems and Internalizing Problems" (Reynolds & Kamphaus, 2004, p. 163). Test-retest reliabilities for the composite scales are high ranging from low 80s to low 90s, with the exception of Internalizing Problems, which was .78. For interrater reliability, the PRS shows median interrater reliabilities to be .74 (preschool), and .69 (child). Correlations between the PRS and the original BASC are extremely high (.90 or higher) with the lowest at .73. Correlations with other behaviour scales like the Conner's Parent Rating Scale Revised are moderate to highly correlated (60s) with the exception of anxiety (.41).

Procedure

The present study was part of the longitudinal NEIRI project tracking the developmental trajectories of families and children with DD receiving EI services. The primary goal of the initiative is to develop and utilize an assessment process to inform public policy on early childhood intervention practice. The ultimate outcome is to develop and implement an action-oriented National blueprint to change current policy and practice in Canadian EI. The NEIRI contributes to broader research in EI, whereas more unique and specific contributions are made to the well-being of mothers of young children with autism and Down syndrome for this study.

Approval from the Human Subject Research Ethics Board was received at the University level and the centres and schools where parents were recruited. A letter explaining the purpose, procedures, rights of the participants, and confidentially along with a consent form were mailed to families who fit the criteria for the larger study inviting them to participate. A package with the following questionnaires along with a return pre-paid envelope was mailed to consenting families: demographics questionnaire, PSI, SCL-90-R, F-COPES, FICD-2, MPOC-20, and

BASC-2 (additional measures not used in this research were also completed by the 34 families in the NEIRI project). A summary report of their data was provided to each family once all data were analyzed. Particular attention was paid when scoring the PSI and SCL-90-R; mothers who scored within the clinical range were provided with resources in their summary report.

The primary author extracted data from the larger project (collected between 2006 and 2009) for all mothers of children with autism and Down syndrome ($n = 31$) for this study. However, because of the low numbers of children with autism and Down syndrome, a second round of recruitment was conducted, which was required to test the research predictions. Advertisements were posted on various Canadian websites, in a parent newsletter, and across recreation centers. Recruitment continued until an adequate sample size was achieved (see results section). An additional 41 families were recruited between July and December 2008 (39 were eligible to participate). To ensure participation, a monetary honorarium and a summary report of their data were provided to the newly recruited families.

<div align="center">Results</div>

Exploratory Data Analysis

Sample size calculation. The G*Power 3.0.5 power analysis program was used to determine sample size (Faul, Erdfelder, Lang, & Buchner, 2007). Determining the sample size was based on (a) sample sizes used in similar studies on well-being in parents of children with autism and other DD that present comparable methodologies, including similar samples of children and families, measures, variables, and procedures; (b) sample size calculations; and (c) recommendations on statistical power analysis for research in the behavioural sciences, which discuss sample size, power analysis, population effect sizes, and significance criterion (Cohen, 1988; Faul et al., 2007; Stevens, 2002). To calculate the minimum required sample size for an

independent power analysis, the alpha level was set at .05, medium effect size at .20 (f^2; Cohen, 1988), and a desired statistical power of .80. A sample size of 70 was generated for a standard multiple regression to yield significant effects.

Collinearity. Bivariate correlations between all predictor variables were checked to see if any predictor variables were highly correlated with each other, thus leading to a distortion in the interpretation of the multiple regression results. Simple correlations of each predictor variable with each other were first examined; no collinearity and multicollinearity were found as correlations between the predictors ranged from .23 to .47. Correlations between the predictor variables and the criterion ranged from .24 to .59. The correlations between the predictor variables did not surpass the correlations between the predictors and criterion (Spicer, 2005), thus leading to greater confidence in their relative contribution.

Multicollinearity was also examined. The tolerance parameter and Variance Inflation Factor (VIF) statistic were checked. According to Alison (1999), a tolerance in the range of .40 and a VIF of 2.50 warrant concern. The data revealed no tolerance level below .56 with VIF statistics well within normal bounds, suggesting no multicollinearity issues. A final inspection of the condition index, which shows how dependent one predictor is on another revealed two indices greater than .30, but no predictor with at least two variance proportions greater than .50. Considering all of the information, there was confidence in proceeding with the multiple regression analyses.

Assumptions

Univariate and multivariate normality. To assess univariate normality, a visual inspection of data plots through box plots and histogram, skewness, kurtosis, and normal Q-Q plots for each predictor variable and the criterion were performed. Depressive symptoms, acquiring social

support, and negative appraisals had approximate normal distributions with skewness and kurtosis falling between -1.00 and 1.00. Parent-related stress had a strong negative skew (-.043), behaviour problems showed a strong positive skew (1.159) as well as extreme kurtosis (2.314), and positive appraisals showed a strong negative skew and kurtosis for the high depressive symptoms group (-1.270 and 1.906) and for the low depressive symptoms group (-1.386 and 2.210), respectively. The values were deemed unacceptably different from the normal curve.

Using the base-10 logarithm function, parent-related stress, behaviour problems, and positive appraisals were transformed. The transformation reduced parent-related stress skewness (-.442), behaviour problems skewness and kurtosis, respectively (.468, .783), and positive appraisals skewness and kurtosis for the high depressive symptoms group (-.725 and -.502) and low depressive symptoms group (-.782 and -.382), respectively. Thus, normality was greatly improved and the transformed variables were used in all subsequent analyses. Stevens (2002) also recommends examining the Shapiro-Wilk statistic for statistical significance for univariate normality. No variables were statistically significant (i.e., did not meet an alpha level of $p <$ .001). Plotted data values on the normal Q-Q plots also appeared to follow a normal distribution for each variable, with data points falling close to the diagonal lines. Residuals scatterplots for multiple regression (plotting standardized residuals as a function of standardized predicted values) were examined for normality. There were no outliers (i.e., standardized residual cases greater than 3 standard deviations above or below the mean; Meyers, Gamst, & Guarino, 2006). The plots were rectangular and centered around the zero value of the residuals, indicating the residuals were distributed normally among the predicted dependent variable scores (Tabachnick & Fidell, 2001). There were no evident curvatures in any of the relationships.

Univariate and multivariate outliers. Preliminary data screening was performed to screen for possible extreme values. One mild univariate outlier with an observation greater than 1.5 inter-quartile range on the boxplot was detected for behaviour problems and two mild univariate outliers were detected for positive appraisals (one for the high depressive symptoms group and one for the low). To further determine a threshold for outlier designation (Hair, Anderson, Tatham, & Black, 1998, as cited in Meyers et al., 2006), behaviour problems scores were converted into standard z scores with a mean of zero and a standard deviation of 1. A standard z score of beyond ± 2.5 for a case is considered a univariate outlier (Hair et al., 1998; Stevens, 2002). According to the z scores, the outlier for behaviour problems had a standard score of 3.06. Further inspection of the raw scores revealed a t score of 102, which exceeded the mean of the distribution for behaviour problems ($M = 59.80$). For positive appraisals, there were two standard scores that were high (-2.58 and -2.93). Although no univariate outliers were detected on the boxplot for depressive symptoms, one case had an unusually low z score value of -2.78 outside the normal ± 2.5 range. The two outliers on behaviour problems and depressive symptoms were temporarily eliminated from the regression analyses to produce a better fit/model (Tabachnick & Fidell, 2001). Eliminating them did not change the adjusted R^2 value (.423 with cases versus .412 without). Also, eliminating the two outliers for positive appraisals did not change the significance of the analysis of covariance (both were not significant at the .05 level).

In the end, outliers were retained because they were few, not extremely different from ± 2.5, and according to Stevens (2002), "…should not necessarily be regarded as bad. As a matter of fact, it has been argued that outliers can provide some of the most interesting cases for further study" (p. 17). Screening was also conducted for the presence of multivariate outliers by computing each case's Mahalanobis distance statistic (D^2). Using the chi-square distribution with

appropriate degrees of freedom equal to the number of predictors in the computation, no D^2 were

equal to or exceeded the threshold to be considered an outlier (i.e., .001).

Linearity and Independence. Bivariate scatterplot shapes for each combination of variables

were screened for linearity (Meyers et al., 2006). All relationships appeared linear with oval or

elliptical shapes thus, validating the use of multiple linear regression. Observations between the

participants were independent of one another as each mother completed her own questionnaire,

therefore not influencing each other. According to Spicer (2005), the more that the Durbin-

Watson statistic deviates from a value of 2, the more likely it is that the residuals are not

independent. An obtained value of 1.822 does not sufficiently deviate to raise doubts and

therefore was not in violation of independence.

Homoscedasticity. Bivariate scatterplots of the relationship between the criterion variable

(depressive symptoms), and each predictor variable were checked with its simple regression line.

The spread of data points should not change noticeably along the regression line, on either side.

The band on either side of the regression line should be uniform, not random (Spicer, 2005). The

assumption was satisfied in the data, showing homogeneity of variance. Multivariate

homoscedasticity (i.e., a composite of all the predictors) was also evaluated via scatterplots,

plotting predicted scores against residual scores. The equality of variance assumption was met

given the data points create a uniform band on both sides of the regression line.

Homogeneity of slopes assumption. Prior to conducting the multivariate analysis of

covariance (MANCOVA), the homogeneity of slopes assumptions were evaluated, which

were supported and deemed appropriate to proceed with the analyses.

Hypothesis 1: Correlations Between Formal Care and Depressive Symptoms

Correlation coefficients were computed using Pearson product-moment correlation analysis among depressive symptoms and the five MPOC-20 scales. Because of the ongoing interaction that parents of children with DD have with their health care provider (Brehaut et al., 2004), it was hypothesized that behaviours of health care professionals by way of enabling and partnership, providing general and specific information to the family, making care coordinated and comprehensive, and being respectful and supportive would be significantly negatively associated with depressive symptoms.

As expected, bivariate negative correlations were significant for providing general information, $r(70) = -.29$, $p < .05$, providing specific information about the child, $r(70) = -.27$, $p < .05$, and coordinated and comprehensive care for child and family, $r(70) = -.27$, $p < .05$ suggesting that mothers with higher depressive symptoms scores have poorer perceptions of the extent to which important behaviours of professionals occur in a family-centered fashion. The hypothesis that depressive symptoms would be related to enabling and partnership as well as respectful and supportive care was not confirmed. Associations are presented in Table 2.

Table 2

Bivariate Correlations: MPOC-20 Scales and Depressive Symptoms (N = 70)

Subscale	*M*	*SD*	Depressive Symptoms
EP	4.31	1.58	-.213
PGI	4.04	1.84	**-.299***
PSIAC	4.90	1.62	**-.265***
CCC	5.14	1.65	**-.266***
RSC	5.37	1.46	-.232

Note: MPOC-20 scales include EP = enabling and partnership, PGI = providing general

information, PSIAC = providing specific information about the child, CCC = coordinated and

comprehensive care for child and family, and RSC = respectful and supportive care.

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

Bivariate Pearson product-moment correlations were computed between the five behaviours

of health care professionals and parent-related stress, as well as informal social support, negative

appraisals, and behaviour problems. Due to the paucity of research examining such variables

corresponding to the formal care scales, no hypotheses were generated.

Significant negative associations emerged, but only for three of the five family-centered care

behaviours and parent-related stress including enabling and partnership, $r(70) = -.26$, $p < .05$,

coordinated and comprehensive care for child and family, $r(70) = -.27$, $p < .05$, and respectful and

supportive care, $r(70) = -.34$, $p < .01$. With the exception of informal social support and providing

specific information about the child, $r(70)$, $= .25$, $p < .05$, no significant associations were found

between the other behaviours of health care professionals and informal social support, negative

appraisals, and behaviour problems. Associations are displayed in Table 3.

Thus, mothers with high parent-related stress in which the source of stress comes from their

own functioning have poorer perceptions of the extent to which important behaviours of

professionals occur in a family-centered fashion namely, feeling involved in the care process,

perceiving care to be continuous and consistent, and feeling respected (King et al., 1997). As

well, mothers who feel satisfied with receiving specific information about their child from their

health provider feel better equipped at acquiring informal social support.

Table 3

*Bivariate Correlations: MPOC-20 Scales and Parent-Related Stress, Informal Social Support,
Negative Appraisals, and Behaviour Problems (N = 70)*

Scale	PSI-P	ISS	FICD-N	BSI
EP	**-.257***	.159	-.122	-.014
PGI	-.233	.188	.054	.017
PSIAC	-.222	**.252***	-.130	-.072
CCC	-.272*	178	-.103	-.097
RSC	**-.337****	.216	-.162	-.067

Note. MPOC-20 scales are EP = enabling and partnership, PGI = providing general information,

PSIAC = providing specific information about the child, CCC = coordinated and comprehensive

care for child and family, and RSC = respectful and supportive care. As well, PSI-P = parent-

related stress, ISS = informal social support, FICD-N = negative appraisals of the family impact

of childhood disability, and BSI = behavioral symptoms index.

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

Hypothesis 2: Correlations Between Depressive Symptoms and Child and Parent Variables

It was hypothesized that depressive symptoms would be significantly positively associated

with parent-related stress, negative appraisals, and child behaviour problems, and negatively

associated with informal social support and positive appraisals. With the exception of positive

appraisals, depressive symptoms were significantly positively correlated with parent-related

stress, $r(70) = .63$, $p < .01$, negative appraisals, $r(70) = .32$, $p < .01$, and child behaviour

problems, $r(70) = .25$, $p < .05$. There was also an inverse correlation between depressive

symptoms and informal social support, $r(70) = -.44$, $p < .01$. See Table 4 for means, standard

deviations, and correlation coefficients.

Table 4

Means, Standard Deviations, and Bivariate Correlations Between Depressive Symptoms and Parent-Related Stress, Informal Social Support, Negative and Positive Appraisals, and Child Behaviour Problems (N = 70)

Subscale	*M*	*SD*	M^T	SD^T	Depressive Symptoms
PSI-P[1]	118.49	22.57	2.10	.086	**.627****
ISS[2]	25.04	6.99	---		**-.437****
FICD-N[3]	27.20	6.52	---		**.321****
FICD-P[4]	29.93	5.96			.106
BSI[5]	59.73	11.58	1.77	.080	**.248***

Note. PSI-P = parent-related stress (minus 9 depression items), ISS = informal social support, FICD-N = negative appraisals of the family impact of childhood disability, FICD-P = positive appraisals of the family impact of childhood disability, and BSI = behavioral symptoms index. For interpretability, the means and standard deviations are presented for the PSI-P and BSI before and after transformations. Transformed means and standard deviations are denoted by a superscripted T. The possible ranges reported by respondents for the PSI-P, ISS, FICD-N, FICD-P, and BSI are explained in footnotes 1 through 5.

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

Depressive symptoms were also related to child distractibility/hyperactivity, $r(70) = .33, p < .01$, adaptability, $r(70) = .31, p < .05$, and demandingness, $r(70) = .29, p < .05$, but not mood (e.g., frequent crying). See Table 5 for means, standard deviations, and correlation coefficients.

Table 5

Means, Standard Deviations, and Bivariate Correlations Between Depressive Symptoms and the PSI Child Domain (N = 70)

Subscale[6]	*M*	*SD*	Depressive Symptoms
Distractibility/Hyperactivity	29.13	6.21	**.331****
Adaptability	31.63	7.38	**.313****
Demandingness	25.43	5.96	**.289***
Mood	11.07	3.93	.194

Note. A description of the possible ranges for the PSI-C subscales can be found in footnote 6.

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

Hypothesis 3: Predicting Depressive Symptoms

A standard multiple regression analysis was conducted to predict depressive symptoms using parent-related stress, informal social support, negative appraisals, child diagnosis, and behaviour problems as predictors. The dichotomous categorical variable of child diagnosis was dummy coded and included in the model as a predictor (i.e., autism was coded zero, Down syndrome was coded 1). The predictors were entered in two blocks. Child diagnosis was entered in the first block. While there was no hypothesis as to how diagnosis might add to the prediction, it was still of interest to see to what extent, it accounted for any variance of depressive symptoms because researchers have suggested that parent well-being varies as a function of the child's disability (e.g., Abbeduto et al., 2004; Gupta, 2007). The second block contained child diagnosis, child behaviour problems, parent-related stress, informal social support, and negative appraisals. The first block with child diagnosis alone did not emerge as a significant predictor, $R^2 = .000$, adjusted $R^2 = -.015$, $F(1, 65) = .019$, $p > .05$. However, the linear combination of the five predictors significantly predicted depressive symptoms, $F(5, 65) = 9.83$, $p < .001$. The sample multiple correlation coefficient was .67 with an R^2 coefficient of .45 and an adjusted R^2 of .40 (see Table 6 for multiple regression coefficients). Approximately 40% of the variance in depressive symptoms can be accounted for by the linear combination of the predictors. Based on Cohen's (1988) effect size calculations the value is considered a medium effect.

The relative importance of each predictor's unique contribution to the prediction of depressive symptoms was also of interest. Parent-related stress, $\beta = .50$, $t(65) = 3.96$, $p < .05$, and informal social support, $\beta = -.27$, $t(65) = -2.46$, $p < .05$ made significant and independent contributions. Inspection of the standardized beta weights revealed that parent-related stress made the greatest unique contribution to depressive symptoms followed by informal social

support. Negative appraisals, child diagnosis, and child behaviour problems did not make

statistically significant independent contributions ($p > .05$). The relationships between each

predictor variable and depressive symptoms after all other predictors were controlled for were of

interest as well. Each partial correlation was squared by calculating the unique contribution

between each predictor and depressive symptoms; parent-related stress and informal social

support predicted 21% and 9.1% of the variance, respectively. Negative appraisals (0.3%), child

diagnosis (0.1%), and child behaviour problem (0.7%) accounted for the remaining variance.

Table 6

Summary of Standard Multiple Regression Analysis for Depressive Symptoms (N = 70)

Subscale	B	SE B	β
Step 1			
Dx	.317	2.33	.017
Step 2			
Dx	-.170	2.08	-.009
BSI	8.43	12.91	.072
PSI-P	55.04	13.90	**.500****
ISS	-.350	.142	**-.271***
FICD-N	.023	.180	.016

Note. Dx = child diagnosis, BSI = behavioral symptoms index, PSI-P = parent-related stress

(minus 9 depression items), ISS = informal social support, and FICD-N = negative appraisals of

the family impact of childhood disability.

$R^2 = .450$, adjusted $R^2 = .404$ ($N = 70$, $p < .05$). * $p < .05$. ** $p < .01$.

The predictive contribution of the variable coordinated and comprehensive care to the regression model was further explored. Because of the low predictive power of child diagnosis and to keep from overfitting the model, diagnosis was eliminated and coordinated and comprehensive care was added to the model. A second standard multiple regression analysis was performed. The overall model was significant, $F(5, 65) = 10.00$, $p < .001$ and explained approximately 41% of the variance in depressive symptoms ($R^2 = .455$, adjusted $R^2 = .409$). Looking at the standardized beta weights parent-related stress, $\beta = .48$, $t(65) = 3.91$, $p < .05$, and informal social support, $\beta = -.26$, $t(65) = -2.41$, $p < .05$ were the only significant and independent contributors to depressive symptoms. Coordinated and comprehensive care was given significantly less weight to the model and did not have an independent significant effect, $\beta = -.069$, $t(65) = -.688$, $p > .05$. Each partial correlation that was squared to calculate the unique contribution between each predictor and depressive symptoms was found to produce the same results as the first multiple regression analysis. See Table 7 for multiple regression coefficients.

Table 7

Summary of Standard Multiple Regression Analysis for Depressive Symptoms (N = 70)

Subscale	B	SE B	β
PSI-P	53.20	13.62	**.483****
ISS	-.342	.142	**-.255***
FICD-N	.021	.158	.015
BSI	8.18	12.70	.070
CCC	-.391	.568	-.069

Note. PSI-P = parent-related stress (minus 9 depression items), ISS = informal social support,

FICD-N = negative appraisals of the family impact of childhood disability, BSI = behavioral

symptoms index, and CCC = coordinated and comprehensive care.

R^2 = .455, adjusted R^2 = .409 (*N* = 70, *p* < .05). * *p* < .05. ** *p* < .01.

High Versus Low Depressive Symptoms

Based on a *t* score cut-off of 60 on the SCL-90-R (Derogatis, 1994), 60% of the total sample

met the clinical cut-off for depressive symptoms, placing these mothers at the 84th percentile

compared to a normative group. Eleven percent of mothers further met the clinical cut-off for

depressive symptoms at the 98th percentile of a normative group. The remaining 41% of mothers

did not meet the clinical cut-off for depressive symptoms. Mothers who met the clinical cut-off

were categorized as the 'high' symptoms group (*M* = 66.71, *SD* = 4.20) and mothers who did not

meet the clinical cut-off were categorized as the 'low' symptoms group (*M* = 50.41, *SD* = 5.49).

Hypothesis 4: Differences Between Mothers with High and Low Depressive Symptoms

First, *t* tests were performed to check for differences between the high and low symptoms

group. Levene's Test for Equality of Variances revealed a significant effect for maternal age,

t(68) = -2.05, *p* < .05, *d* = .49. Mothers in the low symptoms group were significantly older (*M* =

40.48, *SD* = 5.33) than the high symptoms group (*M* = 38.05, *SD* = 4.55). As such, equal

variances are not assumed and age of mother was used as a covariate in the multivariate analysis.

There was no significant difference for chronological age of the child, *t*(68) = -.1.43, *p* = .159, *d*

= .36 and maternal education, *t*(68) = -.336, *p* = .738, *d* = .08. A chi square test of independence

found no significant relationship between the two groups for maternal ethnicity, X^2 (6, *N* = 70) =

.239, *p* > .05, Cramér's V = .33.

A one-way MANCOVA controlling for maternal age was conducted to determine the effect of depressive symptoms status (high versus low) on the following five coping strategies: informal social support, reframing, seeking spiritual support, mobilizing the family to acquire and accept help, and passive appraisal. Significant differences were found between the high and low symptoms groups on overall family coping, Wilks $\lambda = .82$, $F(5, 67) = 2.74$, $p < .01$. The multivariate η^2 was .179. Thus, approximately 18% of the multivariate variance of coping strategies is explained by depressive symptoms status. ANCOVAs on each of the five coping strategies were conducted separately as follow-up tests to determine the locus of the statistically significant multivariate effect. Depression status significantly affected informal social support, $F(1, 67) = 10.67$, $p < .01$, $\eta p^2 = .137$. The means for acquiring social support were ordered as expected with the low symptoms group showing a higher adjusted mean ($M = 28.17$) than the high symptoms group ($M = 22.83$). No significant effects were found for reframing, $F(1, 67) = 2.08$, $p > .05$, seeking spiritual support, $F(1, 67) = .385$, $p > .05$, mobilizing the family, $F(1, 67) = .477$, $p > .05$, or passive appraisal, $F(1, 67) = .000$, $p > .05$.

A one-way MANCOVA controlling for maternal age was also conducted to determine the effect of depressive symptoms status on child-related stress. The MANCOVA was not significant, Wilks $\lambda = .84$, $F(5, 65) = 1.98$, $p > .05$, making the groups indistinguishable. Finally, a one-way between subjects ANCOVA covarying for maternal age, using depression status as the grouping variable and positive appraisals as the dependent variable was not significant, $F(1, 67) = 1.29$, $MSE = .010$, $p = .261$, $\eta p^2 = .019$.

Discussion

In the present study, the combined relationships of parent-related stress, informal social support, negative appraisals of the child's disability on the family, child diagnosis, child

behaviour problems, and coordinated and comprehensive care significantly predicted depressive symptoms in mothers of children with autism and Down syndrome. The best predictors, which were also the only ones to make independent predictions, were parent-related stress and informal social support. The strong link between parent-related stressors and depression adds to the growing body of knowledge showing that psychological stress can lead to serious health outcomes (Davis & Carter, 2008; Montes & Halterman, 2007; Tobing & Glenwick, 2006). Feeling incompetent in the parenting role, isolated, an absent emotional bond with the child, physically unhealthy, restricted in the parenting role, and unsatisfied with spousal support in caring for the child (Abidin, 1995) – all considered parent-related stressors, can increase feelings of hopelessness and withdrawal from life interests (Abidin, 1995).

In line with other researchers (e.g., Bailey et al., 2007; Tobing & Glenwick, 2006), acquiring informal social support was also a significant predictor of depressive symptoms. In an earlier study, Boyd (2002) found that lacking social support was the greatest predictor of depressive symptoms and anxiety in mothers of children with autism. Given its powerful effect on well-being (e.g., Duvdevany & Abboud, 2003), it is not unexpected that informal support made such a contribution. Relying on family, friends, and one's community can buffer against mental health problems beyond that of formal social support (Boyd, 2002).

Because formal social support is such a vital part of the family's energy and time (Olsson & Hwang, 2003), and based on emerging research reporting links between better psychological well-being and formal health care (e.g., King et al., 1999; Raina et al., 2005; Raina et al., 2004), its association to depression was examined. As expected, the greater the depressive symptoms the poorer mothers perceived their professionals to provide information (general and specific) and ensure coordinated and comprehensive care. Nevertheless, the associations were weak to

moderate at best. Greater parent-related stress was also uniquely associated with poorer feelings about how involved mothers felt in the care process, how coordinated and comprehensive they perceived their care to be for the whole family, and how respected and supported they felt during the care process. Mothers who were able to rally informal support on the other hand, felt that more specific information was provided to them by their care provider.

The strength of the relationships between child and parent variables and depressive symptoms highlighted that some variables such as how stressed a mother feels about her own parenting and her capacity to attain informal support in times of need, are essential while others are less so. Coordinated and comprehensive care by service providers had only a weak association to depressive symptoms and almost no predictive power to the overall model. While family-centered care including creating partnerships, should be a goal of health care providers, informal social supports seem to have greater utility for decreasing stress in mothers and should be promoted as a viable outlet for families.

Speculation as to why some variables made little individual contribution to the model and had weak associations warrants attention. With respect to appraisals, it should be noted that most researchers have looked at this variable in relation to stress and not depression (e.g., Saloviita, Itälinna, & Leinonen, 2003; Trute et al., 2007). However, based on our knowledge that depression and stress are strongly associated, the inquiry as to whether appraisals of the child influenced depressive symptoms was explored. While negative appraisals were moderately associated with depressive symptoms and parent-related stress, its predictive value was minimal at best, to the overall prediction model. Thus, the meaning mothers attribute to parenting children with DD is understood better in the context of parent stress rather than depression.

Next, researchers have suggested that there are disparities in parent psychological functioning on account of the child's disability (e.g., Abbeduto et al., 2004). In the present study, disability type did not matter with respect to making an independent contribution to maternal depressive symptoms. This issue of diagnosis is also closely related to children's behaviour problems, given that the two go hand in hand. In this study, children's problem behaviours had relatively little contribution in predicting depressive symptoms. This runs counter to other findings, reporting behaviour problems as the single greatest determinant of parental stress and maladaptive family adjustment (Baker, Blacher, Crnic, & Edelbrock, 2002; Baxter, Cummins, & Yiolitis, 2000; Beck, Hastings, Daley, & Stevenson, 2004; Fidler et al., 2000; Hastings, 2003; Hodapp, 2002; Johnston et al., 2003; McCarthy et al., 2006; Plant & Sanders, 2007; Raina et al., 2005; Raina et al., 2004; Saloviita et al., 2003). That said, measures other than the BASC-2 (which was used in this study) were used in previous studies and children with different DD were sampled thus, direct comparisons cannot be made. The BASC-2 is a well-established measure; still, some items may not have been developmentally appropriate for the present sample. For example, mothers of children who had minimal verbal abilities would have been obliged to rate an item for a verbal behaviour (e.g., says, "nobody likes me") when a rating of 'not applicable' would have been more appropriate. Moreover, other areas of adaptive functioning (e.g., feeding, sleeping) may have had a greater impact on maternal depression than a composite of problem behaviours. The findings support the link between stress and behaviour problems, but not depressive symptoms and behaviour problems. As well, in the present study, the behaviour problems data were transformed to improve normality, which may have affected the results. The warning by Meyers et al. (2006) that data transformations are a "double-edged sword" (p. 71)

and should be used judiciously was considered; however the transformations were retained to meet the assumptions for normality.

Finally, because many families of children with DD in general require ongoing engagement with their child's health care provider (King et al., 2004), it was hypothesized that coordinated and comprehensive care (i.e., the ability to make care available to the whole family and ensure it is continuous and consistent over time; King et al., 1997), would act as an important predictor to maternal depression. The hypothesis however, was not confirmed and it can only be speculated that other, more salient behaviours of health care professionals matter more to mother's mental health. It may be that the behaviours of health care professionals are more relevant to families of children with more chronic or rarer illnesses wherein daily and persistent contact with health care providers is required (e.g., children with childhood cancer). Likewise, whether the behaviours of health care professionals occur in a family-centered fashion may be more pertinent to families for whom services are scant or disjointed. There may also be a decline in the use of formal services once children reach a certain age (the current sample was close to 6 years of age). Conceivably, with a younger sample, coordinated and comprehensive care might have been more salient. Aside from obtaining a rating of mothers' perceptions of behaviours of health care providers, information about the actual hours of services received and quality of those services was not analysed, but might have provided greater insight about its relation to depression.

It is alarming, but not surprising that 60% of mothers reported clinical levels of depressive symptoms. Such a finding is in corroboration with Benson (2006) who reported clinical levels for approximately 50% of parents of children with autism, Singer (2006) who estimated 29% in a meta analysis, 23.6%, which was found in a review by Bailey et al. (2007), between 35 and 53%

found by Veisson (1999), and 47% reported by Olsson and Hwang (2001). The rates vary likely because of the different populations, ages, and measures used across the studies.

In addition, mothers with low levels of depressed feelings had greater overall family coping. The additional resources that these mothers' seemed to have included the ability to acquire social support from relatives, friends, neighbours and extended family; redefine stressful events to make them more manageable; find spiritual support; seek out community resources and get help from others; and avoid engaging in inactive or avoidant coping behaviours (e.g., watching television, wishing the problem away; McCubbin, Olson, & Larsen, 1981). Out of these coping strategies, acquiring social support was the strategy to independently differentiate the two groups. Thus, the greatest source of comfort for mothers in times of need is to draw support from one's spouse, extended family members, friends, and neighbour; doing so is critical for experiencing good psychological health (Boyd, 2002; Tobing & Glenwick, 2006) and adaptation (e.g., Luthar et al., 2005; Twoy, Connolly, & Novak, 2007).

Based on the strong ties between stress and depressive symptoms (e.g., Davis & Carter, 2008; Montes & Halterman, 2007) we evaluated whether mothers of low and high depression status differed with respect to their perceptions of their child's behaviour problems – specifically how distractible and hyper, demanding, inflexible, and moody they were; these behaviours render it a challenge to parents when elevated (Abidin, 1995). Mothers with high depressive symptoms however, did not differ significantly from mothers with low depressive symptoms on reported child-related stress. Nonetheless, in general, high depressive symptoms were linked to high stress attributable to the child's distractibility and hyperactivity, adaptability, and demandingness. Thus, child-related stressors are of value in understanding maternal mental

health given that aberrant behaviours can be especially trying for parents (Benson, 2006; Tomanik et al., 2004).

In addition to the more pathologically-oriented approach to well-being, the positive influence that a child with a DD elicits on the family can help parents sustain their caregiver demands over time (Folkman & Moskowitz, 2000). Negative and positive appraisals about the child's disability and its impact on the family can occur simultaneously for mothers and fathers (Dykens, 2005; Hastings & Taunt, 2002). Trute et al. (2007) suggest that "…people can feel happy and sad at the same time" (p. 7). The importance of this juxtaposition was recognized in this study by including a measure of positive appraisals and hypothesizing that it would differ for mothers who were experiencing high and low depressive symptoms. However, consistent with Lloyd and Hastings (2008), mothers with low and high depression did not differ on how positive they felt about their child. In fact, there was no relationship between positive appraisals and depression. To speculate, it is conceivable that the median split that divided the mothers into low and high symptom status affected the findings. Had a different cut-off been used (e.g., extreme 5% of symptoms), the results may have differed. This alternative cut-off however was not an option; a t score of 60 was used because this was the cut-off for having clinical depressive symptoms. Despite the non-significant findings, further research on the positive aspects of parenting children with DD is warranted given that eventual adaptation may be experienced as children grow older and as families learn to adjust to their circumstances. Likewise, anecdotal reports have shown that maladaptive and adaptive experiences tend to co-exist (e.g., Myers, Mackintosh, & Goin-Kochel, 2009).

The limitations of the current study must be addressed. Mothers were assessed at one-time, providing only a snapshot of their symptoms. A person's lifetime history of psychological

problems is critical in evaluating depression because the trajectory of it can change over time (e.g., Glidden & Schoolcraft, 2003). As well, mothers were not asked about their pre-existing (i.e., before the child's birth) mental health issues unrelated to the child. As such, we cannot be certain that the sample was truly normative with respect to their psychological states. Further, because multiple self-report measures were used in the same analyses, shared method variance might have affected how the scores predicted the outcome. Multiple measures reported by the same mother may have created spurious correlations among measures (Weiss, 2002). Having mothers as the sole reporters may have also been implicated in the findings. For example, it is conceivable that mothers who are depressed perceive their formal supports to be less efficient, less family-centered, and less available, and even further, perceive their children to have more problematic behaviours *on account of* their depression. This respondent issue is a statistical and interpretive one that can be circumvented with the use of more objective measures of well-being (e.g., asking in a concrete manner about how often mothers are in contact with friends).

Despite these limitations, there are important implications for practice. First, knowing just how important certain stressors and coping resources are to mothers of children with DD can guide health care professionals to develop and implement targeted interventions that can minimize parent-related stressors and maximize informal social supports. For example, professionals can introduce mothers to techniques that have been useful for reducing stress in other populations including massage therapy (Field, 2007), mindfulness-based stress reduction (Bishop, 2007), yoga (Gura, 2007); psychotherapy (Everly & Lating, 2007), and exercise (Babyak et al., 2007). Professionals can also encourage the use of informal supports for mothers by inviting extended family members to meetings related to the child's well-being, for example.

The right stress-reducing techniques can decrease stress, prevent further mental health issues, and build and maintain social networks and resources with family, friends, and community.

Second, being cognizant as to how the behaviours of health care professionals relate to stress and depression might lead to positive changes to the way that services are delivered to families (King et al., 2004). According to King et al. (2004) "the interactions between providers and parents of children with disabilities may contribute powerfully (in either a positive or negative way) to parental well-being" (p. 37). The findings add to the growing evidence for family-centeredness, ensuring parents are treated equally and are key players in the decision-making process, which is critical to best practices in EI (Dunst, 2002; Dunst et al., 2002; King et al., 2004). Family-centered practice can lead parents to feel more satisfied with their providers and in turn, better about their own psychological states and their child's outcome (Dunst, 2002).

Experiencing psychological difficulties is a critical public health issue and more than ever, a risk for mothers raising children with DD (Khamis, 2007; Yamada et al., 2007). In this study, keeping psychological stress to a minimum and nurturing an informal connection with others were two key players in understanding maternal depression. Greater efforts are needed to elucidate the role of other key factors related to the child, the parent, and the environment, so that appropriate and timely interventions can be catered to those at the greatest risk for maladjustment. Doing so can lead to favourable outcomes for parents, the developing child, and the entire family system.

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Footnotes

[1]Raw cut-off scores for high stress in the PSI Parent Domain differ based on the age norms of

the child. Thus, to interpret the untransformed means in Table 4, Appendix A from the PSI

manual was consulted. A raw-to-percentile score conversion at each age norm was computed

(from 1-8 and 9-12 years of age). The lowest score at the 85th percentile and the highest score at

the 99th percentile were used to create a range of scores that were considered critical. The range

(i.e., the lowest raw score at the 85th percentile and the highest raw score at the 99th percentile)

for the Parent Domain was 109 to 151, respectively. However, it should be noted that the

reported PSI Parent Domain mean and standard deviation in Table 4 ($M = 118.49$, $SD = 22.57$) is

lower than it actually should be because the nine depression items were omitted and the omission

is not taken into consideration in Appendix A (i.e., the Depression subscale is included in the

Parent Domain score).

[2]The minimum and maximum score a respondent can attain on the Acquiring social support

subscale is 9 and 45, respectively.

[3]The minimum and maximum score a respondent can attain on the Family Implications of

Childhood Disability (negative scale) is 10 and 40, respectively.

[4]The minimum and maximum score a respondent can attain on the Family Implications of

Childhood Disability (positive scale) is 10 and 40, respectively.

[5] The standardized scores on the Behavioral Symptoms Index are classified as average when

scores are between 41 and 59, at-risk when scores are between 60 and 69, and clinical when

scores are 70 and above.

[6]Interpreting raw scores for each individual PSI Child Domain subscale is achieved by using

percentile scores generated from the frequency distribution of the normative sample (Abidin,

1995). In the present study, the means were analyzed for several individual domains within the

Child Domain subscales including Distractibility/Hyperactivity, Adaptability, Demandingness,

and Mood. To interpret the findings in a meaningful way, a range of the minimum and maximum

scores for each domain was created. The minimum score was derived by adding up the number

of items within each subscale and multiplying by one (i.e., the lowest value that a respondent can

score). The maximum score was derived by adding up the number of items and multiplying that

number by five (i.e., the highest value that a respondent can score). For example, the

Distractibility/Hyperactivity domain has 9 items therefore, the lowest possible score is nine and

the highest possible score is 45. The minimum and maximum means respectively, are

Distractibility/Hyperactivity (9 and 45); *Adaptability* (11 and 55); *Demandingness* (9 and 45),

and *Mood* (5 and 25).

Bridging Manuscripts

In Article 1, the depressive symptoms of a group of 70 mothers of children with autism and Down syndrome were examined. A significant proportion of mothers experienced clinical levels of depressive symptoms. Psychological stress was the most salient predictor of depression from a model that included a number of child and parent variables. Several aspects of Article 1 were the impetus for Article 2. First, there is a large and consistent body of research attesting that parental well-being varies as a function of the child's diagnosis. Second, the majority of family well-being research has focused exclusively on mothers; this first study is no exception. Researchers have reported more difficulty securing father participation and much more ease accessing mothers because they are more likely to identify themselves as the primary caregiver than fathers (e.g., Bromley et al., 2004; Feldman et al., 2007). Despite this, it cannot be assumed that mothers and fathers experience stress the same way. Families constitute more than just mothers, hence the motivation to examine fathers in Article 2. As well, while evaluating global stress is useful, locating the sources of stress gives added information as to where stress materializes. A more comprehensive methodology in study 2 is refined by (a) specifying groups of parents by child diagnosis so that differences across autism and Down syndrome are explored; (b) including a sample of fathers to examine gender differences; and (c) teasing apart global stress to elucidate specific sources of stress. Child diagnosis and father stress are the focus of Article 2 and as such, help bring an understanding to the stress levels experienced by mothers *and* fathers of children with autism and Down syndrome.

CHAPTER 3

ARTICLE 2

Psychological Stress in Parents of Children with Developmental Disabilities: Do Parent Gender

and Child Diagnosis Matter?

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Abstract

The purpose of the present study was to examine the effect of child disability on maternal and paternal stress levels in a sample of 141 mothers ($n = 76$) and fathers ($n = 65$) of children with autism or Down syndrome. A high proportion of parents reported clinically significant child-related stress (67% mothers; 60% fathers), and to a lesser extent, parent-related stress (49% mothers; 28% fathers). Significant differences were found between mothers and fathers with mothers in general showing greater stress levels concerning depression, role restriction in the parenting role, and spousal support compared to fathers. When mothers and fathers were further separated and compared by child diagnosis, significant differences emerged regarding depression and role restriction, and regarding the child's demanding behaviour, ability to positively reinforce the parent, and mood. Mothers of children with autism reported the highest psychological child- and parent-related stress compared to the other three parent groups. In addition to mothers, fathers also reported critical levels of stress, particularly for the challenging characteristics their children exhibit. The findings highlight that in addition to mother groups, we must also focus on understanding the psychological well-being of fathers. Irrespective of disability, intervention services that minimize one's own parent functioning as a source of stress are warranted for mothers. Decreasing the challenging behaviours of children with autism would likely have a direct impact on the experienced stress of mothers and fathers.

Key words: Parents, mothers and fathers, psychological stress, autism, Down syndrome

Psychological Stress in Parents of Children with Developmental Disabilities:

Do Parent Gender and Child Diagnosis Matter?

Psychological stress is a particular relationship between the person and the environment that is appraised as taxing to one's well-being (Lazarus & Folkman, 1984). Parents of children with developmental disabilities (DD) are particularly vulnerable to feeling high levels of stress (e.g., Davis & Carter, 2008). Elevated psychological stress can significantly jeopardize a parent's physical health, social, interpersonal, and professional life (Singer, 2006) and has been reported by parents of children with DD to lead to other, more deleterious mental health problems of depression, anxiety, and somatization (e.g., Feldman et al., 2007; Olsson & Hwang, 2001; Weiss, 2002). Parent stress not only adversely influences the individual's own functioning, but also impacts the parent-child relationship (Magill-Evans & Harrison, 2001), and the developing child (Crnic, Gaze, & Hoffman, 2005), that can manifest into behavioural and emotional difficulties (Abidin, 1995). There are various factors that influence parent stress with evidence to suggest that it varies as a function of parent gender (e.g., Hastings et al., 2005) and child disability (Abbeduto et al., 2004; Gupta, 2007).

Child Disability and Behaviours

Children with autism show marked impairments in three domains of functioning including reciprocal social interaction such as developing and sustaining peer relationships; verbal and nonverbal communication such as initiating a conversation; and restricted, repetitive, and stereotyped patterns of behaviour such as complex whole-body movements (American Psychiatric Association, 2000; Perry, Dunlap, & Black, 2007). For many parents, the inappropriate social, communicative, and ritualistic behaviours are burdensome and frustrating (Pakenham, Samios, & Sofronoff, 2005; Tomanik, Harris, & Hawkins, 2004).

Tomanik et al. (2004) investigated the relationship between stress and children's adaptive and maladaptive behaviours in 60 mothers of children with autism. Children who were more irritable, socially withdrawn, hyperactive/non-compliant, incapable of caring for themselves, and who had limited communication and interaction skills with others produced the greatest psychological stress in mothers. There was also a negative relationship between aberrant behaviours and adaptive behaviour, suggesting that high levels of problem behaviours in children were related to their own low levels of functional behaviour. Parents may find themselves strained in their efforts to increase their child's self-care skills and decrease maladaptive behaviours including being socially withdrawn or engaging in self-stimulation (Perry et al., 2007; Tomanik et al., 2004). Plant and Sanders (2007) also found that parents of children with more severe behaviour problems, namely children with autism, reported high levels of stress.

In contrast, children with Down syndrome tend to have gregarious personalities, are sociable, affectionate (Ricci & Hodapp, 2003), and easily accommodated (Holroyd & McArthur, 1976). Children with Down syndrome also display lower rates of maladaptive behaviour and a general lack of psychopathology relative to children in mixed etiological groups (Dykens & Kasari, 1997; Hodapp, Ricci, Ly, & Fidler, 2003; Ricci & Hodapp, 2003). Hodapp, Ly, Fidler, and Ricci (2001) consider the etiology-related behaviours a Down syndrome advantage, predisposing parents to less stress and more positive effects on well-being. Despite the positive experiences, researchers have reported mixed findings about the Down syndrome advantage.

Abbeduto et al. (2004) found that compared to mothers of children with autism and fragile X syndrome, mothers of children with Down syndrome reported lower levels of pessimism about their child's future, lower depressive symptomatology, and a close relationship with their child. Hodapp et al. (2003) found overall lower levels of child-related stress in children with Down

syndrome compared to children in a mixed disability group, concerning how acceptable the child was to others and their reinforcement to mothers. Using a slightly larger sample, Hodapp et al. (2003) subsequently analyzed why mothers of children with Down syndrome were less stressed. They found that children's problem behaviours were associated with elevated levels of child-related stress. Moreover, parents who reported their children as more outgoing and pleasant also judged them as more acceptable and reinforcing.

Other researchers contend that only some aspects of a Down syndrome advantage hold true. For example, Ricci and Hodapp (2003) examined the perceptions, stress, and involvement in fathers of children (10-11 years on average) with Down syndrome versus fathers of children with other types of intellectual disabilities. Fathers in the Down syndrome group rated their children as having personalities that were more sociable and less maladaptive behaviour thereby experiencing less stress. They also reported less overall child-related stress with respect to how acceptable, adaptable, and demanding their child was. There were no differences between the two groups on parent-related stress (e.g., competence) however, as children got older, fathers in the Down syndrome group reported them to be less reinforcing and less acceptable to others.

Others still, have found no support for a Down syndrome advantage (e.g., Hanson & Hanline, 1990). In addition to their affectionate, upbeat personalities, children with Down syndrome also display difficult temperamental styles, attention problems, and generally disruptive behaviour (Dykens & Hodapp, 2001; Lovering & Percy, 2007). Although a Down syndrome advantage may present itself at a single point in time, changes in stress level may occur as children's personalities and behaviours develop. Most, Fidler, Booth-Laforce, and Kelly (2006) found that while mothers of children with Down syndrome reported lower levels of stress than mothers of children with mixed intellectual disabilities when children were 12 to 15 and 30 months of age,

levels of maternal stress increased and were reportedly equal to the mixed disability group when children were 45 months of age. The increase in maternal stress may have been contributed by children's functioning such that as the behavioural problems and deficits in cognitive-linguistic skills became pronounced, higher levels of stress were also more obvious (Most et al., 2006).

Parent Gender

Until recently, the prime focus of stress research in parents of children with DD has been on mothers; this is not unexpected given the traditional role of the mother as the primary caregiver (Davis & Carter, 2008). Mothers also tend to self-identify as the primary caregivers in research. Feldman et al. (2007) found that out of 178 parents, 153 biological and 11 adoptive mothers identified themselves as the 'primary caregiver' compared to only four biological fathers.

The exclusive attention on mothers however, is a significant shortcoming to understanding how the whole family functions. Examining fathers' views about stress underscores the importance of their role in rearing their child with DD and "...provides insight into why fathers feel and act as they do" (Ricci & Hodapp, 2003, p. 289). McNeill (2004) found that fathers are significantly affected by their child's chronic health condition. They experience strong emotions of "…guilt, anger, pain, anxiety, and sadness" (p. 533), and worry and are uncertain about their child's future. On the other hand, fathers of children with Down syndrome also view their children as more sociable and exhibiting less maladaptive behaviour compared to fathers of children with intellectual disabilities, leading to less parent stress (Ricci & Hodapp, 2003).

There is a small but emerging line of research comparing stress in mothers and fathers of children with autism and Down syndrome (Ricci & Hodapp, 2003), and the results have been mixed. Whereas some researchers have reported greater stress for mothers, others have found similar stress levels between parents. For example, Hastings et al. (2005) compared mothers and

fathers of children with autism and found no significant differences on parent stress, perhaps reflecting a change to the traditional roles that parents assume.

Variability has also been found within-groups for child- and parent-related stress. For example, Noh, Dumas, Wolf, and Fisman (1989) found that when mothers and fathers of children with Down syndrome were compared on child-related stress, fathers reported less stress overall and less stress concerning their child's acceptability, adaptability, and demandingness. In another study, Krauss (1993) found that mothers of children with DD were stressed due to their own personal health, restricted parenting role, and a lack of spousal support in managing childcare, however there were no significant differences between mothers and fathers feelings' of isolation, depression, or parenting competence. Fathers however, reported stress due to their child's mood, adaptability, lack of reinforcement and attachment to their child. Beckman (1991) on the other hand, reported no child-related stress differences for parents of children with autism, which is consistent with Freeman, Perry, and Factor (1991) and Hastings (2003). However, greater overall parent-related stress in mothers due to depression, role restriction, competence, spousal support, and health was found, and partially congruent with Krauss' findings.

Depressive symptoms have typically been an issue for mothers of children with DD. Bailey, Golden, Roberts, and Ford (2007) estimated depressive symptoms in mothers of children with various DD to be 23.6%, whereas Singer (2006) reported an estimated 29% in their meta-analysis. However, the authors note caution in the interpretation of the findings; the measures were limiting because they served the purpose of screening for depressive symptoms as opposed to providing population estimates of clinical depression (Bailey et al., 2007). Even their conservative estimate of 12-15% is alarming.

Mothers have consistently reported depressive symptoms as a greater source of stress compared to fathers (Hastings et al., 2005; Scott, Atkinson, Minton, & Bowman, 1997). Olsson and Hwang (2001) found normal depressive outcomes in fathers of children with autism (with and without intellectual disabilities) when comparisons were made to mothers. However, Hastings (2003) examined the interrelationships between mothers' and fathers' stress and general mental health as well as predictors of stress and based on 18 couples of children with autism, found no significant differences between mother and father levels of stress and depression. Significant differences emerged for anxiety showing more symptoms in mothers than in fathers.

Caregiving roles. Traditional caregiving roles held by mothers and fathers are still evident and have been linked to greater stress for mothers than fathers. Gray (2003) suggests that fathers generally adhere to a more conventional role in parenting, and thereby experience less stress and need for different coping mechanisms. Mothers in contrast, tend to assume the major caregiving duties related to medical appointments, educational needs, and managing challenging behaviours (Hastings et al., 2005; Saloviita, Itälinna, & Leinonen, 2003), which can be demanding and overwhelming. It is likely that because of their greater involvement (Bristol, Gallagher, & Schopler, 1988), mothers feel significantly more stressed than fathers, taking a toll on their well-being (Gray, 2003). Roach, Orsmond, and Barratt (1999) support the notion that traditional parenting roles held by mothers lead to greater stress. A combined group of mothers of children with Down syndrome and without DD reported greater stress over fathers with respect to daily caregiving tasks, child-related activities, and child socialization. Fathers were more involved in their careers than mothers. Mothers who were more involved in childcare reported increased problems with their physical health, role restriction, and support from spouse. Traditional parenting roles can lead mothers to feel more restricted in their parenting roles than fathers.

Social support. The amount of spousal support one receives can also affect stress. Mothers anecdotally expressed that the support they received from their husbands was instrumental in coping at the time of receiving their child's diagnosis and over time (Gray, 2003; Poehlmann, Clements, Abbeduto, & Farsad, 2005). Mothers generally seek support from their spouses before turning to formal services because informal spousal support can be especially effective against stress (Boyd, 2002). Konstantareas and Homatidis (1989) found that 24 out of 44 mothers of children with autism reported needing additional spousal support from their husbands by way of respite relief, disciplining their child, and taking the initiative to help with daily household tasks. Fathers also require support from their spouses and have reported their partners support to be the most helpful in supporting them personally (Herman & Thompson, 1995).

Parents of children with DD have psychological reactions that are unique to their specific gender and to their child's disability. Gathering information about the location of stress and making comparisons between mothers and fathers can help elucidate the sources of stress and to what extent different parent groups are affected. Based on the predominant focus on mothers, the move towards etiology-based research (Hodapp, 2002), and the unfavourable effects that stress can have on the family (Bishop, Richler, Cain, & Lord, 2007; Singer, 2006), the aim of the study was to compare mothers and fathers to assess whether stress varies because of child disability and to build the research on father stress. The research questions were (a) How do the clinical stress profiles of mothers compare to fathers? (b) Does stress differ for mothers and fathers and if so, what specific domains vary? (c) Does stress differ as a function of child disability for four parent groups (mothers/fathers of children with autism/Down syndrome)? (d) Does a child's demanding behaviour, inability to reinforce the parent, and mood differ across the four parent groups? and (e) Do the four parent groups differ on depression and role restriction?

Method

Participants

One hundred and forty one mothers (*n* = 76) and fathers (*n* = 65) of children with autism and Down syndrome participated in the study. Mothers and fathers from the same family who were proficient in English, read at a grade 6 level, and had a child between birth and 9 years of age with autism or Down syndrome met the inclusion criteria and completed a self-report measure on stress. Three fathers declined (2 Down syndrome, 1 autism), two fathers could not be reached after initial contact (both Down syndrome), and six fathers did not live in the home, or were not involved in the family (2 autism, 4 Down syndrome). See Table 1 for demographics.

Data for 36 families were drawn from the National Early Intervention Initiative (NEIRI) project. An additional 42 families were recruited from the community by the primary author, of which 40 were eligible for analyses. Together, participants included 41 families of children with autism (28 males, 13 females) and 35 families of children with Down syndrome (18 males, 17 females). The child's diagnosis was gathered from a demographics questionnaire completed by parents and verified through school/center records. Based on DSM-IV criteria (American Psychiatric Association, 2000), 37 children had Autistic Disorder and four had Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Although a diagnosis of PDD-NOS is distinct from Autistic Disorder, the four children with PDD-NOS were retained because their impairments were comparable to children with Autistic Disorder. The etiology of all but two children with Down syndrome was Trisomy 21. The other two etiologies were from another genetic source.

Children ranged in age from 8 months to 11.6 years (autism *M* = 5.78, *SD* = 1.98; Down syndrome *M* = 5.07, *SD* = 2.93). Mothers of children with autism were between the ages of 26

and 48 ($M = 38.17$, $SD = 4.91$) and fathers were between the ages of 29 and 55 ($M = 40.54$, $SD = 6.44$). Mothers of children with Down syndrome were between the ages of 27 and 48 ($M = 40.14$, $SD = 4.94$) and fathers were between the ages of 33 and 56 ($M = 42.28$, $SD = 5.10$).

Table 1

Child and Parent Demographics

Characteristic	Autism	Down syndrome
Child age in years (*M*, *SD*)	5.78 (1.98)	5.07 (2.93)
Gender (*no.*)		
Male	28	18
Female	13	17
Participating families		
Mothers	41	35
Fathers	38	29
Mother's age (*M*, *SD*)	38.17 (4.91)	40.14 (4.94)
Father's age (*M*, *SD*)	40.54 (6.44)	42.28 (5.10)
Mother's education in years (*M*, *SD*)	15.15 (.882)	14.83 (1.10)
Mother's level of education (*no.* and %)		
High school	1 (2.4%)	2 (5.7%)
Some college	7 (17.1%)	12 (34.3%)
College graduate	16 (39.0%)	9 (25.7%)
Graduate/Professional	17 (41.5%)	12 (34.3%)
Father's education in years (*M*, *SD*)	15.00 (1.25%)	14.52 (1.55%)
Father's level of education (*no.* and %)		
High school	4 (9.8%)	7 (20.0%)
Some college	5 (12.2%)	4 (11.4%)
College graduate	10 (24.4%)	8 (22.9%)
Graduate/Professional	19 (46.3%)	10 (28.6.4%)

Marital Status (*no.* and %)		
Married	37 (90.2%)	28 (80%)
Divorced/Remarried	0	1 (2.9%)
Divorced/Single	3 (7.3%)	1 (2.9%)
Separated	0	1 (2.9%)
Single	1 (2.4%)	1 (2.9%)
Common-law	0	3 (8.6%)
Mother's ethnicity (*no.* and %)		
European-Canadian	25 (61.0%)	30 (85.7%)
Middle-Eastern (non-Jewish)	2 (4.9%)	0
Jewish	8 (19.5%)	4 (11.4%)
Asian	1 (2.4%)	0
African-Canadian	1 (2.4%)	0
East Indian	3 (7.3%)	1 (2.9%)
Latin	1 (2.4%)	0
Father's ethnicity (*no.* and %)		
European-Canadian	23 (56.1%)	23 (65.7%)
Middle-Eastern	2 (4.9%)	0
Jewish	9 (22.0%)	3 (8.6%)
Asian	1 (2.4%)	1 (2.9%)
African-Canadian	0	1 (2.9%)
East Indian	2 (4.9%)	1 (2.9%)
Latin	1 (2.4%)	0

Residence by province (*no.* and %)		
Québec	33 (80.5%)	7 (20%)
Ontario	6 (14.6%)	21 (60%)
British Columbia	1 (2.4%)	6 (17.1%)
Nova Scotia	1 (2.4%)	1 (2.9%)

Measure

Parenting Stress Index (PSI, long version; Abidin, 1995). The PSI was used to examine levels of perceived parent stress in the parent-child system. The PSI is a standardized self-report measure that consists of 101 likert-scale items where respondents read a statement and circle a response: strongly agree, agree, not sure, disagree, or strongly disagree (Abidin, 1995). Two subscales are formed, the Child Domain and the Parent Domain, which locate sources of stress based on child and parenting behaviours. The Child Domain represents the actual and perceived stressors related to child characteristics and includes the subscales Distractibility/Hyperactivity (9 items); Adaptability (11 items); Reinforces parent (6 items); Demandingness (9 items); Mood (5 items); and Acceptability (7 items). The Parent Domain represents specific traits of the parent and family context and includes the subscales Competence (13 items); Isolation (6 items); Attachment to child (7 items); Health (5 items); Role restriction (7 items); Depression (9 items); and Spouse (7 items). The two domains create a composite Total Stress Domain. High levels of defensive responding were not identified in this sample (i.e., raw score of 24 or less).

Higher scores on each domain signify greater levels of perceived stress. A Total Stress raw score at or above 260 falls in the critical range and identifies individuals who should seek psychological help (Abidin, 1995). A critical range is considered above or below normal, with

normal being between the 15th and 80th percentile. Total Stress can be within normal limits while a domain score falls in the critical range. In this study, all three stress domains were examined.

The PSI has been normed on 2,633 mothers and 200 fathers and used extensively in research on parents of children with DD (Hanson & Hanline, 1990; Smith, Oliver, & Innocenti, 2001). The alpha coefficients for internal consistency reliability were computed for each subscale, domain, and Total Stress. Coefficients ranged from .70 to .83 for the Child Domain and .70 to .84 for the Parent Domain. Child, Parent, and Total Stress alpha coefficients were .90, .93, and .95, respectively, showing a high degree of internal consistency. Test-retest reliability was calculated for a clinical sample of 30 mothers. Correlation coefficients between Time 1 and 2 were .63 (Child Domain), .91 (Parent Domain), and .96 (Total Stress). A two-factor model assessed the factorial validity of the Child and Parent Domain showing the items to have a good fit as indicated by the Child Domain: Distractibility/Hyperactivity (.52); Adaptability (.63); Reinforces Parents (.60); Demandingness (.70); Mood (.76); and Acceptability (.74); and the Parent Domain: Competence (.60); Isolation (.73); Attachment to child (.52); Health (.62); Role Restriction (.72); Depression (.73); and Spouse (.65).

Procedure

This study was part of a longitudinal multisite NEIRI project tracking the developmental trajectories of families and children with DD receiving EI services. The goal of the NEIRI is to reform Canadian public policy in early childhood intervention so that appropriate and timely services are provided to children with various delays and DD and their families. The NEIRI contributes to the broader field of EI in Canada, whereas more specific offerings are made about the psychological stress of parents of children with autism and Down syndrome from this study.

The study received approval from the Human Subject Research Ethics Board at the University level and from the individual centres and schools where parents were recruited from. A letter explaining the purpose, procedures, rights of the participants, and confidentially along with a consent form were mailed to families who fit the criteria, inviting them to participate. A package of questionnaires (each containing a PSI for the mother, and PSI for the father, PSI response booklet, and other self-report questionnaires not reported here) along with a pre-paid envelope was mailed to families who consented to the study. Mothers and fathers from the same family were instructed to answer the PSI items independently.

The primary author extracted the NEIRI data (collected between 2006 and 2009) for all families of children with autism and Down syndrome ($n = 36$) for the present study. However, because of the low numbers, the primary author conducted a second round of recruitment. Advertisements were posted on Canadian websites catered to families of children with autism and Down syndrome, in a parent newsletter, and at local recreation centers. Recruitment continued until an adequate sample size was achieved (see sample size calculation in results). In the end, an additional 42 families were recruited. An honorarium and summary report were provided for each family from the second recruitment phase; families from the NEIRI sample received a summary report, but not an honorarium.

<div align="center">Results</div>

Exploratory Data Analysis and Assumptions

Prior to conducting the main analyses, the reliability and validity of the PSI (see description under measure) were examined and found to be a valid and reliable measure. A power analysis was conducted, and assumptions of independence, normality, univariate and multivariate outliers, statistical control, and homogeneity of slopes were also tested.

Sample size calculation. The G*Power 3.0.5 general power analysis program (Faul,

Erdfelder, Lang, & Buchner, 2007) was used to determine sample size. To calculate the

minimum required sample size, the alpha level, effect size (*f*; Cohen, 1988), and desired

statistical power for an apriori analysis of covariance (ANCOVA) power analysis was set at .05,

.40 (large effect; Cohen, 1988), and .95 respectively. The result was a sample size of 112 across

four parent groups, which should yield large effects.

Independence. Mothers and fathers in the study were instructed over the telephone and in

writing to complete the PSI independently, which was confirmed by each mother during follow-

up telephone calls.

Normality. Histograms were found to approximate normal with the exception of *reinforces*

parent, which was significantly positively skewed. The plotted data values on the Normal Q-Q

plots appeared to follow a normal distribution, with data points falling close to the diagonal line.

The coefficients for skewness and kurtosis of all variables were examined by comparing the

skewness value to twice the standard error of skewness. The inspection helped decide whether

the value for skewness fell within the range of $\pm$ twice the standard error of skewness. Skewness

values were high for *reinforces parent* for mothers of children with Down syndrome (skewness =

1.407, kurtosis = 1.691) and fathers of children with Down syndrome (skewness = 1.810,

kurtosis = 5.344). The Shapiro-Wilk test of normality was statistically significant for *reinforces*

parent in the mother and father groups (*p* = .001), indicating a possible violation of normality.

In most cases, a type of transformation would be applied to make the distributions normal.

However, the primary author decided against the transformation because of what low scores (i.e.,

a positive skew) on the *reinforces parent* variable signify. According to Abidin (1995), high

scores on the *reinforces parent* subscale is interpreted as parents who do not view their child as a

source of positive reinforcement. Thus, the scores that clustered on the low end of the scale indicate lower *reinforces parent* scores and in turn, parents who do view their child to be a source of positive reinforcement. The observation supports the literature showing adjustment that is more positive in parents of children with Down syndrome on account of their child's positive disposition (Ricci & Hodapp, 2003). Stevens (2002) also states that only one variable deviating from normality would not have much of an effect on power and not be of concern.

Univariate and multivariate outliers. Box plots and histograms were run to summarize the set of data and examine graphically, the variables location, spread, and a display of possible outliers. Mild univariate outliers were detected by their separation from the bulk of the cases in the box plots. To determine a threshold for outlier designation (Hair, Anderson, Tatham, & Black, 1998, as cited in Meyers, Gamst, Guarino, 2006), all scores for the variables with outliers were converted into standard z scores with a mean of zero and a standard deviation of 1. A standard z score of beyond ±2.5 for a case was considered an outlier (Hair et al., 1998; Stevens, 2002).

Based on the z score conversion, 10 outliers were detected, one for each of the following variables: Child Domain and Total Stress for mothers of children with autism; *reinforces parent*, *demandingness*, *mood*, and *depression* for mothers of children with Down syndrome; *reinforces parent, mood*, and *role restriction* for fathers of children with Down syndrome; and finally, Child Domain for fathers in both disability groups. All ANCOVAs were run again to see if the outliers were creating a bias or distortion of the data. Excluding the outliers did not change the outcome of the findings, therefore were retained. Multivariate outliers were also checked by computing each case's Mahalanobis distance (D^2) statistic. Using the chi-square distribution with appropriate degrees of freedom equal to the number of independent variables included in the computation, no cases reached the significance threshold for multivariate outlier (0.001 or less).

Statistical Control. According to Seltzer, Abbeduto, Krauss, Greenberg, and Swe (2004), in comparison studies of families with children with DD, the variance associated with potentially confounding between-group differences should be statistically controlled for. Independent samples *t* tests for mothers and fathers were conducted to identify differences on chronological age of the child, years of education of the parent, ethnicity, and age of parent.

Homogeneity of slopes assumption. Prior to each ANCOVA, the homogeneity of slopes assumptions were evaluated and indicated an ability to proceed with the analyses.

Clinical Levels of Stress

Means of participants were compared to PSI normative means (Abidin, 1995) to confirm previous findings that parents of children with DD show increased stress levels compared to the general population (e.g., Brehaut et al., 2004; Montes & Halterman, 2007; Sivberg, 2002). As expected, mothers reported higher clinical Total ($M = 270.50$ vs. $M = 222.8$), parent-related ($M = 142.30$ vs. $M = 123.1$) and child-related stress ($M = 128.10$ vs. $M = 99.7$) than the normative sample. Compared to the normative sample, fathers also showed higher Total ($M = 250.96$ vs. $M = 201.6$ to 215.0), parent-related ($M = 127.58$ vs. $M = 108.7$ to 112.6), and child-related stress ($M = 123.34$ vs. $M = 92.9$ to 101.3). See Table 2 for means, standard deviations, and percentage of mothers and fathers within the clinical range of stress.

Table 2

Parenting Stress Index Means and Standard Deviations and Percentages at the Clinical Level

	M (*SD*)		% of clinical stress	
	Mothers (*n* = 76)	Fathers (*n* = 65)	Mothers (*n* = 76)	Fathers (*n* = 65)
Total stress	270.50 (45.38)	250.96 (48.50)	57%	46%
Parent domain	142.30 (26.50)	127.58 (27.91)	49%	28%
Child domain	128.10 (25.47)	123.34 (25.06)	67%	60%

Note. To calculate the percentage of critical stress for mothers and fathers, the respondent's score

in Appendix A of the PSI manual was consulted (Abidin, 1995, Tables A1-3) by its

corresponding child age (categorized by 1-3, 4-6, and 7-12 years of age) and percentile rank.

Any score that was at or above the 85th percentile for Total, Parent, and Child Domain stress,

was considered clinical. The number of respondents with clinical levels of Total, Parent, and

Child Domain stress was divided by the total number of respondents.

Group Differences

Levene's Test for Equality of Variances revealed a significant effect, $F = .186$, $p = .015$,

or $t(141) = -2.46$, $p < .05$, d = -.41 showing that age of parents was significantly different

between the two genders. Maternal age was significantly lower ($M = 38.95$, $SD = 4.99$) than

paternal age ($M = 41.21$, $SD = 6.00$). As such, equal variances were not assumed and parent age

was used as a covariate in subsequent analyses. There was no significant difference between

mothers ($M = 65.18$, $SD = 29.68$) and fathers ($M = 66.18$, $SD = 27.06$), for chronological age of

the child $t(141) = -.208$, $p = .84$, and for years of education between mothers ($M = 15.03$, $SD =$

1.00) and fathers ($M = 14.78$, $SD = 1.44$), $t(141) = 1.19$, $p = .24$. A chi square test of

independence was also performed and identified no significant relationship between ethnicity and parent gender (mothers, fathers), X^2 (6, N = 152) = .466, p > .05, Cramér's V = .055.

Stress Differences Across Mothers and Fathers

To test whether the means of mothers and fathers differed significantly on the dependent variable stress, three separate one-way between subjects ANCOVAs were conducted using parent age as a covariate. The independent variable for all three ANCOVAs was Parent Group and included two levels: mothers (of children with autism and Down syndrome) and fathers (of children with autism and Down syndrome). The dependent variables were Total Stress, Parent Domain stress, and Child Domain stress.

Total stress. The ANCOVA was significant for Total Stress, $F(1, 140)$ = 5.03, MSE = 2197.53, p = .027. The strength of the relationship between the parent group factor and Total Stress was small, as assessed by partial eta (ηp^2 = .035). The means of the Total Stress adjusted for initial differences were ordered as expected across the two parent groups. Mothers had a larger adjusted mean (M = 269.76) than fathers (M = 251.77).

Parent domain. The ANCOVA was significant for the Parent Domain, $F(1, 140)$ = 9.44, MSE = 742.46, p = .003. The strength of the relationship between the parent group factor and Parent Domain stress was small, as estimated by partial eta (ηp^2 = .063). The means of the Parent Domain stress adjusted for initial differences were ordered as expected with mothers showing a larger adjusted mean (M = 142.10) than fathers (M = 127.77). Mothers fell in the critical range for stress[1] (i.e., raw score between 135 and 190), whereas fathers did not. Further analyses were conducted to test gender differences on depression, role restriction, and spousal support.

Depression, role restriction, spouse. The ANCOVA was significant for *depression*, $F(1, 140)$ = 12.84, MSE = 35.06, p = .000. The strength of the relationship between parent group and

depression as estimated by partial eta was small ($\eta p^2 = .084$). As expected, the adjusted means

for mothers of children with autism were higher ($M = 23.40$) than for fathers ($M = 19.77$).

Similarly, the ANCOVA was significant for *role restriction*, $F(1, 140) = 8.15$, $MSE = 38.35$, $p =$

.005. The strength of the relationship between parent group and *role restriction* was small, as

assessed by a partial eta ($\eta p^2 = .055$). The means of *role restriction* adjusted for initial

differences were ordered as expected with mothers showing a larger adjusted mean ($M = 22.14$)

than fathers ($M = 19.11$). Mothers' and fathers' means on the role restriction domain scale lie

closer to the maximum score a respondent can obtain than the minimum (i.e., 7 versus 35)[2].

Finally, there was a significant difference for spouse, $F(1, 140) = 10.17$, $MSE = 26.95$, $p = .002$.

The effect size estimated by partial eta was small ($\eta p^2 = .068$). The means for *spousal support*

adjusted for initial differences were ordered as expected with mothers reporting a larger adjusted

mean ($M = 20.77$) than fathers ($M = 17.93$).

   Child domain. The ANCOVA for the Child Domain stress was not significant, $F(1, 140) =$

.686, $MSE = 635.24$, $p = .409$, showing no differences between mothers and fathers. However,

the means adjusted for initial differences were ordered as expected, showing a larger adjusted

mean for mothers ($M = 127.54$) than fathers ($M = 123.97$). Mothers and fathers fell within the

critical range for stress[1] (i.e., raw score between 109 and 151).

Stress Differences Across Parent Gender and Child Disability

   Levene's Test for Equality of Variances revealed a significant effect, $F = .339$, $p = .026$ for

parent age when the two diagnostic groups were analyzed. Parents of children with autism were

significantly younger ($M = 39.08$, $SD = 5.76$) than parents of children with Down syndrome ($M =$

41.16, $SD = 5.18$). As such, equal variances were not assumed. Years of education for parents of

children with autism ($M = 15.09$, $SD = 1.10$) and parents of children with Down syndrome ($M =$

14.70, $SD = 1.35$) approached significance, $F = 5.04$, $p = .058$ and as such, was used as a covariate in addition to parent age in subsequent analyses. T tests revealed no significant differences between the diagnostic groups on the chronological age of the child. Three separate chi square tests of independence were also performed and identified no significant relationship between the diagnostic groups on maternal ethnicity, X^2 (6, $N = 76$) = 7.36, $p > .05$, Cramér's V = .31, paternal ethnicity, X^2 (6, $N = 72$) = 7.28, $p > .05$, Cramér's V = .32, and gender of child, X^2 (1, $N = 76$) = 2.25, $p > .05$, Cramér's V = .17.

Three separate ANCOVAs were performed using a 2 Child Diagnosis (Autism, Down syndrome) x 2 Parent Gender (Mother, Father) analysis on Total Stress, Parent and Child Domain stress, controlling for parent age and education. The independent variable of parent group included four levels: mothers of children with autism, mothers of children with Down syndrome, fathers of children with autism, and fathers of children with Down syndrome.

Total stress. The ANCOVA for Total Stress was significant, $F(3, 137) = 3.33$, $MSE = 2168.29$, $p = .022$. The strength of the relationship between parent group and Total Stress was small as evaluated by partial eta ($\eta p^2 = .068$). The means of the Total Stress adjusted for initial differences were not ordered as expected across the groups. It was expected that mothers and fathers of children with autism would have higher adjusted means for overall stress, followed by mothers and fathers of children with Down syndrome, respectively. However, mothers of children with autism had the largest adjusted mean ($M = 277.17$), followed by mothers of children with Down syndrome ($M = 262.03$), fathers of children with autism ($M = 260.11$), and fathers of children with Down syndrome ($M = 239.73$). Follow-up tests were conducted to evaluate pairwise differences among the adjusted means. Based on the least significant difference (LSD) procedure,

there was a significant difference between fathers of children with Down syndrome and mothers of children with autism.

Parent domain. The ANCOVA for the Parent Domain was significant, $F(3, 137) = 3.50$, $MSE = 749.70$, $p = .017$. The strength of the relationship between parent group and Parent Domain stress was small as estimated by partial eta ($\eta p^2 = .071$). Based on the traditional role of mother as primary caregiver (e.g., Simmerman, Blacher, & Baker, 2001), the means of the Parent Domain stress adjusted for initial differences were ordered as expected with mothers in both groups experiencing more stress than fathers in both groups. Mothers of children with autism had the largest adjusted mean ($M = 142.80$), followed by mothers of children with Down syndrome, ($M = 141.70$), fathers of children with autism ($M = 130.29$), and fathers of children with Down syndrome ($M = 123.96$). Based on the raw stress scores that fell within the critical range[1] (i.e., between 135 and 190), mothers in both groups, but neither father group met the cut-off criteria. Pairwise comparisons using the adjusted means were computed and based on the LSD procedure, the adjusted means for mothers of children with Down syndrome differed significantly from fathers of children with Down syndrome. Similarly, there were significant differences between mothers of children with autism and fathers of children with autism. Fathers of children with Down syndrome also differed from mothers of children with autism.

Depression and role restriction[2]. As expected, *depression* in parents differed significantly across the groups, $F(3, 137) = 4.22$, $MSE = 35.80$, $p = .007$. The effect size estimated by partial eta was small ($\eta p^2 = .085$). As predicted, mothers of children with autism followed by mothers of children with Down syndrome had the highest adjusted means, respectively ($M = 23.79$; $M = 23.11$); fathers of children with Down syndrome followed with a slightly higher adjusted mean ($M = 19.66$) than fathers of children with autism ($M = 19.32$). The variable *role restriction* was

also significant, $F(3, 137) = 3.87$, $MSE = 38.13$, $p = .011$. The effect size estimated by partial eta was small ($\eta p^2 = .078$). Mothers of children with autism had the highest adjusted mean ($M = 22.41$), followed by mothers of children with Down syndrome ($M = 21.94$), fathers of children with autism ($M = 20.23$), and fathers of children with Down syndrome ($M = 17.50$).

Child domain. The ANCOVA was significant for the Child Domain, $F(3, 137) = 3.90$, $MSE = 598.81$, $p = .010$. The effect size estimated by partial eta was $\eta p^2 = .079$. The order of the means of Child Domain stress adjusted for initial differences were as expected. It was hypothesized that parents (mothers and fathers) of children with autism would score higher than parent (mothers and fathers) of children with Down syndrome, supporting the notion that the characteristics of children with autism are a significant factor in stress outcomes (e.g., Hastings et al., 2005). Mothers of children with autism showed the largest adjusted mean ($M = 134.23$), followed by fathers of children with autism ($M = 129.82$), mothers of children with Down syndrome ($M = 120.22$), and fathers of children with Down syndrome ($M = 115.69$). All parent groups fell within the cut-off range for stress[1] (i.e., 109 and 151).

Demandingness, reinforces parent, mood[2]. As predicted, child qualities that differed significantly across groups were *demandingness*, $F(3, 137) = 2.90$, $MSE = 39.53$, $p = .037$, *reinforces parent*, $F(3, 137) = 3.98$, $MSE = 14.83$, $p = .009$, and *mood*, $F(3, 137) = 5.60$, $MSE = 12.95$, $p = .001$. The order of means was as expected for *demandingness,* with mothers of children with autism evidencing the largest adjusted mean ($M = 26.87$), followed by fathers of children with autism ($M = 25.87$), mothers of children with Down syndrome ($M = 23.91$), and fathers of children with Down syndrome ($M = 22.40$). For *reinforces parent,* fathers of children with autism had a slightly higher adjusted mean ($M = 12.35$) than mothers of children with autism ($M = 11.96$), which was expected to be the other way around. Mothers of children with

Down syndrome showed a higher mean ($M = 10.24$) than fathers of children with Down

syndrome ($M = 9.52$). Finally, the adjusted means for *mood* were ordered as expected for

mothers of children with autism ($M = 12.34$) and fathers of children with autism ($M = 11.96$),

whereas fathers of children with Down syndrome had a slightly higher mean ($M = 9.80$) than

mothers of children with Down syndrome ($M = 9.49$).

Discussion

The current study enhances our understanding of the role that an autism and Down syndrome

diagnosis has on the psychological stress of mothers and fathers while identifying key child- and

parent-related sources of stress. As expected, overall stress attributed to parent and child

characteristics were perceived by mothers to be higher compared to fathers. Parent-related stress

consists of personal traits and family variables such as perceived isolation that make it difficult

to function competently in the parenting role (Abidin, 1995). Child-related stress consists of

child qualities such as adverse mood that render it a challenge for parents to carry out their

parenting role (Abidin, 1995). In this study, 49% of mothers reported clinical levels of parent-

related stress and 67% was reported for child-related stress. Though it is typical for mothers to

report higher child- and parent-related stress than fathers (Abidin, 1995), it is noteworthy that

28% of fathers also reported clinical levels of parent-related stress and 60% was reported for

child-related stress. While mothers and fathers appear more adversely affected by their child's

qualities they still feel clinically stressed about their own parent qualities (Abidin, 1995).

The findings were echoed in a study where close to 60% of mothers of children with autism

reported elevated distress levels as a direct result of their child's problem behaviours (Bromley,

Hare, Davison, & Emerson, 2004). However, the present findings are significantly more severe

than findings made by other investigators. Davis and Carter (2008) reported that 11% of fathers

and 24% of mothers met the clinical cut-off for stress related to the child, whereas 13% of fathers and 26% of mothers met the clinical cut-off for parent-related stress. Children in the present study however, were older with a mean of 5.7 years, and included children with Down syndrome, whereas Davis and Carter (2008) sampled only children with an autism spectrum disorder who were 2.2 years old, which may account for the discrepant findings. In general, parents of children with autism report higher levels of total, parent- and child-related stress compared to other parent groups (Benson & Dewey, 2008; Davis & Carter, 2008; Gupta, 2007; Olsson & Hwang, 2001).

The large percentage of parents that experience enough stress to necessitate professional assistance is mirrored in a qualitative exploration by Gray (2003) who found that mothers reported the stress in caring for their child with high functioning autism was significant enough to warrant psychiatric treatment in the form of psychotherapy and medication. The higher stress reported by mothers in this study is also consistent with other researchers who found greater psychological stress in mothers of children with DD than in fathers (e.g., Davis & Carter, 2008; Hastings & Brown, 2002; Konstantareas & Homatidis, 1989; Olsson & Hwang, 2001; Wolf, Noh, Fisman, & Speechley, 1989).

The precise sources of parent-related stress that were significantly higher for mothers than for fathers were depression, restrictions in the parenting role, and spousal support. The expectation that both mothers of children with autism and Down syndrome would report higher parent-related stress related to these stressors was confirmed with the exception of spousal support, across the four parent groups. Davis and Carter (2008) also found greater depressive symptoms of clinical significance for mothers (33%) than fathers (17%). Similarly, of 14 studies that reviewed depression in mothers and fathers of children with DD, nine (64%) found greater

symptoms of depression for mothers while the remaining five did not (Bailey et al., 2007). Even though Hastings et al. (2005) reported no stress differences between mothers and fathers, they found significantly higher depressive symptoms in mothers of children with autism than in fathers. The findings are mixed however, as some earlier studies have found no significant differences between maternal and paternal stress (Hastings, 2003; Hastings et al., 2005; Wolf et al., 1989).

Mothers of children with autism and Down syndrome also felt significantly more confined in their parenting role. Gray (2003) contends that overly strict gender roles can lead to restricted feelings. Characteristically, mothers are more involved in the day-to-day caretaking tasks that can take a toll on their psychological well-being (Gray, 2003; Saloviita et al., 2003). Gray (2003) found that mothers of children with high functioning autism felt their careers and personal lives were gravely affected by the demands of their child with high functioning autism. A number of mothers reported feeling resentment or unfairness that their careers were significantly disrupted. They also felt overwhelmingly restricted and burdened by their domestic work. Fathers on the other hand, did not report significantly restricted feelings, either personally or professionally. Instead, they claimed to have a role at work that was separate from home life, which Gray speculates has a buffering effect on stress. Mothers of children with fragile X and Down syndrome (Poehlmann et al., 2005) have also anecdotally reported feeling dominated and controlled by their child's special needs and less in control than fathers (Bristol et al., 1988).

Mothers in the present study also felt significantly more emotionally and actively unsupported by their spouses in managing their children's needs. This finding is supported by Bristol et al. (1988) who found that compared to fathers, mothers of children with DD felt they carried a disproportionally larger burden of caring for their child; both agreed that they assumed

less of the childcare responsibilities. Similarly, Krauss (1993) found that mothers of children with Down syndrome, motor impairment, and global developmental delay felt more stressed than fathers as a result of parenting role restriction, lack of spousal support, and physical health. Significant differences between mothers and fathers of young children with conduct problems were also found as mothers reported increased stress concerning their attachment to their child, depression, role restriction, competence, spousal support, and physical health (Webster-Stratton, 1988). Despite the restriction mothers felt, Gray (2003) reported that mothers of children with high functioning autism rely heavily on the support of their husbands.

With respect to child-related stress, significant differences emerged when mothers and fathers were examined by child disability. Mothers of children with autism reported the greatest stress, and the expectations that both mothers and fathers of children with autism would report greater stress than parents of children with Down syndrome supports individual and gender differences (Davis & Carter, 2008). Specifically, children with autism were perceived as more demanding, less positively reinforcing to the parent, and moodier than children with Down syndrome. These characteristics are consistent with the behaviours of children with autism (APA, 2000; Bromley et al., 2004; Pisula, 2007). For example, children with autism have stereotyped behaviours (e.g., finger flicking), self-injure, show aggression, perseveration and compulsiveness, have a high activity level, impulsivity, and mood problems (e.g., anxiety; Volkmar & Wiesner, 2009). Socially, they may prefer to be alone, ignore others, or be aloof (Perry et al., 2007), making it difficult for others to interact with them (Bishops et al., 2007). Such behaviours can be troubling to parent and lead to a dysfunctional parent-child system where parents may feel rejected by the child (Abidin, 1995; Hastings, 2003) or unable to control these behaviours. The added distress of the child's severe behaviour disturbances as well as a more

difficult temperament and higher symptom severity corroborates the findings by others (e.g.,

Hastings & Brown, 2002; Hastings & Johnson, 2001; Konstantareas & Papageorgiou, 2006). In

short, the problem behaviours of children with autism are stressful for parents (Tomanik et al.,

2004) and in this case, were stressful for mothers and fathers alike.

Conversely, children with Down syndrome tend to be less demanding and more positive in

their temperament and disposition (Ricci & Hodapp, 2003). Ricci and Hodapp (2003) found

children with Down syndrome to have more positive characteristics than children with other

types of DD. Fathers reported less stress and viewed their children as more acceptable,

adaptable, and less demanding than fathers of children with nonspecific intellectual disabilities.

Parents of children with Down syndrome may feel less stressed because their children tend to

show more prosocial behaviours than children with autism or other DD.

At least two practical applications for service provision can be gleaned from the findings.

First, fathers like mothers also perceive their children's qualities to be disruptive and

unfavourable to the point that stress is a clinical concern. Professionals can ensure that mothers'

and fathers' psychological needs are identified during a family needs assessment (Orsmond,

2005). Once clinicians have identified the risk for stress, a brief stress screener can be used to

understand any potentially dysfunctional parent-child systems (Orsmond, 2005). When

professionals are sensitive and consider the goals of the family, assessments can quickly

recognize problems (Krauss, 2000). Knowing how parents view their stress levels can avert

chronic and potentially disastrous problems that can lead to disruptions within the parent, the

child, and their relationship (Guralnick, 2005).

Second, identifying the unique sources of stress can lead to targeted interventions. Mothers

of children with autism especially, might benefit from behavioural intervention plans, or parent-

training programs that alleviate problem behaviours (e.g., demandingness) and increase positive

ones (e.g., learning how to positively reinforcing the parent). Mothers of children with autism

and Down syndrome might benefit from professional consultation, learning to manage their

feelings of depression and role restrictions, which can impinge on their parenting. Consulting

with a professional can also help mothers find strategies for changing the division of childcare

responsibilities so that partners support each other better (Boyd, 2002).

A salient strength of the study is the inclusion and evaluation of father's stress. In general,

mothers tend to self-identify as the primary caregivers (Davis & Carter, 2008; Fidler, Hodapp, &

Dykens, 2000), yet fathers are also key caregivers to their children. What is more, they also

report experiencing psychological stress (e.g., McNeill, 2004). That 60% of fathers were

clinically affected by their child's characteristics and 28% by their own parenting functions

supports further inquiry about why this is the case, and the role that coping might play. Inquiring

about father's well-being not only implies that their opinions are valued, but helps to identify

how and why mothers and fathers are affected (Blacher & Hatton, 2007). Such an inquiry leads

to an enhanced understanding of the well-being of the entire parent-child system.

A second strength is that families of children with specific diagnoses were examined

(Dykens & Hodapp, 2001; Hodapp & Burack, 2006). The differentiations that were found across

the diagnoses help to understand the developmental approach to DD and in designing and

providing tailored interventions (Hodapp & Burack, 2006). In addition, the within-group

variability of the two groups was acknowledged by keeping the groups as homogeneous as

possible. This precise design component is important because of the extensive quantitative and

qualitative group differences that children on the autism spectrum display (e.g., significant

communication and cognitive delays in children with Autistic Disorder that are not found in children with Asperger's; APA, 2000).

The limitations of the study should be considered when interpreting the findings. First, there may have been a potential for sampling bias in the sampling procedure because participants were not selected randomly. Rather, participants were recruited from referred-based organizations representing 'serviced' parents. It is possible that families experiencing high levels of stress were more inclined to participate than families with low levels of stress. In the recruitment stage, parents were informed that the goal of the larger study was to change Canadian policies regarding EI services. Parents may have gravitated towards being in the study to voice their concerns about EI, such as having a negative experience with the system, or not having their needs met (Bromley et al., 2004).

Second, the parent groups in the study could be considered highly advantaged. Parents were older when they had their children, well-educated, and most were married. A conscious effort was made to recruit a regionally diverse sample (i.e., rural and urban communities and large metropolitan cities across Canada). However, the sample may not have represented Canadian parents of children with autism and Down syndrome and thus, not generalize well. Finally, the mental health status (e.g., asking whether they were depressed) was not obtained therefore we do not know if the sample was truly representative of a nonclinical sample.

The recommendation for family researchers is to continue addressing the psychological needs of fathers by examining other possibly revealing aspects of their well-being including how they cope with, and think about raising children with DD. In the present study, only stress was measured, limiting the ability to assess other potentially noteworthy aspects of their well-being. As well, researchers might consider including multiple comparison groups (Burack et al., 2001)

to make greater comparisons across different groups of families, who may also be experiencing significant stress in their lives. Finally, families of children with DD are constantly changing (Hodapp & Burack, 2006) and parental stress is no exception. Researchers that measure stress across multiple time points may find diverse patterns and important changes over time that can influence family supports and services.

In conclusion, the present findings underscore how child diagnosis can uniquely affect different sources of psychological stress in mothers and fathers of children with autism and Down syndrome. The findings can provide professionals with a more precise understanding of parent stress and lead to supports and services that are targeted to the unique needs of family members. Mothers of children with autism have garnered the greatest attention on family well-being, yet the current findings reveal that fathers and mothers of children with Down syndrome also necessitate attention, albeit for different reasons. Psychological stress can significantly compromise one's well-being and identifying the specific sources of stressors for particular parents can improve family functioning.

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Footnotes

[1]Raw cut-off scores for high stress in the Parent Domain and Child Domain differ based on

the age norms of the child. Thus, to interpret the means of the ANCOVAs for the Parent and

Child Domains, Appendix A from the PSI manual was consulted. A raw-to-percentile score

conversion at each age norm was computed (from 1-8 and 9-12 years of age). The lowest score at

the 85th percentile and the highest score at the 99th percentile was used to create a range of scores

that were considered critical. The range (i.e., the lowest raw score at the 85th percentile and the

highest raw score at the 99th percentile) for Parent Domain was 135 to 190 and for Child Domain

was 109 to 151.

[2]Interpreting raw scores are done by using percentile scores generated from the frequency

distribution of the normative sample (Abidin, 1995). In the present study however, the means

were analyzed for several individual stress domains including *depression, role restriction,*

spouse, demandingness, reinforces parent, and *mood*. To interpret and present the findings in a

meaningful way, a range of the minimum and maximum scores was created for each domain.

The minimum score was derived by adding up the number of items within each subscale and

multiplying by one (i.e., the lowest value that a respondent can score). The maximum score was

derived by adding up the number of items and multiplying that number by five (i.e., the highest

value that a respondent can score). For example, the Depression domain has nine items, thus, the

minimum possible score is nine and the maximum possible score is 45. The minimum and

maximum means respectively, are *Depression* (9 and 45); *Role Restriction* (7 and 35); *Spouse* (7

and 35), *Demandingness* (9 and 45); *Reinforces Parent* (6 and 30); and *Mood* (5 and 25).

Bridging Manuscripts

Investigating the differences between mothers and fathers of children with autism or Down syndrome provided evidence to suggest that all mothers, irrespective of diagnosis, exhibited higher levels of stress compared to fathers. The primary sources of stress were depression, role restriction, and lack of spousal support. When child diagnosis was explored, parents of children with autism exhibited greater stress than parents of children with Down syndrome. Child-related stressors included the child's demanding behaviour, inability to positively reinforce the parent, and negative mood. The differences in parent stress based on child diagnosis supports the notion that characteristics inherent in the disability are indeed, implicated in stress outcomes (e.g., Hastings et al., 2005). The differences are also substantiated in the premise for family-centered services, which recognizes that families are unique and must be serviced with this in mind. In Article 1, children's behaviour problems were also moderately related to stress and depression, which corroborates with an established line of research. Nonetheless, it is recognized that other behaviours, not maladaptive in nature, may also relate to stress. The goal of Article 3 was to explore children's peer-related social competence because peer interactions are fundamental to children's everyday lives. More specifically, the interest was in the stress reactions of mothers of children with autism and Down syndrome separately, given that different children elicit different reactions in their parents. For example, children with autism are difficult to engage with socially compared to children with Down syndrome; children with Down syndrome can be stubborn and temperamental too (Poehlmann et al., 2005). How then, are children's peer competencies uniquely associates with mother's stress? Recommendations for clinical practice that benefit mothers should emerge from this increased understanding.

CHAPTER 4

ARTICLE 3

Peer-Related Social Competence in Children with Autism and Down Syndrome: Relations to

Maternal Stress

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Abstract

In this exploratory study, the social competence of 75 children with autism and Down syndrome was examined to facilitate an understanding of its relation to maternal stress. Children with Down syndrome outperformed children with autism on overall socialization and on specific peer-related competencies including emotional regulation, peer involvement, and purpose of initiations (i.e., making social initiations with peers such as gaining attention, giving affection, and proposing joint play). Children's receptive and expressive communication was implicated in their ability to interact with peers, regulate emotions, and share an understanding of social rules and everyday events. For mothers of children with autism, greater stress related to parenting competence and depression, was linked to poorer pretend play skills. Likewise, greater social isolation in mothers was related to children's poorer success with peer initiations, play and use of leisure time, and coping. For mothers of children with Down syndrome, greater stress from parenting competence and role restriction was connected to children's poorer emotional regulation. As well, greater stress related to parenting competence, isolation, health, role restriction, and lack of spousal support was associated with poorer coping skills in children. Finally, role restriction and lack of spousal support was associated with children's poorer interpersonal and play and leisure skills. Findings are discussed in terms of their implications for early intervention while considering individual maternal needs.

Key words: Peer-related social competence, children, autism, Down syndrome, psychological stress, mothers.

Peer-related Social Competence

in Children with Autism and Down Syndrome

It can be argued that social competence is one of the most, if not *the* most desirable set of life skills for a child to develop. Social competence in children is the ability to successfully select and carry out interpersonal goals with others such as entering peer groups, resolving conflicts, and agreeing upon a play space (Guralnick, 1990, 2003, 2006); it forms the foundation to build strong and lasting relations with parents, peers, and siblings (Raver & Zigler, 1997; Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004). However, the social experiences of children with developmental disabilities (DD) have the propensity to be significantly more demanding, different, and challenging than for children without DD and can be a massive undertaking (Diamond, 2002; Guralnick, 1999; Shonkoff & Phillips, 2000). Approximately 60 to 65% of children with DD have difficulty socializing with peers (Guralnick, 1999b, 2001).

Children's social difficulties can be especially straining to families as they realize the social barriers their children face, the value of social competence in everyday life, and the time, energy, and money spent seeking specialized professionals, services, resources, and training (Guralnick, 2000; Minnes, 1998, as cited in Iarocci, Virji-Babul, & Reebye, 2006). Hodapp (2007) adds, "how lack of friendships affect parents and families has rarely been examined, even as it must certainly affect parents, siblings, and the family as a whole" (p. 285). According to Guralnick (2000), social competence is amenable to change much more so than IQ, and can be developed via early intervention (EI) services (as cited in Iarocci et al., 2006). The purpose of this paper is to explore the relationship between children's peer-related social competence and maternal stress. A literature review delineating the social difficulties of children with DD is presented followed by a review on children with autism and Down syndrome and the relation to parent stress.

Social Difficulties in Children with DD

Compared to typically developing children, children with DD engage in fewer peer interactions and are generally unsuccessful at gaining peer entry (Guralnick, 2005; Odom, McConnell, & McEvoy, 1992). They spend more time alone (Sigman & Ruskin, 1999), report more loneliness (Bauminger, Shulman, & Agam, 2003), are excluded and less preferred in playgroups (Diamond, 2002), have trouble regulating emotions (Baker, Blacher, Crnic, & Edelbrock, 2002), and lack strategies to resolve conflicts in social situations (Guralnick, 1999; Shonkoff & Phillips, 2000). Such experiences often lead to difficulty forming and sustaining peer relations (Guralnick, 2005).

Behavioural and cognitive weaknesses are often attributed to these social difficulties. In an investigation of peer interactions in children with mild developmental delays, Guralnick, Hammond, Connor, and Neville (2006), found that children's cognitive and language abilities, externalizing behaviours, parent stress, and social support were not related to their peer interactions across two time points. However, when subgroups were further identified (i.e., high and low initial level of interaction), cognitive and language abilities were significant predictors of children's peer interactions for the high interacting group at time 1. At time 2, these predictors as well as externalizing behaviours and stress for children in the low initial interaction subgroup were significantly related to their peer interactions. Specifically, children with lower cognitive and language development had poorer peer interactions and parents at greater risk for stress were related to children with lower peer interactions. The considerable insufficiencies in cognition and language that are established in children with severe DD are also part of the insufficiencies in several social-cognitive procedures that structure social competence, such as being sensitive to others' feelings (Diamond, 2002; Quill, 2000).

Social Competence: Children with Autism and Down Syndrome

Factors that encumber social competence are also disability-specific. Children with Down syndrome for example, show weakness in their expressive language, a failure to persist on difficult tasks (Dykens, Hodapp, & Finucane, 2000), and difficulties processing expressions of emotions (Wishart & Pitcairn, 2000). Sigman and Ruskin (1999) found communicative competence to be significantly associated with high levels of social play in children with autism and nonspecific DD, but not in children with Down syndrome. Children with autism and nonspecific DD with better language skills were more involved with their peers.

Although individuals with Down syndrome show less maladaptive behaviour than children with other DD, aggression (6.5%), attention-deficit/hyperactivity (6.1%), and oppositional defiant disorder or conduct disorder (5.4%) are still more frequent than in children without DD and can interfere with making friends. Freeman and Kasari (2002) investigated the friendships of children with Down syndrome via play dates and found that one third of children failed to meet the criteria for a true friend (i.e., reciprocal nominations, parent nomination of the same friend, and stable friendship for 6 months). While two thirds of the children met criteria, the importance and functions were observed to be unlike that of the friendships of children without DD. The authors suggest the friendships that children with Down syndrome have may be a precursor to 'true' friendships.

Relative to normative development, children with autism display marked and qualitative impairments in their social interactions, verbal and nonverbal communication, and show restricted, repetitive, and stereotyped patterns of behaviour or interests (American Psychiatric Association, 2000). Social deficits include difficulty understanding and interpreting others' intentions, thoughts and cues in social situations (Diamond, 2002; Quill, 2000), regulating emotions (Baker et al.,

2002), and less likelihood to initiate joint attention (Sigman, Spence, & Wang, 2006). Children with autism also exhibit higher rates of repetitive non-functional movement, less proximity to peers (Kasari, 2002; McConnell, 2002), and appear aloof and uninvolved (Quill, 2000).

Maladaptive social behaviours of children with autism emerge early in life, typically before the age of three (Sigman et al., 2006). Infants and toddlers with autism have a marked inability to gage affective features in social relations with others (Bauminger & Kasari, 2000). Unfortunately, abnormal nonverbal social-communicative interaction patterns tend to persist well into the preschool years when social development among peers becomes pronounced and intricate (Quill, 2000). Negative social behaviours include failure to respond to other children or immersion in pretend play (Kohler, Anthony, Steighner, & Hoyson, 2001), avoidance and non-responsive to overtures elicited by peers (Quill, 2000), and little understanding of the affective and emotional gestures in social situations with others (Bauminger & Kasari, 2000).

Lord and Magill-Evans (1995) found that children with autism spent less time interacting with peers than did children without DD, had lower-quality interactions when playing, engaged more in purposeless or no activity as well as kept greater physical distance from peers. Sigman and Ruskin (1999) compared children with autism, Down syndrome, other DD, and without DD and found children with autism were socially isolated not because they avoided other children, or because there was little initiation from others, but because of the behaviours related to their diagnosis. Thus, it is not unexpected that "displaying an attachment to objects, repetitive isolated play and activity, lack of eye contact, and flat affect make it difficult for the child or adult with autism to form social relationships" (Groden, Baron, & Groden, 2006, p. 17).

Children's Social Competence and Parent Stress

To date, much of the research on parent stress and children's behaviours has focused on

children's externalizing and internalizing and emotional behaviours, documenting strong ties to

elevated levels of stress and mental health problems (e.g., Abbeduto et al., 2004; Hastings, 2003;

Herring et al., 2006; Olsson & Hwang, 2001; Saloviita, Itälinna, & Leinonen, 2003). Often,

parents and children find themselves isolated from the community owing to these challenging

behaviours (Guralnick, 2006). Other researchers have focused on the broader construct of

adaptive functioning and its impact on parent stress. For example, McCarthy, Cuskelly, van

Kraayenoord, and Cohen (2006) found a significant relationship between lower levels of

adaptive functioning in children with fragile X syndrome and higher parent stress.

Fewer researchers have looked at children's socialization and parent stress. Webster,

Majnemer, Platt, and Shevell (2008) examined the health and well-being of school-aged children

with global delay or language impairment and its effect on parent stress. They assessed

functional abilities in socialization, communication, and activities of daily living and found

socialization to be the strongest predictor of parent stress, both functionally and developmentally.

Likewise, Tobing and Glenwick (2006) found a significant link between functional impairment

and stress, such that mothers of children with pervasive developmental disorders who reported

greater levels of impaired social and communication functioning also reported elevated stress

levels.

One important aspect of social functioning is children's peer-related social competence,

which can contribute to parent psychological well-being as parents recognize that having social

deficits can have negative effects on the family, in inclusive educational settings, and in making

and sustaining friendships. In a study by Guralnick, Neville, Connor, and Hammond (2003) a

path analysis model was tested using parent variables to predict child peer competence. In addition to other significant paths, child peer competence predicted 36% of the variance of parent stress. The sources of stress included lack of parenting competence, feeling restricted in the parenting role, social isolation, and depressive symptoms, which were related to lower child peer competence. Findings from a national survey on Down syndrome revealed that parents of school-aged children are most concerned about their child's social functioning, especially in making friends (Virji-Babul, Kisly, Eichman, & Duffield, 2004). The underlying principle is that children's social-behavioural functioning can induce stress for parents particularly when they lack the necessary skills. According to Raina et al. (2004), "…these behaviors require surveillance, control and exertion on the part of the caregiver" (p. 9).

Based on the significance of peer-related social competence to everyday life (Rosner et al., 2004), the substantial social challenges of children with autism and Down syndrome, and the rates of elevated stress reported by mothers, the authors explored links between children's observed peer-related social competence and self-reported parent-related stress. Documenting the social interactions of children with autism in their natural environment helps to understand their social behaviours (Lord & Magill-Evans, 1995). Guralnick (2002) adds that observational studies on social competence in children with Down syndrome compared to other children are scarce.

Examining the links between children's social behaviours and stress separately for mothers of children with autism and Down syndrome are of value because these links can highlight how strengthens and vulnerabilities that are disability-specific help or hinder parent well-being. Differentiating the strengths and vulnerabilities can lead to targeted and individualized services that meet the unique demands of mothers. In turn, targeted services can bring about improved

social behaviours for children and reduced levels of stress for mothers, ultimately leading to better family functioning.

Because the study is exploratory, there were no formal hypotheses about the links between children's social competence and maternal stress. The research questions were (a) How does the peer-related social competence of children with autism compare to that of children with Down syndrome? (b) Are there differences between children with autism and Down syndrome on their interpersonal relationships, play and use of leisure time, and coping? What is the nature of the relationship between: (c) peer-related social competence and expressive and receptive communication? (d) peer-related social competence and parent-related stress? and (e) children's interpersonal relationships, play and use of leisure time, and coping and parent-related stress?

<div align="center">Method</div>

Participants

Eighty-one Canadian mothers and their children with autism and Down syndrome consented to participate. Mothers and children were included if children were between birth and 9 years of age and diagnosed with autism or Down syndrome, and if mothers read at a grade six level and were proficient in English. Children with Asperger's Disorder and Rett's Disorder were excluded because these disorders are significantly different from Autistic Disorder. However, children with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) were included in the study because their characteristics and impairments were comparable to the children with Autistic Disorder.

The responses for 6 of the 81 mothers were excluded from the analyses for the following reasons: two mothers did not complete several of the measures and could not be reached to complete them; two children had Asperger's Disorder; one child's diagnosis changed from

Autistic Disorder to Rett's Disorder in the middle of the study; and one mother withdrew for undisclosed reasons. Thus, a final group of 75 mothers and their children remained.

Data for 34 mothers and their children were drawn from the National Early Intervention Initiative (NEIRI) project and an additional 41 families who met criteria for participation were recruited from the community via flyers and websites. There were 41 children with autism (28 males, 13 females) and 34 children with Down syndrome (18 males, 16 females). Diagnoses were identified by consulting school records and parents. Based on DSM-IV criteria (American Psychiatric Association, 2000), 37 children were diagnosed with Autistic Disorder and four with PDD-NOS. The etiology of children with Down syndrome was Trisomy 21 except for two children who had Down syndrome from another genetic source.

Children ranged in age from 8 months to 11.6 years (autism $M = 5.78$, $SD = 1.98$; Down syndrome $M = 5.17$, $SD = 2.86$). All children entered the study before they turned 10, but some children were not assessed until after 10, hence the upper range reaching 11.6 years. Mothers were between the ages of 26 and 48 ($M = 39.06$, $SD = 4.99$) and all were the biological mothers. Mothers were predominately married (85%), had a college (31%), or graduate/professional education (38%), and were predominately European-Canadian (73% mothers). Families resided in rural and urban settings across Ontario, Québec, Nova Scotia, and British Columbia.

Measures

Parenting Stress Index (PSI, long version; Abidin, 1995). The PSI was used to examine levels of perceived stress in the parent-child system. The PSI is a standardized self-report measure that consists of 101 likert-scale items where respondents read a statement and circle a response: strongly agree, agree, not sure, disagree, or strongly disagree (Abidin, 1995).

Two subscales are formed, the Child Domain and the Parent Domain, which locate sources of stress based on child and parenting behaviours. The two domains create a composite Total Stress Domain. For the current study, only the Parent Domain and its subscales were used because the interest was to understand the sources of stress specific to parent functioning. The Parent Domain represents specific traits related to the parent and to the family context and includes the subscales Competence (13 items); Isolation (6 items); Attachment to child (7 items); Health (5 items); Role restriction (7 items); Depression (9 items); and Spouse (7 items). Total raw scores corresponding to percentile scores for each subscale are generated. Higher scores signify greater levels of perceived stress. A critical range is considered above or below normal, with normal being between the 15th and 80th percentile. High levels of defensive responding were not identified in this sample (i.e., raw score of 24 or less).

The PSI has been normed on 2,633 mothers and 200 fathers and is used extensively in research on parents of children with various DD. The alpha coefficients for internal consistency reliability ranged from .70 to .84 for the Parent Domain. Parent Domain alpha coefficient was .93 showing a high degree of internal consistency. Test-retest reliability was calculated for a clinical sample of 30 mothers at two time points. Correlation coefficients between time 1 and 2 was .91 for the Parent Domain. A two-factor model was used to assess the factorial validity of the Parent Domain and shows the items to have a good fit as indicated by the Parent Domain subscales: Competence (.60); Isolation (.73); Attachment to child (.52); Health (.62); Role Restriction (.72); Depression (.73); and Spouse (.65).

Vineland Adaptive Behavior Scales-II, Survey Interview Form (VABS-II; Sparrow, Cicchetti, & Balla, 2005). The VABS is a semistructured parent interview used to obtain a measure of children's adaptive functioning. There are four domain composites: Communication (receptive,

expressive, written), Daily Living Skills (personal, domestic, community), Socialization (interpersonal relationships, play and leisure time, coping skills), and Motor Skills (gross, fine), which make up the Adaptive domain expressed by an Adaptive Behaviour Composite score. In this study only the Communication (excluding written) and Socialization domains were of interest and the standard scores for these were used. When conducting the interview, not all items are asked because the items are organized in developmental sequence based on the child's age and functioning (Beck, Hastings, Daley, & Stevenson, 2004). Interviewers in this study used a start point of 1-year below the child's chronological age and worked backwards or forward depending on the response provided by mothers. Behaviours are rated on a 3-point scale: performs the behaviour independently – usually (score of 2), sometimes (score of 1), and never (score of 0). Higher scores reflect better adaptive functioning.

Researchers have found fair to good inter-interviewer reliability for communication (.81) including receptive and expressive language (.79, .66) and socialization (.73) including interpersonal relationships (.63), play and leisure time (.51), and coping (.68). Internal consistency using the split-half reliability coefficients is excellent for ages 0 to 5 and 6 to 11, respectively: communication (.92 and .93), receptive (.80 and .76), expressive (.93 and .88); socialization (.93 and .93), interpersonal (.87 and .85), play and leisure time (.83 and .77), and coping (.87 and .88).

Assessment of Peer Relations (APR; Guralnick, 2003). The APR is a comprehensive clinical observational tool that was used to assess children's peer-related social competence. The APR has educational and clinical purposes. Educationally, it is useful based on the notion that establishing peer relationships for children with DD is a progression that highly depends on developmental abilities, skills, and processes (Guralnick, 2003). Foundational processes related

to shared understanding and emotional regulation are assessed as well as social tasks critical to social competence including peer group entry, conflict resolution, and maintaining play. As a clinical tool, the APR helps professionals understand underlying problems associated with the inability to ascertain peer relations. Clinicians often use the information to plan interventions.

The following three sections (and their subscales) were used: (a) overview (level of involvement, purpose of initiations, success of initiations) where the general level and profile of the child's peer-related social interaction is evaluated. Sample items are: *tends to be unoccupied* (level of involvement), *gains the attention of others* (purpose of initiations), and *peers respond to child's request for assistance* (success of initiations); (b) emotional regulation (emotional regulation), where general patterns or tendencies of emotional regulation are assessed. A sample item is: *becomes angry or hostile during interactions with peers*; and (c) shared understanding (social rules, pretend play complexity and diversity, everyday events), where the shared understanding about social rules of ownership and turn-taking, pretend play complexity and diversity, and the sequence and structure of everyday scripts is evaluated. Sample items are: *child appears to understand general rules regarding sharing and turn taking with peers* (social rules), *engages in pretend play using simple single actions* (pretend play complexity and diversity), and *demonstrates either through actions or descriptions a basic knowledge of shared themes involving everyday events similar to other children* (everyday events).

The APR uses a 4-point likert scale (rarely, sometimes, often, almost always). A rating of 'not applicable' could also be used and if this was the case in this study, the item was omitted from the total score. According to Guralnick (2003), "As a clinical tool, the assessment depends extensively on the judgments of those carrying out the observations. No numbers or cut-off

scores are generated by the Assessment of Peer Relations" (p. ii). There are no measures of inter-observer reliability because of its clinical purposes (Guralnick, 2003).

Procedure

Recruitment and parent data collection. Thirty-four mothers and their children with autism and Down syndrome were drawn from the NEIRI. However, to achieve greater statistical power a larger sample was required. Thus, a second recruitment was undertaken, advertising the study on websites, in a parent newsletter, and at recreation centers. The primary author recruited an additional 42 families (of which 41 were eligible).

First, consenting families received a letter explaining the study and several self-report questionnaires to be completed about their family and child (here only the PSI is reported). In some cases where mothers requested it, the questionnaires were completed over the telephone with a NEIRI research associate. Next, mothers were interviewed by doctoral and master's level students to estimate their child's adaptive functioning (social and communication). Interviewers had extensive clinical experience with families and children with DD. Interrater reliability of 85% or more was established for all interviewees, four of which were reliable with a clinician who uses the VABS clinically with families of children with autism. Interviews ranged from 30 minutes to an hour, depending on the child's level of functioning. Finally, children were observed in their natural play setting to get an estimate of their peer-related social competence.

Pilot testing the APR. To ensure the APR was easy to use and to gage administration time, the tool was pilot tested on a 3-year-old child suspected of a DD. The observations took place at the child's daycare on three separate occasions, for 20 observed hours. Based on this observation, the primary author deemed it necessary that all observations should be a minimum of 3 hours of observation time to ensure familiarity with the child's behaviours. The subscales

used in the study were deemed comprehensive and easy to use on the condition that the observer had prior knowledge about the behaviours of children with DD. Guralnick (2003) also specifies that observers should be familiar with the child's social development and be able to make conclusions about their behaviours.

Training on the APR. Senior members of the NEIRI team trained 6 graduate and undergraduate students in psychology and education to administer and score the APR. All had previous work experience with children with DD (e.g., special needs camp counsellor). Training sessions included information on children's social, motoric, language, cognitive development and behaviours, as well as play (e.g., pretend play, differences between types of play). Trainees were also instructed how to conduct naturalistic observations (e.g., taking notes, describing behaviour, being unobtrusive, ethical issues). Mock scenarios of children's play behaviour were also presented. Trainees read the APR manual and familiarized themselves with the items and scoring. All trainees practiced scoring and observed children under supervision before they administered any APRs. Trainees were deemed competent by the NEIRI team members based on their previous experience with children and participation in the APR training sessions.

Inter-observer reliability and teacher-observer agreement. Three children were observed on two separate occasions by different observers so that inter-observer reliability could be calculated. Inter-observer agreements on the APR were 77%, 81%, and 85%. The primary author and the observers met to discuss and rectify the discrepancies. For all the other children, professionals who worked with these children were consulted to confirm the APR ratings. These professionals included teachers, therapists, and educational assistants. If there were discrepancies between the observers' ratings and the professionals' ratings, they were rectified through further discussion about what was 'typical' behaviour for that child. Greater confidence was given to the

ratings made by the professional because most of them had a long-standing relationship with the child, which lead them to be able to more accurately, comment on and make a judgment about their behaviours. At least one professional was consulted for each child's APR, which gave greater insight and reflection about the child's behaviours.

Child observations. Extensive observations were conducted in the child's natural social setting. Guralnick (2003) stresses that a variety of play situations should be observed over several days. In this study, children were observed across a variety of educational settings including daycare, preschool, inclusive and segregated school. Observations took place in music, art, physical education, homeroom, before and after school, at recess, and during lunch. Some children were also observed on fieldtrips and at their local park. Both structured and unstructured play was observed for each child. The most frequently observed setting was the child's unstructured play in their classroom. For the most part, children were observed only once, but some observers had time to visit the child across different days and these repeated observations helped ensure intrarater reliability (Creswell, 2002). The observers acted discreetly and with as little intrusion as possible during the observations to minimize effects on children's behaviour. In a few cases, children approached the observer at which point the observer smiled and redirected the child successfully. If teachers felt that the child would understand the nature of the observation (mostly in the case of older children), the observer was introduced as a 'visitor'.

Observers completed their ratings by observing social behaviours outlined in the APR scales. In cases where the child did not spontaneously elicit a behaviour that needed to be rated, the observer met with the child's teacher/educational assistant to obtain feedback on that behaviour. Many children had a stable one-on-one educational assistant and when necessary, assistants were consulted. After each observation, trainees met with a NEIRI associate to debrief.

Observations for the children recruited from the community were conducted in an identical manner to the NEIRI observations with the addition of contacting each individual school/EI setting and organizing observation times with parents, teachers, and principals/directors. Two children could not be observed by the NEIRI team because the family was moving out of the country during data collection. Instead, teachers observed the children and completed the APRs over the telephone with the primary author.

To avoid bias, all observers were blind to other information about the child (e.g., level of adaptive functioning, reported behaviour problems) and the mother (e.g., stress, coping, depression levels). Once all questionnaires were returned, interviews completed, and children observed, a summary report was provided to all families. Families from the second recruitment phase also received a monetary honorarium.

Results

Exploratory Data Analysis

Sample size calculation. The G*Power 3.0.5 general power analysis program (Faul, Erdfelder, Lang, & Buchner, 2007) was used to determine sample size. To calculate the minimum required sample size using a two-group independent samples *t* test power analysis, the alpha level was set at .05, medium effect size at .40 (f^2; Cohen, 1988), and a desired statistical power of .80. A sample size of 78 was calculated. The sample size of 70 must be interpreted with caution as it fails to meet the criteria set out by the power analysis.

Assumptions

Univariate and multivariate outliers and normality. Several univariate outliers were detected on the VABS Communication Domain (2 mild outliers), Interpersonal (2 mild outliers), and Coping (4 mild, 1 extreme outlier) of the Socialization Domain as well as on the APR Purpose of

Initiations (3 mild outliers), Success of Initiations (3 mild outliers), and Pretend Play scales (5 mild, 5 extreme outliers). Skewness and kurtosis values deviated from the normal distribution for these variables. To adhere to the statistical assumption of normality and in an attempt to eliminate outliers, transformations were performed using the base-10 logarithm function. The transformations helped reduce negative and positive skewness for the VABS Socialization Domain - Interpersonal (.740 to .056) and Coping (from 1.662 to -.153), the APR Success of Initiations (from 1.468 to .664), and Pretend Play (2.675 to 1.711). It did not however, eliminate the outliers on the VABS Communication Domain or the APR Purpose of Initiations scale (both skews were within normal limits between -1.00 and 1.00). Outliers also remained on the APR Pretend Play scale despite the transformation.

A second attempt was made to correct for the unsuccessful transformations using a square root transformation. However, the procedure was also unsuccessful. In the end, the transformed values for the VABS Socialization (Interpersonal and Coping scales), and the APR Success of Initiations and Pretend Play scales were used. The Communication and Purpose of Initiations scales were left untransformed with outliers still present. A small percentage of extreme values can be expected in any data set and according to Stevens (2002), "…outliers should not necessarily be regarded as bad. As a matter of fact, it has been argued that outliers can provide some of the most interesting cases for further study" (p. 17). Screening was also conducted for the presence of multivariate outliers by computing each case's Mahalanobis distance statistic (D^2). Using the chi-square distribution with appropriate degrees of freedom equal to the number of independent variables included in the computation ($n = 9$), no D^2 were equal to or exceeded the threshold to be considered a multivariate outlier.

Linearity and Independence. Bivariate scatterplots for each combination of variables were screened for linearity. Although not perfect, all relationships appeared linear, with somewhat oval or elliptical shapes, depicting enough linearity in the relationships to proceed with analyses. Observations between participants were independent of one another as each mother completed their own questionnaire and scores were independent of all other scores.

Group Differences: Child and Parent Demographics

An independent samples *t* test and chi square tests of independence were performed to determine if differences between the autism and Down syndrome groups existed. No significant differences were found on chronological age, $t(73) = 1.12$, $p = .267$. Chi square tests for gender, ethnicity, and sibling status were also performed. Sibling status was examined because children with more exposure to typically developing children engage in more high-level social interactions (Sigman & Ruskin, 1999). Thus, children who lived with similarly-aged siblings would likely have greater exposure to other children and opportunities to practice social skills compared to children without live-in siblings. An arbitrary cut-off of 10 years of age was chosen to categorize sibling status because children are more likely to "play" with siblings within their age range. No significant differences emerged for gender, $X^2 (1, N = 75) = 1.85$, $p > .05$, Cramér's V = .16, ethnicity, $X^2 (6, N = 75) = 7.03$, $p > .05$, Cramér's V = .31, or sibling status, $X^2 (1, N = 75) = .005$, $p > .05$, Cramér's V = .008.

Group Differences: Children's Peer-Related Social Competence

To evaluate whether the mean values of peer-related social competence for children with autism differed significantly from children with Down syndrome, independent samples *t* tests were conducted. The tests were significant for emotional regulation, $t(70) = -4.13$, $p = .000$, involvement, $t(70) = -3.33$, $p = .001$, and purpose of initiations, $t(70) = -2.70$, $p = .009$. Children

with Down syndrome showed better emotional regulation (M = 31.91, SD = 3.32)[1] than children with autism (M = 28.29, SD = 3.96)[1], with a large effect size, d = .98. They also showed higher levels of participation in play (M = 26.59, SD = 4.78)[1] than children with autism (M = 22.91, SD = 4.56)[1] with a large effect size, d = .79. Finally, their social initiations with others were more advanced (M = 16.28, SD = 4.21)[1] than children with autism (M = 13.91, SD = 3.24)[1], generating a medium effect size, d = .63. Children did not differ on their success with initiations, social rules, everyday events, or pretend play.

Group Differences: Children's Socialization and Communication

To evaluate whether the mean values of receptive and expressive communication and socialization for children with autism differed from children with Down syndrome, independent samples t tests were conducted. There were no significant differences between the two groups on mean scores for receptive and expressive communication, however a significant difference for socialization (includes interpersonal relationships, play and leisure time, and coping skills) was found, $t(73)$ = -3.40, p = .001. Children with Down syndrome displayed better overall socialization (M standard score = 77.53, SD = 11.14)[2] than children with autism (M standard score = 68.88, SD = 10.83)[2]. This generated a large effect, d = .80.

Correlations: Children's Peer-Related Social Competence and Communication

For children with autism, correlations were computed between social competence and communication. Receptive communication was significantly related to success of initiations, $r(38)$ = .58, p = .000, social rules, $r(40)$ = .49, p = .001, and everyday events, $r(40)$ = .44, p = .004. Expressive communication was significantly correlated with emotional regulation, $r(40)$ = .54, p = .000, involvement, $r(40)$ = .51, p = .001, success of initiations, $r(38)$ = .67, p = .000,

social rules, $r(40) = .62$, $p = .000$, and everyday events, $r(40) = .43$, $p = .006$. See Table 1 for

correlations. Except for everyday events, all correlations were large (Cohen, 1988).

Table 1

Bivariate Correlations Between APR Subscales and VABS Communication Subscales – Autism
(n = 41)

Subscale	Receptive	Expressive
Emotional regulation	.270	**.541****
Involvement	.267	**.512****
Purpose of initiations	.211	.236
Success of initiations	**.583****	**.671****
Social rules	**.493****	**.622****
Pretend play	.027	.147
Everyday events	**.442****	**.429****

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

For children with Down syndrome receptive communication was significantly correlated

with involvement, $r(32) = .41$, $p = .019$, purpose of initiations, $r(32) = .37$, $p = .036$, social rules,

$r(31) = .48$, $p = .006$, and everyday events, $r(31) = .39$, $p = .031$. Expressive communication was

significantly correlated with involvement, $r(32) = .55$, $p = .001$, purpose of initiations, $r(32) =$

.54, $p = .002$, success of initiations, $r(26) = .50$, $p = .009$, social rules, $r(31) = .59$, $p = .000$, and

everyday events, $r(31) = .57$, $p = .001$. According to Cohen (1988), all correlations were

considered to have a moderate to large effect. See Table 2 for correlations.

Table 2

Bivariate Correlations Between APR Subscales and VABS Communication Subscales –Down Syndrome (n = 34)

Subscale	Receptive	Expressive
Emotional regulation	.257	.221
Involvement	**.413***	**.546****
Purpose of initiations	**.371***	**.538****
Success of initiations	.298	**.501****
Social rules	**.482****	**.594****
Pretend play	.199	.296
Everyday events	**.388***	**.571***

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

Correlations: Children's Peer-Related Social Competence and Parent-Related Stress

Bivariate Pearson correlations were computed between the following APR scales and parent-related stress: emotional regulation, involvement, purpose of initiations, success of initiations, social rules, pretend play, and everyday events. For the autism group no significant correlations were found for overall parent-related stress, or on any of the social competence scales. However, further analyses of the parent-related stress subscales including competence, isolation, attachment, health, role restriction, depression, and spousal support revealed significant correlations between children's pretend play and competence, $r(39) = -.41$, $p = .010$, pretend play and depression, $r(39) = -.33$, $p = .040$, and success of initiations and isolation, $r(38) = -.38$, $p = .019$. For the Down syndrome group, significant correlations were found between children's

emotional regulation and overall stress, $r(32) = -.39$, $p = .028$, competence, $r(32) = -.48$, $p = .006$, and role restriction, $r(32) = -.37$, $p = .037$.

Correlations: Children's Socialization and Parent-Related Stress

Bivariate Pearson correlations were computed between children's interpersonal relationships, play and leisure time, and coping skills and overall maternal stress as well as parent competence, isolation, attachment to child, health, role restriction, depression, and spousal support. There were no significant correlations for children's socialization and overall stress for the autism group. However, isolation was significantly correlated showing a moderate relationship with children's play and leisure time, $r(41) = -.39$, $p = .013$, and coping skills, $r(40) = -.43$, $p = .006$.

For mothers of children with Down syndrome overall parent-related stress and children's interpersonal relationship was significantly correlated, $r(34) = -.42$, $p = .014$, with a particularly strong relationship to children's coping skills, $r(32) = -.61$, $p = .000$. Children's coping skills were also significantly related to parent competence, $r(32) = -.45$, $p = .009$, isolation, $r(32) = -.44$, $p = .012$, health, $r(32) = -.44$, $p = .013$, role restriction, $r(32) = -.62$, $p = .000$, and spousal support, $r(32) = -.43$, $p = .013$. Interpersonal relationship was correlated significantly with role restriction, $r(34) = -.35$, $p = .041$, and spousal support, $r(34) = -.39$, $p = .023$. Finally, there was a moderate association between play and use of leisure time and spousal support, $r(34) = -.36$, $p = .038$. Correlations are presented in Table 3 and 4.

Table 3

Bivariate Correlations Between VABS Socialization Subscales, PSI Parent Domain Stress and Subscales – Autism (n = 41)

Subscale	Interpersonal Relations	Play and Leisure	Coping
Parent domain stress	-.045	-.165	-.191
Competence	.073	.004	-.062
Isolation	-.293	**-.385***	**-.429****
Attachment	-.184	-.120	-.234
Health	.054	-.032	-.172
Role restriction	-.036	-.251	-.110
Depression	.107	.045	.046
Spousal support	-.061	-.138	-.126

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

Table 4

Bivariate Correlations Between VABS Socialization Subscales, PSI Parent Domain Stress and Subscales – Down Syndrome (n = 34)

Subscale	Interpersonal Relations	Play and Leisure	Coping
Parent domain stress	**-.419***	-.311	**-.613****
Competence	-.215	-.144	**-.452****
Isolation	-.310	-.205	**-.440***
Attachment	-.241	-.061	-.272
Health	-.294	-.254	**-.435***
Role restriction	**-.352***	-.268	**-.622****
Depression	-.289	-.239	-.343
Spousal support	**-.388***	**-.357***	**-.432***

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

Discussion

This study is the first to explore specific aspects of peer-related social competence in two separate disability groups – children with autism and children with Down syndrome, with the intention of understanding whether and to what extent, children's social behaviours are connected to maternal stress. Before exploring links to maternal stress, children with autism were compared to children with Down syndrome on specific aspects of their social competence. In general, children with Down syndrome exhibited better emotional regulation compared to children with autism. Children with autism were less involved, less successful at getting their

peers to respond to their social bids, and showed less complexity in their peer interactions. The findings corroborate with Sigman and Ruskin (1999), who found that children with autism had more nonsocial play compared to children with Down syndrome and other DD, engaged in self-stimulatory behaviour such as shaking leaves, and spent more time alone at the periphery of the schoolyard than with others. They also found that 11 children with autism never received a social bid from their peers compared to five with Down syndrome and two with other DD.

Children with Down syndrome in the present study were also rated more favourably by their mothers than children with autism regarding how they interact with others, play and use their leisure time, and demonstrate responsibility and sensitivity toward others. Hauck, Fein, Waterhouse, and Feinstein (1995), found children with autism had poorer social interactions compared to children with intellectual disabilities (ID). They compared the social initiations of children with low functioning autism matched on language to children with ID and found greater social isolation, initiations that were more ritualistic, routinized, and developmentally poorer interactions, and overall fewer peer interactions. Children with ID made more positive initiations during free play, whereas children with autism engaged in behaviours that were deemed developmentally lower, such as only looking at another child.

While both children with autism and Down syndrome lack certain social skills that make them vulnerable to engaging with peers, children with autism are characterized by distinct impairments in social interactions (American Psychiatric Association, 2000) including less eye contact and turn taking, poorer face and emotion regulation (Sigman et al., 2006), and less likelihood of understanding social situations. Children with Down syndrome tend to be characterized as more amiable with positive moods (Hodapp, 2002). They also look longer at faces rather than objects or other events in social referencing situations with caregivers (Kasari,

Freeman, Mundy, & Sigman, 1995), and enjoy participating in social activities such as song and dance (Rosner et al., 2004). Rosner et al. (2004) compared the everyday social competence of 177 individuals with Down syndrome, Williams syndrome, and Prader-Willi syndrome and found that individuals with Down syndrome had greater overall social competence. With the exception of skill and time spent in activities, a distinct pattern showed better socialization, participation in organized social activities, behaviour with others, and job/chore performance, which likely all play a role in more successful peer relations.

Because of the established interplay between social and communication functioning (Guralnick, 1999) including play and language skills (Lewis, 2003), and the linguistic shortcomings of children with autism (Perry, Dunlap, & Black, 2007) and Down syndrome (Dykens et al., 2000) peer-related social competence and its relation to their expressive and receptive communication was examined. Receptive and expressive communication in children with autism were highly correlated to their success with peer initiations, shared understanding about social rules of ownership and turn-taking, and shared understanding about the sequence and structure of everyday scripts such as circle time or lunch.

In addition, expressive communication was positively associated with emotional regulation and involvement, such that better verbal skills resulted in better emotional regulation and increased participation that is more complex in peer interactions. For children with Down syndrome, better receptive and expressive language was linked to increased participation and more complexity in peer interactions (involvement), more sophisticated reasoning when interacting with peers (purpose of initiations), shared understanding of social rules of ownership and turn-taking, and shared understanding of the sequence and structure of everyday scripts.

Expressive communication was also significantly associated with children's ability to get peers to respond to their social interactions (success of initiations).

Sigman and Ruskin (1999) explored the correlates between language abilities (among other characteristics) and peer interactions in 3 to 6 year olds with autism, Down syndrome, and DD and also found that children with better cognitive and communication skills were more involved with their peers. Cognitive and language abilities were associated with high levels of social play, but only for children with autism and DD. Stone and Yoder (2001), also found significant links between level of play and language production at a 2-year follow up in children with autism and PDD-NOS. However, when language production was partialled out the findings were no longer significant. The findings from the study support the notion that children's social and communication skills are vital to social tasks such as social initiations, requesting desirable objects and toys, and negotiating with other children (Guralnick, 2002; Sigman & Ruskin, 1999). Communication, cognition, and behaviour problems are intricately embedded within this social process (Guralnick, 1999).

The final inquiry, and in fact impetus for the study was to explore children's social functioning in relation to maternal stress. Different facets of social competence were linked to different aspects of maternal stress. For mothers of children with autism, overall parent-related stress was not systematically associated with children's interpersonal relationships, play and use of leisure time, and coping skills, or to any peer-related social competencies. However, closer inspection of the *specific sources* of stress revealed a different picture. Social isolation in mothers of children with autism was moderately associated with children's play and leisure time, coping skills, and success of peer initiations. In other words, mothers who reported more stress because they felt secluded from family, friends, and neighbours were linked to children with

greater challenges playing and using leisure time appropriately, being responsible and sensitive to others, and getting peers to respond to their social interactions.

The link may be that mothers shy away from, actively avoid, or have few opportunities to take their children to social events such as birthday parties, or the park either because of their child's inability to play and cope well with others, or because mothers feel socially isolation. Little social participation may hinder the child's opportunity to acquire social appropriateness and may further perpetuate the deficits. Equally important, isolation may lead mothers to feel disconnected from their support systems and in turn, stressed. Parents of children with various DD reportedly arrange play experiences less often than parents of children without DD and this has been found to compromise social opportunities (Guralnick et al., 2003).

Supported by Guralnick (1997) and Baker et al. (2003), parents and children with DD often find themselves increasingly isolated from community activities and from family and community members. Successful social inclusion is especially critical for children with autism and Down syndrome given there is a tendency for these children to experience increased social withdrawal and decreased sociability in later childhood and adolescence (Dykens, Shan, Sagun, Beck, & King, 2002).

In addition, greater parenting incompetence and depressive symptoms were linked to poorer pretend play in children with autism. Children with autism have severe impairments imitating and expressing spontaneous and creative symbolic play compared to typically developing children (Jarrold, 2003). They have unusual, intense, and circumscribed interests with objects and their play is routinized, stereotyped, and nonfunctional (Perry, Dunlap, & Black, 2007; Sigman et al., 2006). Children with autism may perseverate on an activity or object at the expense of peer play. Parents who feel less competent in parenting tend to lack the skills to

manage their children or understand the way they develop (Abidin, 1995). It is plausible that mothers of children with autism felt less competent nurturing appropriate play skills in their children. Likewise, those who felt unhappy and dissatisfied with their life circumstances may not have had the psychological or physical energy to cultivate their children's play skills, as this requires intensive time, effort, and resources on the part of the caregiver (Guralnick et al., 2003).

For mothers of children with Down syndrome, overall parent-related stress was significantly associated with children's social functioning such that higher stress was related to poorer child interpersonal relationships, coping skills, and emotional regulation. In a national survey of families, Virji-Babul et al. (2004) found that a prime concern for parents of children with Down syndrome of school age was their child's social challenges and deficits making and maintaining meaningful friendships. The authors suggest that such challenges raise questions about the influence of children's social competence to overall family well-being and quality of life. The finding was also supported by Siklos (2002), who identified 'having friends of their own' as one of the greatest needs parents have for their children with Down syndrome.

Some researchers have posited that parents of children with Down syndrome tend to experience a 'Down syndrome advantage' with less stress and better psychological outcomes compared to parents of children with other DD due to their child's characteristics. While children with Down syndrome outperformed children with autism on social competence in this study, the copious associations between stress and social competence cannot be ignored in the mothers of children with Down syndrome. Specifically, poorer child coping was linked to greater parenting incompetence, isolation, health problems, role restriction, and problems with spousal support. Coping skills in children include having appropriate manners, apologizing, showing responsibility and sensitivity toward others, and transitioning and controlling impulses (Sparrow

et al., 2005). Such an association is not unexpected if one considers the extreme obstinacy, oppositional defiance, conduct problems, and attention difficulties that some children with Down syndrome display (Dykens et al., 2000).

Mothers who felt restricted in the parenting role and unsupported by a spouse also had children with poorer interpersonal relations. Lack of spousal support, particularly in managing the child was also associated with children's difficulties in playing and using leisure time. Finally, poorer perceptions of parenting competence and feeling restricted in their freedom were linked to children who had poorer emotional regulation. Deficits in social behaviours with others can indeed, lead mothers to experience various stressors.

Thus, it appears that besides the commonly associated affectionate and upbeat personalities, children with Down syndrome also display difficult temperamental styles, attention problems, and disruptive behaviour (Dykens & Hodapp, 2001; Lovering & Percy, 2007). Approximately one third of mothers reported anecdotally that their children were stubborn, impulsive, aggressive, moody, and anxious and that these behaviours were a basis for their family stress (Poehlmann, Clements, Abbeduto, & Farsad, 2005). It seems that mothers of children with Down syndrome feel frustrated and confined in the parenting role, unsupported from their spouses in managing the child, and incompetent in parenting, attesting to the notion that stressors are also present in mothers whose children have generally positive dispositions.

The limitations of the study must be considered. First, the observation measure used in this study is nonstandardized and typically used for clinical and educational purposes. The APR is also designed specifically for children with *mild* DD (Guralnick, 2003), thus some of the items that require advanced skills related to pretend play for example, were difficult to rate for our

children. Even so, the APR is the most appropriate tool and a first-hand account of the child's

peer relations, which is an advantage that cannot be gleaned from parent or teacher reports.

Second, many children spent a large portion of their playtime in one-to-one interaction with

their educational assistants. Similar to Sigman and Ruskin's findings (1999), children in this

study spent more time with their assistants than with peers during unstructured and structured

playtime. It is possible that spontaneous social interactions were hampered unintentionally.

Whether the assistants facilitated the interaction, or the company of an adult was simply

preferred by the child is difficult to speculate. While effort was made to observe children

engaging with their peers, adult interactions could not be controlled for entirely and thus may

have affected the ratings.

Third, children were observed in diverse settings, which may have affected the amount, type,

and quality of social interactions observed. Specialized settings were facilitated, structured,

monitored, and controlled, and allowed children few opportunities to interact with typically

developing peers. The setting was in contrast to inclusive settings. To control for the variability,

Sigman and Ruskin (1999) rated the level of structure (e.g., playground and classroom) using a

five-point scale and examined whether there were significant differences regarding children's

play structure. Controlling for the 'setting' may have yielded different outcomes in this study.

Finally, children were not matched on a case-by-case basis during participant selection,

which is a central methodological consideration for observing behaviours in children with DD

and in comparative research in general (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). To

control for differences, Seltzer et al. (2004) suggest matching children and parents on a particular

variable such as gender, mental or chronological age, or ethnicity, or statistically controlling for

them. The participant selection procedure did not allow for matching children on these variables, but statistical tests of differences were performed.

Findings from the study must be viewed as preliminary with respect to generalizability. Nonetheless, implications for practice are offered, as are directions for future research. According to Burack, Iarocci, Bowler, and Mottron (2002), social competence should be an overarching goal of EI because it considers the multiple domains of children's functioning as a dynamic, integrated, and interdependent system. Based on the findings, children's communication and social skills are intricately intertwined therefore professionals in EI need to nurture them together. Service providers might apply a top down approach to EI, which is transdisciplinary, holistic, and integrated versus a bottom-up approach (Iarocci et al., 2006). A top down approach may include speech-language pathologists, behaviour specialists, and educators jointly using domain-specific expertise to optimize the child's functioning across domains of functioning (Iarocci et al., 2006). Likewise, since social behaviours are first nurtured through parent-child interactions, EI professionals can encourage parents to actively engage in social-communicative activities so skills can be generalized to peers (Guralnick, 1999; Virji-Babul, Hovorka, & Jobling, 2006).

Children with autism and Down syndrome also have distinctive social weaknesses that relate to different stressors in mothers. Their unique profiles are consistent with a developmental approach to DD wherein differentiating the organic category of different etiologies helps identify individual profiles and leads to targeted interventions (Hodapp & Burack, 2006). For mothers of children with autism, tailored interventions might focus on minimizing social isolation through parent support groups. Because children with autism do not naturally acquire social abilities, targeted interventions might include facilitated and integrated playgroups whereby the mission is

to cultivate children's social needs. Based on the findings in this study, these needs would include increasing their peer interactions, using their play and leisure time appropriately, and learning to cope in social situations. The overriding objectives of integrated playgroups are to reach the child's potential, have fun, and develop friendships (http://www.yaldei.org/integratedPlayGroups.asp).

Based on the current findings targeted interventions would be tailored differently for mothers of children with Down syndrome. These mothers reported many stressors that were related to children's limited coping skills. Interventions might for example set out to teach mothers how to identify those coping behaviours that trigger stress (e.g., controlling impulses, manners, transitioning from one activity to the next). More importantly, mothers could learn new ways to foster good coping skills in their children so they become acquired behaviours. As well, it would be beneficial to give mothers the tools to communicate the importance of mutual support in childcare management to their partners, which could significantly reduce stress and in turn, foster better family functioning. Currently, interventions accessed by parents of children with Down syndrome such as infant development programs tend to focus on the child and are designed *generally*, for children with various DD in mind (Guralnick, 2000 as cited in Iarocci, Yager, Rombough, & McLaughlin, 2000). Iarocci et al. (2008) contend that EI models that bear in mind the goals of enhancing children's social competence and familial well-being are more attuned to the goals and needs of families.

In general, formal care such as organized playgroups and parent support groups can offer opportune practice for children to develop social and communication skills and simultaneously, for mothers to share their experiences with other parents who may also feel strained in the parenting role. Although formal services can equally benefit mothers of children with autism and

Down syndrome, the present findings offer professionals the knowledge that mothers and children have unique parenting and social characteristics that necessitate specialized services. Clearly, a replication of the findings is needed before changes to EI service delivery are considered. Nonetheless, the differentiations of two mother groups and their unique needs are underscored in this study. Simultaneous nurturance of children's social competence and maternal well-being is a shrewd public investment that has great potential payoffs for families, children, and service providers.

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Footnotes

[1] The minimum and maximum raw score a child can obtain on the APR subscales was calculated by multiplying the number of items within that subscale with the lowest (i.e., 1) and highest (i.e., 4) score on the likert scale. The minimum and maximum values are as follows, respectively: *Level of Involvement* (11 and 44), *Purpose of Initiations* (8 and 32), *Success of Initiations* (6 and 24), *Emotional Regulation* (10 and 40), *Social Rules* (4 and 16), *Pretend Play* (5 and 20), and *Everyday Events* (3 and 12). Mean scores in the analyses should be interpreted with these values in mind.

[2]The VABS uses standard scores with a mean of 100 and a standard deviation of 15 to interpret the raw scores for an individual's level of functioning on the adaptive behaviour domains (of specific interest here is the Socialization domain). The standard score is based on an individual's performance as it relates to a same-aged reference group. The following standard score ranges help contextualize the corresponding adaptive level of an individual's socialization: 130 and above (high adaptive level or 2 SDs from the mean); 115-129 (moderately high or 1.0-2.0 SDs from the mean); 86-114 (adequate or -1.0-1.0 SDs from the mean); 71-85 (moderately low or -2.0 to -1.0 SDs from the mean); and 70 and below (low or -2.0 SDs from the mean). The mean standard score of 77.53 (*SD* = 11.14) found in this study falls within the moderately low adaptive range, and the mean standard score of 68.88 (*SD* = 10.83) falls within the low adaptive range.

CHAPTER 5

Conclusion

Summary of Findings and Original Contributions to Knowledge

Using McCubbin and Patterson's (1983) double ABCX model of adjustment and adaptation and components of Lazarus (1999) and Lazarus & Folkman's (1984) stress and coping model as guides, the objective of this research program was to understand the influence of multiple child and parent factors on the psychological well-being of parents of children with autism and Down syndrome. Psychological well-being was operationalized in this research (study 1) using symptoms of depression as an outcome. Perceived stress was used both as a predictor and variable of interest (studies 1-3). Stress and depression are multifaceted and real-world phenomena for parents raising children with DD. Only by investigating the prime factors related to children's characteristics, family coping resources, and negative and positive appraisals made by parents, can we fully know about the psychological functioning of parents. In the concluding chapter, I present a summary of the study findings as well as original contributions to knowledge, implications for practice, and future research directions.

In Article 1, maternal depression was predicted by a combined set of child and parent variables of which parent-related stress and acquiring informal social support made the greatest contribution. As well, a significant proportion of mothers (60%) met the criteria for clinical levels of depressive symptoms. In corroboration with Feldman et al. (2007), mothers who met clinical thresholds reported significantly poorer family coping and poorer abilities in acquiring informal social support such as sharing concerns with close friends when they face difficulties. When mothers were categorized by high or low depression status there were no group differences for child-related stress or positive appraisals of the child's DD.

Study 1 is the first of its kind to evaluate the key components that McCubbin and Patterson (1984) and Lazarus and Folkman (1984) contend are critical for delineating family well-being in mothers of young children with autism and Down syndrome. In effect, taking into account multiple variables moves beyond simple independent effects and towards an understanding of maternal depressive symptoms as a multifaceted issue. Such an approach is imperative given that depression do not materialize in isolation. It is also the first study to measure the extent to which mothers of children with autism and Down syndrome perceive the behaviours of their health care professionals to actually occur in a family-centered way, which to date, has predominantly been examined in families of children with nonprogressive neurodevelopmental disorders such as cerebral palsy, given their ongoing interaction with health care providers (e.g., King, King, Rosenbaum, & Goffin, 1999). Although the behaviour of health care was not a significant predictor of depressive symptoms, including it in the model acknowledges family-centeredness as a prime aspect of maternal well-being and deems the beliefs that mothers hold to be of great value. Indeed, the high rate of maternal depressive symptoms and the variables that predicted it, calls attention to the need for continued inquiry about other potentially revealing child, parent, and service-related factors.

In Article 2, differences between maternal and paternal stressors were examined in two prevalent disability groups. Mothers reported significantly higher total stress and stress related to depression, role restriction, and spousal support compared to fathers. When mothers and fathers were further differentiated by child diagnosis, the same differences for parent-related stress appeared, with the exception of spousal support. Mothers of children with autism were the most adversely stressed, overall. They also attributed their feelings of depression and role restriction and their child's demanding behaviour, inability to positively reinforce them, and negative mood

as the source of stress and potential dysfunction in the parent-child system. The results from this study also lead to the conclusion that fathers cannot be ignored as 60% of them reported clinical levels of stress, pinpointing the source of stress to be the child's challenging qualities.

Researchers have compared stress in different parent groups including parents of children of mixed DD to parents of children with other special health needs (e.g., Gupta, 2007); parents of children with Down syndrome to parents of children with typically developing children (e.g., Roach, Orsmond, & Barratt, 1999); and mothers of children with autism to mothers of children with Down syndrome (e.g., Pisula, 2007). However, study 2 is an original contribution to knowledge because both mothers and fathers of children with autism and Down syndrome were evaluated and compared, evaluating the precise sources of child- and parent-related stress. The findings provide new insight on the distinct psychological vulnerabilities of mothers and fathers. Highlighting their unique profiles can lead professionals to ensure that interventions are targeted. Two lines of family research are also supported based on the findings namely, an etiology-based approach to understanding how the direct effects of a child's etiology have indirect effects on parents (Hodapp, 1999) and father well-being (Blacher & Hatton, 2007).

Indeed, the qualities exhibited by children in study 2 were significant sources of stress for mothers and fathers. To explore how other important aspects of children's behaviours might contribute to our knowledge about parents, the relationship between children's peer-related social behaviours and parent-related stress was explored in Article 3. Children with Down syndrome had better peer-related social competence compared to children with autism. Children's social competence and parent-related stress were significantly related when separate analyses were performed for each diagnostic group. However, the sources of stress and specific social competencies differed for each group. To illustrate, mothers of children with autism who

did not feel competent in the parenting role and felt isolated and depressed had children who were poorer at pretend play, social initiations, play and use of leisure, and coping. Mothers of children with Down syndrome who felt incompetent, isolated, physically unhealthy, restricted in the parenting role, and unsupported by their spouses were linked to children with poorer coping, emotional regulation, interpersonal relations, and play and use of leisure time.

The findings from study 3 make an original contribution to knowledge providing evidence to suggest that unique aspects of children's peer-related social competence are associated with unique aspects of parent-related stress, both for mothers of children with autism and mothers of children with Down syndrome. Conducting separate analyses on mothers of children with autism and Down syndrome indexed the variance shared between children's unique social characteristics and mothers unique parenting functions. Identifying the significant relationships between mothers and their children underscores that families of children with autism and Down syndrome have distinctive strengths and weaknesses; using separate lenses helps highlight their characteristics and in turn, can lead to targeted interventions (Hodapp & Burack, 2006).

Implications for Practice

Based on the findings, the larger goal for practice is to consider the unique strengths and needs that parents and their children with DD embody. Family service providers in particular, have the ability to re-evaluate the psychosocial, educational, and health-related services that are currently offered (Trute & Hiebert-Murphy, 2002). Collectively, the findings support services that are individualized to meet the needs of parents. Individualization of services for families of children with DD is a critical component of family-centeredness and considered best practice (King et al., 1999; King Teplicky, King, & Rosenbaum, 2004).

Based on the findings of the research program, individualized services might include behavioural parent training for parents who found their children's behaviours demanding, or who did not feel well-equipped in the parenting role; parent support groups for mothers who felt socially isolated from their family and community; couple therapy for those who felt unsupported by their spouse in managing childcare; and psychotherapy for mothers who experienced persistent dissatisfaction with their self and life circumstances that manifested into clinical levels of depressed symptoms.

Parents of children with autism have indicated that specific services such as support groups are especially beneficial. Support groups facilitate sharing not just of difficulties, but also of accomplishments (Luther, Canham, & Young-Cureton, 2005). One mother reported, "The more I am associated with other parents, the better I feel" (Hutton & Caron, 2005, p. 186). Likewise, individualized services can address issues related to low self-esteem by teaching mothers how to reinforce their self-image. Enhancing self-esteem is critical for mothers who identified *themselves* as the source of the problem because this thinking pattern can lead to dysfunctions of the self and the parent-child system. Individualized and tailored programming for mothers who reported greater social isolation could consist of professionals helping to expand their social networks with family, friends, and the local community to buffer the effects of the remoteness.

Being cognizant of individual strengths and vulnerabilities ensures that all parents and children are serviced according to their varying needs. Compared to mothers of children with Down syndrome and other father groups, mothers of children with autism reported higher rates of child- and parent-related stress and greater associations between elevated stress and depressive symptoms. Such psychological difficulties are a clear indication that more immediate attention is required on the part of mental health providers. Hastings et al. (2005), suggest that practitioners

develop interventions where parents of children with autism utilize more adaptive coping strategies.

Irrespective of the autism diagnosis, mothers in general experience many child- and parent-related stressors. Likewise, 60% of all fathers experienced clinical levels of stress due to their child's challenging qualities. Recognizing the unique sources of stress for mothers and fathers can lead to tailored services and better outcomes (Cuskelly, Chant, & Hayes, 2004; McCarthy, Cuskelly, Kraayenoord, & Cohen, 2006). Identifying challenges that vary across parent groups can contribute significantly to understanding their differential experiences and plan services that are disability-specific (Abbeduto et al., 2004). The findings underscore the need to consider that in addition to mothers of children with autism, other family members and disability groups experience psychological problems that require professional attention.

Overall, the findings in the present research program offer practitioners a wealth of information that can be used to design interventions that help reduce specific aspects of psychological stress and improve well-being (Johnston et al., 2003; Lessenberry & Rehfeldt, 2004). Service providers who pay special attention to the unique characteristics of the family are more responsive and supportive, help parents manage their stress better (Warfield, Hauser-Cram, Krauss, Shonkoff, & Upshur, 2000), and view their clients' needs on a continuing basis. Such qualities are fundamental to a family-centered approach and are considered best practice in EI.

Implications for Policy

The findings generated from the current program of research can also have a considerable influence on Canadian early intervention (EI) policy. Specifically, the research presented is tied to a National initiative entitled *A Dynamic Assessment of Early Intervention Models in Children with Developmental Delays: Creating a Paradigm Shift in EI Childhood Intervention Policy and*

Practice. The ultimate goal of the initiative is to implement an action-oriented National blueprint to change current Canadian EI policy and practice for children at risk for delays and established DD, and their families (Sladeczek, 2009). The findings underscore that specific families and their children have unique psychological strengths and vulnerabilities that must be considered when allocating funding and providing supports and services. In conjunction with other recent findings from the larger NEIRI project, policymakers will be in a better position to understand where precise changes are needed.

Directions for Future Research

Based on past research and the present findings, much has been learned about the well-being of parents of children with autism and Down syndrome within a stress and coping paradigm. Still, future directions for research in the area remain fertile. First, a focus on father well-being needs to become an even greater priority than it currently is. Fathers are an integral part of most families and although different, their needs cannot be considered less important than the needs of mothers. In this research, only their perceptions of stress based on child qualities and parenting functions were measured, providing a glimpse of the overall picture of well-being. Exploring other facets related to their well-being including coping resources, the positive and negative feelings they have towards their child's disability, and views about their child's characteristics would be equally informative to theories on family adjustment and coping (Lazarus, 1999; Lazarus & Folkman, 1984; McCubbin & Patterson, 1983) and real-world practice. In light of the different reactions that mothers and fathers of children with autism and Down syndrome reported in this research, future researchers might also consider how children with autism or Down syndrome influence their siblings' well-being and the challenges and rewards of such an experience (e.g., Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).

A second research priority would be to cast the research net wider, examining the psychological needs of parents from diverse backgrounds. The parents in this research were a predominantly homogeneous group – married, of European descent, well-educated, and living largely in metropolitan cities. To gain a better insight about a larger scope of parents and to be able to generalize the findings to Canadian families, researchers need to include parents in same-sex relationships, single parents, and those from different cultures (Hodapp, 2007), neighbourhoods, levels of education, and socioeconomic conditions.

Moreover, future researchers would benefit from adopting a more *balanced* view of the family that considers the positive experiences of parenting children with DD (Blacher & Baker, 2007). Besides family coping, only one measure was used to assess positive aspects of parenting in this research. Indeed, it cannot be denied that families of children with DD have negative experiences however; these outcomes and beliefs are not necessarily everyone's reality. Over the last decade, there has been an emerging trend focusing on the positive contributions of rearing children with various DD (e.g., Blacher & Baker, 2007; Hastings, Beck, & Hill, 2005; Hastings & Taunt, 2002). Hodapp and Ly (2005) recognize this as a "movement from more pathological and less differentiated views to more stress and coping perspectives" (p. 197).

Ultimately, more sophisticated, longitudinal models that examine psychological well-being should be a priority given that families of children with autism and Down syndrome do not exist within a vacuum and are constantly changing (Hodapp & Burack, 2006). While assessing stress and depression at multiple times was beyond the scope of this research program, it is acknowledged that psychological reactions are not static and vary from one developmental period to the next. For example, parents may feel heightened distress around the time of their child's diagnosis (i.e., birth, or later in the case of autism), and less so when children are older

and when parents have had time to adjust to their family circumstances. Longitudinal models reveal different patterns of well-being and can inform about causal and bidirectional relationships that Sameroff and Chandler (1975) contend parents and children with DD have on each other.

Concluding Remarks

The psychological well-being of parents of children with autism and Down syndrome is a multifaceted phenomenon; any number of child and parent factors can significantly influence parental reactions. In this program of research, child- and parent-related stress and psychological symptoms of depression were studied given that excessive stressors and depressed feelings can jeopardize a parent's personal health and their ability to care for their child in optimal ways (Lessenberry & Rehfeldt, 2004). A healthy, enriching, and stimulating context is where children with autism and Down syndrome flourish. If psychological disruptions arise in parents the very essence of development can be drastically compromised (Guralnick, 2005; Shonkoff & Phillips, 2000). Parents who are afforded with appropriate and timely supports and services have a greater chance of achieving success in the parenting role. Early intervention that is targeted to children and their parents is a wise public investment and the catalyst to set in motion, positive and long-term health outcomes for the entire family.

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PARENTAL CONSENT FOR PARTICIPATION IN THE CANADIAN EARLY INTERVENTION PROJECT

_____ I agree to participate in the study conducted by Dr. Ingrid E. Sladeczek, Mr. Daniel Amar, and Ms. Nancy Miodrag.

- I understand the purpose of the study and know about the benefits and no foreseen risks that this research project entails.

- I understand that I am free to withdraw at any time from the study without penalty or prejudice.

- I understand how confidentiality will be maintained during this project.

- I understand the anticipated uses of data, especially with respect to publication, communication and dissemination of results.

Name of Child
(Please Print)   _____

Name of Parent or
Guardian (Please Print)   _____

Signature of Parent or
Legal Guardian   _____

Date   _____