

Exploring parenting factors as possible predictors and moderators of
mothers' cognitive appraisals of the family impact of raising their child with a neurodisability.

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November 2017

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree
of Doctor of Philosophy in School and Applied Child Psychology

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Abstract

Families raising a child with a neurodisability face challenges in various areas of their lives due to caregiving demands. When compared to typically-developing children of the same age, children with a neurodisability have multiple needs related to their functional and behavioural challenges. Many parents are nonetheless able to appraise the positive impact of raising their child along with the negative impact. The construct of cognitive appraisal of the family impact of childhood disability refers to parents' subjective interpretation of this phenomenon and serves as the main construct of interest in this study. Given the presence of difficult behaviour and health complexity in children with a neurodisability, whether factors related to mothers' experience of their parenting, such as their parenting behaviours and attributions, could affect their cognitive appraisals of the family impact were assessed. The overall aim of the present study was to learn about the experiences of families with a child with a neurodisability and to gather new knowledge to develop improved intervention for improving family outcomes. The specific research questions were to investigate whether parenting factors were predictive of, and moderated mothers' formation of positive and negative cognitive appraisals of the family impact of caring for their child with a neurodisability. The first set of hypotheses addressed whether certain child (i.e., difficult behaviour and health complexity) and parenting (i.e., parenting behaviours and parent attributions) characteristics predicted the outcome variables, mothers' positive and negative cognitive appraisals of the family impact of child neurodisability. The second set of hypotheses addressed whether the relationship between the child's difficult behaviour and mothers' cognitive appraisals changed (i.e., was moderated) depending on the parenting factors (i.e., parenting behaviours and parent attributions). For example, did the relationship between the child's difficult behaviour and mothers' negative cognitive appraisals

change depending on their level of hostile/ineffective parenting behaviour? This study was conducted as a secondary data analysis of the CIHR funded Parenting Matters! study dataset. The sample consisted of 196 Canadian mothers with a child with a neurodisability age 4 to 12 years old, and were recruited from major health centers in Quebec, Ontario and Alberta. The first set of hypotheses were analyzed using two hierarchical multiple regressions, and the second set, via a moderation analysis. The variance in positive cognitive appraisal was predicted by three variables and the relationships were inverse; household income, child's age at diagnosis, and parent attribution of adult control over failure. Child health complexity predicted negative cognitive appraisal and the relationship was direct. None of the parenting behaviour variables nor parenting attribution variables moderated the relationship between the child's difficult behaviour and mothers' negative or positive cognitive appraisals. The findings have increased the knowledge of the factors that contribute to the cognitive appraisal of the family impact of raising a child with a neurodisability. The discussion is focused on explaining the results within a family context, and the implications for families raising a child with a neurodisability.

Résumé

Les familles avec des enfants souffrant d'un handicap neurologique rencontrent des difficultés dans divers domaines de leur vie en raison des exigences de soins. De nombreux enfants avec un handicap neurologique ont des besoins multiples relatifs à des problèmes comportementaux et des problèmes de santé complexes, en comparaison avec des enfants typiques du même âge. Malgré ces obstacles, de nombreux parents sont capables d'évaluer l'impact positif de l'éducation de leur enfant parallèlement à l'impact négatif. La formation de l'appréciation cognitive de l'impact familial du handicap d'un enfant est l'interprétation subjective par les parents de leur situation. Elle a été explorée dans le but de comprendre comment les familles s'adaptent à leur enfant handicapé. L'appréciation cognitive a été reliée à des résultats positifs dans les familles avec un enfant handicapé; une plus grande quantité d'appréciation cognitive positive, et moins d'appréciation cognitive négative, est reliée à un bien-être familial supérieur. Étant donnée la présence de comportements difficiles et de problèmes de santé chez les enfants avec un handicap neurologique, nous avons évalué si les facteurs liés à la parentalité pouvaient affecter l'appréciation cognitive de l'impact familial par les parents. Le but de cette étude était d'investiguer les expériences des familles ayant un enfant avec un handicap neurologique et de réunir de nouvelles connaissances pour développer des interventions. L'objectif était d'investiguer si les facteurs de parentalité prédisent et modèrent la formation d'une appréciation cognitive positive ou négative par la mère de l'impact familial des soins nécessaires à un enfant avec un handicap neurologique. L'objectif principal de cette étude était de savoir si certains facteurs prédisent une appréciation cognitive positive ou négative par la mère de l'impact familial des soins à un enfant avec un handicap neurologique. Le second objectif de cette étude était de vérifier pour qui la relation entre le comportement difficile de l'enfant et l'appréciation cognitive de la mère changeait en fonction d'une autre variable, les facteurs de parentalité (c.-à-

d. les comportements parentaux et attributions parentales). Par exemple, est-ce que la relation entre le comportement difficile de l'enfant et l'appréciation cognitive de la mère change en fonction des comportements parentaux hostiles/inefficaces? Cette étude constituait une analyse secondaire de la base de données Parenting Matters!. L'échantillon était constitué de 196 mères Canadiennes ayant un enfant avec un handicap neurologique entre 4 et 12 ans, recrutées dans des centres médicaux majeurs au Québec, en Ontario et en Alberta. Le premier objectif a été analysé à l'aide de deux régressions hiérarchiques multiples, et le second via une analyse de modération. Les résultats du premier objectif ont montré que la variance de l'appréciation cognitive positive était prédite par le revenu du foyer, l'âge de l'enfant au diagnostic, et le contrôle de l'adulte en cas d'échec. La relation était inverse entre l'appréciation cognitive positive et le revenu du foyer, l'âge de l'enfant au diagnostic, et le contrôle de l'adulte en cas d'échec. La variance de l'appréciation négative était expliquée par la complexité médicale de l'enfant, une complexité médicale plus élevée prédisant une plus grande appréciation cognitive négative. Les résultats du second objectif ont montré que ni les variables de comportements parentaux, ni les variables d'attributions parentales, n'étaient des modérateurs de la relation entre les difficultés comportementales de l'enfant et l'appréciation cognitive positive ou négative de la mère. Certaines de nos hypothèses étaient partiellement appuyées, et les résultats ont augmenté les connaissances sur les facteurs qui contribuent à l'impact familial de l'éducation d'un enfant avec un handicap neurologique. La discussion se concentre sur l'explication des résultats dans le contexte familial, et les implications pour les familles élevant un enfant avec un handicap neurologique.

Acknowledgements

Reflecting back on this dissertation journey, there are many people to thank that have supported me. I would first and foremost like to thank in no particular order, my supervisors, Dr. Lucyna Lach and Dr. Armando Bertone, for their unwavering support throughout my dissertation journey. Lucy, thank you for your guidance, insight, patience, flexibility, and your time. I look up to you as a role model - your dedication and commitment to your work with families has motivated me throughout the dissertation process and will continue to motivate me as I begin my career. Thank you for your generosity in giving me the opportunity to work with the Parenting Matters! study. Armando, thank you for taking me under your wing and offering me your support when I needed it most. Your enthusiasm and optimism throughout this process has always been uplifting and motivating. Thank you for your steadfast commitment to supporting me and for standing by me in achieving this goal; without your efforts it would not have been possible.

I would like to thank the members of the Parenting Matters! team who worked on the study since its' inception, and the staff at the Centre for Research on Children and Families, who I consulted with throughout this project. I am grateful and thankful to the families that participated in the Parenting Matters! study - with your efforts, we are continuously learning about the unique experiences of raising a child with a neurodisability.

Thank you to the numerous professors at McGill that inspired me throughout graduate school. Many of your teachings have and will stay with me throughout my career. Thank you for the assistance of Dr. James Hayton, your mentorship and wisdom were invaluable in writing this dissertation, and to Dr. Rachel MacNair, thank you for your strategic and timely support regarding statistics and editing. To the members of Phinished, thank you for providing me with a

Ph.D. community as I journeyed through this degree. To the number of friends who took this journey ahead of me, thank you for showing me it could be done.

To my immediate and extended family, thank you for your support throughout this process. Thank you to my mother and father, for keeping me grounded. Your inspiring and motivating words always lifted me. To my sisters, thank you for helping me in creative ways whenever it was needed. To my Grams, your love for school always drove me to dedicate myself fully to my education. Thank you for your steady encouragement and for believing in me. I am forever grateful.

Last but certainly not least, I extend my deepest thanks to my husband, Matei, for standing by me throughout my education. Your patience, kindness, good humor and absolute belief in my abilities have motivated me throughout my years in university and especially during my doctoral degree. I am indebted to you for your consistent and unwavering encouragement and support. Finally, to Clara, thank you for motivating me and deepening my understanding of what it means to be a parent.

My degree was completed with support from the Social Sciences and Humanities Research Council of Canada (SSHRC).

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Chapter 1: Introduction

In the neurodisability literature, there is an unequivocal narrative documenting that parents' well-being is compromised in families with a child with a disability. The tasks that parents who are raising a child with a disability face are that much more daunting, particularly when considering that parents experience significantly higher stress levels than those who are raising and providing care to a typically developing child (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Estes, Hus, & Elder, 2011; Hayes & Watson, 2013). The additional burden of care is present in various areas, including but not limited to effects on the relationship between the parents, finances, employment opportunities as well as mental and physical health in families with a child with a variety of neurodisabilities (Bourke-Taylor et al., 2012; Grein & Glidden, 2015; Lach et al., 2009; Turcotte, 2013). To begin, the non-categorical approach is presented and the challenges in caring for a child with a neurodisability follow.

Researchers are increasingly starting to adopt a non-categorical approach to describe neurodisability, where children with a variety of disabilities are included in a particular study. Research using a non-categorical approach examines issues that are common to children with various neurodevelopmental disorders, thereby being relevant to a greater number of individuals (e.g., Etherington et al., 2016; Gillberg, 2010; Miller, Mâsse, Shen, Schiariti, & Roxborough, 2013; Miller, Shen, & Mâsse, 2016). Thus, the research studies covered in this introduction pertain to children with various neurodevelopmental disorders.

There is a significant caregiving burden to Canadian caregivers as indicated by data provided by Statistics Canada (Turcotte, 2013). According to these data, 28% of individuals 15 years and older provided care to a relative or friend with a chronic health condition in 2012. Five percent of these individuals were parents providing care to their own child with a long-term

health problem or disability. Of this five percent, the main reason for providing care was due to their child's mental illness (23%); the second most common reason was to provide care for their child with a developmental disorder (22%); and the third most common reason was to provide care for their child with a neurological disease (14%). These parents spend a substantial amount of time caring for their child; 29% of them reported spending 30 hours or more per week providing care.

One of the challenges to the family's life is the toll that caregiving takes on the relationship between the parents, or the couple relationship. The effects on the couple relationship were evident in a longitudinal study of mothers raising their child with a disability conducted over a 23-year span in the USA, in which mother, child and family characteristics were investigated (Grein & Glidden, 2015). The participants were 85 mothers and their child with a disability, which included Down syndrome (47%), cerebral palsy (9.5%), and a variety of other disorders including fetal alcohol syndrome, other chromosomal abnormalities, and intellectual disability. Mothers were increasingly separated or divorced as time passed, with 89% married when children were a mean age of 7 years, and 59.5% were married when children were approximately 26 years-old (Grein & Glidden, 2015). There was a 29.5% decrease in married participants over the time period of the study, from 1988 to 2011 (Grein & Glidden, 2015). The percentage of divorcing couples highlights their struggle to maintain their relationship while caring for a child with a disability. The couple relationship is one aspect of parents' lives that is affected; consequences to their finances and employment are also present.

In addition to the couple relationship, there is also a financial burden that comes with providing care, in that parents raising their child with a neurodisability may not be able to maintain gainful employment and afford the expenses relating to meeting the child's needs. For

example, in the 2012 Canadian General Social Survey on Caregiving and Care Receiving, 76% of parents of children with a long-term health problem or disability reported at least 500 dollars of out-of-pocket expenses and approximately 50% spent more than 2000 dollars over the past year. Twenty-eight percent of the parents reported financial hardship due to these expenses, while 10 to 12% have had to borrow money from others, including relatives or friends, or take out loans from a financial institution. Parents' caregiving responsibilities for their child with a long-term health problem or disability interfered with their professional responsibilities as well. Approximately 50% of the parents reported lost productivity due to arriving late to work, needing to leave early, and/or taking three or more consecutive days off. For 34% of the parents, their caregiving responsibilities had prevented them from being employed (Turcotte, 2013). Productivity loss for caregivers of children with autism is estimated at \$18,000 dollars per year in the United States (Buescher, Cidav, Knapp, Mandell, 2014). Indeed, in a study of families that have a child with autism, families had an annual loss of household income of 14% after controlling for a number of factors, including parental age, parental education, minority ethnicity, type of family, and location of household. Families with a child with another type of disability, including learning disability, intellectual disability, speech/language delay, and other disabilities, had an annual loss of 2% of their household income (Montes & Halterman, 2008). In a study of economic consequences to 3,183 families caring for their child 5 to 14 years old with a mild, moderate, severe or very severe disability in Canada, parents experienced opportunity costs. In the families, mothers were reported to be most affected by work-related issues (68%) and fathers were most affected in 10.9% of families. Some of these issues included that they worked fewer hours, changed hours, did not take a job, quit or turned down a promotion. Families with a child with a higher severity of disability experienced more labour market costs

than those with a milder form of disability, as did those with a child with a chronic condition or with a condition with an earlier onset. For example, the probability of a parent not taking a job was 36.1% more likely in families with child with a very severe disability in comparison to a mild disability. Parents with a child with a chronic condition, such as spina bifida, were 5% more likely to turn down a promotion and 14% more likely to work fewer hours compared to other conditions (Burton & Phipps, 2009). Many parents' finances and employment opportunities are significantly affected; and for some, so is their mental and physical health.

Given the additional stressors faced by these families, the empirical literature further documents that parents caring for a child with a neurodisability also suffer consequences to their mental and physical health. Their health tends to vary depending on the severity of their child's disability. In a group of mothers caring for a child with a range of disabilities, their mental health was two standard deviations below the average range and considered poor (Bourke-Taylor et al., 2012). Similarly, mothers with a child with autism spectrum disorder were more likely to develop and suffer from an emotional condition, such as anxiety or depression (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). In families with a child with a developmental disability, mothers' symptoms of depression were predicted by how severe their child's cognitive impairment was, with higher severity predicting greater number of symptoms (Grein & Glidden, 2015).

The stress of meeting the child's caregiving needs can be more severe on parents' health if the child has a neurodevelopmental disorder and behaviour problems, such as those defined by externalizing or internalizing behaviour. This has been demonstrated in a Canadian study by Lach and colleagues (2009) in which caregivers with children with neurodevelopmental disorders and externalizing behaviour problems had poorer mental and physical health. In terms

of mental health, caregivers with children with a disability that was more complex, such as having a neurodisability and externalizing behaviour, reported more depressive symptoms than caregivers with children with neither a neurodisability nor externalizing behaviour. In addition, physical health was poorer for caregivers of children with both a neurodevelopmental disability and an externalizing behaviour compared to caregivers with a child with neither a neurodisability nor externalizing behaviour condition. They had more chronic health conditions including back problems, migraines, asthma, arthritis, and other chronic conditions (Lach et al., 2009). To conclude, there is significant evidence that caregivers of children with a variety of neurodisabilities suffer to a greater extent from mental health difficulties, such as anxiety and depression, and have poorer physical health than other caregivers.

Despite the many consequences of the caregiving burdens experienced by parents raising a child with a neurodisability, many parents are nonetheless able to appreciate and identify positive aspects of their experience. This positive dimension can be understood by considering the concept of resilience, and how it applies to the situation that these caregivers are living through. Resilience, as defined by Luthar (2006), is an individual's ability to attain positive outcomes despite adversity. Many caregivers of children with neurodisabilities are resilient; they face numerous extraordinary challenges, and despite these challenges they are able to experience positive outcomes. Several of these positive outcomes were identified in a summary of key themes of the nature and structure of parents' positive perceptions and experiences from several studies (i.e., Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & McDonald, 1999; Stainton & Besser, 1998; Behr, Murphy, & Summers, 1992) reviewed by Hastings and Taunt (2002). They identified a range of themes regarding positive perceptions and experiences among parents raising a child with a neurodisability that include: pleasure and satisfaction in providing care for

the child, increased challenge or opportunity to learn and develop, strengthened family, obtaining a new or increased sense of purpose in life, development of new skills, abilities, or new career opportunities, increased personal strength or confidence, expanded social and community networks, increased spirituality, and making the most of each day (Hastings & Taunt, 2002). Such positive development in parents raising their child with a neurodisability would suggest that other individuals in the family would experience similar benefits. This has been supported in a qualitative study where one parent explains how their young children have become more tolerant of others with differences (Green, 2007). In another study of siblings of children with Rett's and Down syndrome, the majority of siblings also experienced benefits, including tolerance and understanding of differences in others, more maturity in comparison to same-aged peers, and increased compassion, caring and patience. They were also helpful and supportive, and tended to show appreciation of their own health (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2007). Therefore, benefits for other family members exist, but what about benefits for the family as an entity?

Some research has focused on both the benefits and consequences of child disability on the family and has most often focused on gathering this information from the parents' perspective. For example, in an article entitled "The positive impact of children with an intellectual disability on the family", by Stainton and Besser (1998), most of the variables of interest pertain to the impact on the parents or couple. Findings included benefits such as increased sense of purpose and priorities and an improved couple relationship. Except for increased family unity, it is unclear whether the benefits in Stainton and Besser's study were reported as pertaining to the family unit, and not just the parents. Investigating the effect of the

impact of child disability on the family as a unit, rather than the effects on individual family members, provides a unique and broader view of the family.

Cognitive Appraisal of the Family Impact

How the family unit is affected by a child with a disability has been studied by Trute and colleagues by assessing how the entry of a child with a disability into the family affects the parents' cognitive appraisal of the family impact. Trute and Hiebert-Murphy (2002) wanted to discover the impact beyond the effects on the parent subsystem, or the effects on the child and his/her own world. Their research into cognitive appraisals revealed that parents adapt; some parents were more positive about the impact of raising a child with a disability on their family than others; similarly, some were less negative about this family impact. One wonders what accounted for this variability in positive and negative cognitive appraisals. Did it have something to do with the severity of the child's neurodisability characteristics? The current research study addresses this question by examining the role that complexity of the child's needs as well as the child's behavior plays in predicting variability in maternal positive and negative appraisals of child's impact on the family.

In this study, the cognitive appraisal of the family impact of childhood disability is the meaning or the subjective interpretation that the child's disability holds for the parents, and can be positive and/or negative (Lazarus, Averill, & Opton, 1974 as cited by Trute & Hiebert-Murphy, 2002). Measuring cognitive appraisals can be helpful in determining how parents are adapting to their child with a disability (Trute & Hiebert-Murphy, 2002). Parents can interpret an event in an adaptive way by making a positive cognitive appraisal, such as viewing the consequences of having a child with a disability in terms of the positive meaning that he or she has added to their life (i.e., leading them to become more spiritual). A parent can also make a

negative cognitive appraisal when in their view, the consequences of caring for their child with a disability has led to undesirable disruption to the routine of the family (Trute & Hiebert-Murphy, 2002). Positive and negative cognitive appraisals can be upheld simultaneously; one is not the opposite of the other.

Some examples of cognitive appraisals of the family impact of child disability and its relationship to adaptive outcomes are evident in parents and families. For example, mothers of children and adolescents with various types of neurodevelopmental or physical impairments who had higher proportions of positive cognitive appraisals, also had a higher ratio of positive to negative emotions (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Lower levels of negative cognitive appraisals have been found in parents reporting a higher level of well-being over time (Trute et al., 2007). The cognitive appraisal of family impact of raising a child with a disability has been related to favourable outcomes in parents as discussed above, and has also been associated to adaptive outcomes in families, as described below.

Parents' positive and negative cognitive appraisals predicted their family outcomes, such as family well-being, has been demonstrated by Trute and colleagues (Trute et al., 2010; Benzies et al., 2011). For example, higher levels of healthy family adjustment were evident in mothers that make a higher proportion of positive cognitive appraisals throughout their day in comparison to mothers who make lower amounts of positive cognitive appraisals (Trute et al., 2010). Higher family well-being was predicted by both the higher amount of positive, and lower amount of negative cognitive appraisals that mothers made. Fathers raising a child with a neurodisability reported higher family well-being when their negative cognitive appraisals were lower compared to fathers with higher negative cognitive appraisals (Trute et al., 2007). In addition, family functioning in families with a child with a developmental, physical, or sensory condition or

impairment, mental disorder, or complicated health condition was predicted by mothers' positive cognitive appraisals made one year earlier (Benzies et al., 2011). Therefore, parents' cognitive appraisals serve adaptive purposes; parents that make higher positive and lower negative cognitive appraisals have families with higher well-being and adjustment. If positive and negative appraisals play such a pivotal role in family well-being, it is important to understand what factors can explain higher positive and lower negative appraisal. This study will examine whether and how parenting, and more specifically parenting behaviours and attributions, has anything to do with positive and negative cognitive appraisal among families raising a child with a neurodisability.

Parenting Factors

A relatively large body of research presently exists pertaining to parenting behaviours and attributions for typically developing children (Bugental & Happaney, 2000; Chao, 2001; Dooley & Stewart, 2007; Nix et al., 1999; Querido, Warner, & Eyberg, 2002; Winsler, Madigan, & Aquilino, 2005). In contrast, studies of parenting of children with neurodisabilities are beginning to emerge (e.g., Garner et al., 2011; Suzuki et al., 2015; Woolfson & Grant, 2006). For example, some studies are beginning to document how parenting of children with neurodisabilities differs from parenting children without neurodisabilities (e.g., Garner et al., 2011; Arim et al., 2012). In studies of typically developing children, the relationships between parenting variables and outcomes pertaining to the child or family, are more often examined. In such cases, parenting that is characterized by positive interaction is more favorable than parenting that is characterized by hostility and ineffectiveness, due to their respective links with healthy emotional regulation versus physical aggression in typical children (e.g., Côté, Vaillancourt, LeBlanc, Nagin, & Tremblay, 2006; Eisenberg et al., 2005).

Some research has focused on how parenting makes a difference to family outcomes in families with a child who is typically-developing and with a child with a neurodisability. For example, in families with typically-developing adolescents, parenting style has been linked to family functioning; parenting by mothers and fathers that is characterized by more affection, empathy and warmth is linked to higher family functioning (McFarlane, Bellissimo, & Norman, 1995). Parenting behaviours have also been studied in relation to family functioning in children with a neurodisability and another aspect of parenting, parent attributions have also been linked to aspects of the family environment. Parents who perceive that they have low control over the success or failure of an event, and that the child has high control, are more likely to be neglectful while parenting (Bugental et al., 1989). Therefore, taking into account how parenting factors affect family outcomes can be fruitful in learning more about families with a child with a neurodisability.

Concept of Family

In investigating family outcomes, one must define what is meant by family. There are many heterogeneous definitions of family available depending on the discipline from which one is investigating the concept (Lach, 2013). However, for the current study, a psychological standpoint is used and family is defined as a group of individuals who are connected emotionally, behaviourally and cognitively (Crosbie-Burnett & Klein, 2009).

One challenge that is present in family research is the reliance on one individual's perspective as the source of the family's perspective. Ideally, in order to understand the family impact of raising a child with a neurodevelopmental disability, both parents, siblings, grandparents, and other relatives would be asked to provide their perspective. Fathers have been included in research more often in the past few decades, however, the majority of research

participants in pediatric psychology are mothers (Phares, Lopez, Fields, Kamboukos, & Duhig, 2006). Mothers can provide valuable insight into the family life; they spend a higher amount of time in child care than fathers (Bianchi & Milkie, 2010), and they take on primary roles such as multitasking, spending time alone with the children and are generally more responsible for managing their child (Craig & Mullan, 2011). Although information from many different family members was not gathered in the current study, information was gathered about the family, mothers, and their children. Given the extensive undertaking needed to obtain perspectives from various family members, the mothers' perspective of the impact of disability on the family was the primary focus and outcome of this study.

Purpose of the Current Study

The overall aim of the present study was to learn about the experiences of families raising a child with a neurodisability, and to gather new knowledge that could be used to develop interventions that target family outcomes. The specific research questions were developed to investigate whether parenting factors were predictive of, and moderated mothers' formation of positive and negative cognitive appraisals of the family impact of caring for their child with a neurodisability. The first set of hypotheses addressed whether certain child (i.e., difficult behaviour and health complexity) and parenting characteristics (i.e., parenting behaviours and parenting attributions) predicted mothers' positive and negative cognitive appraisals of the family impact of child neurodisability. The outcome variables were positive cognitive appraisal and negative cognitive appraisal. The second set of hypotheses addressed whether the relationship between the child's difficult behaviour and mothers' cognitive appraisals changed, or was moderated, depending on the parenting factors (i.e., parenting behaviours and parent attributions). For example, did the relationship between the child's difficult behaviour and

mothers' negative cognitive appraisals change depending on their perceived level of hostile/ineffective parenting behaviour? The goals and hypotheses are further detailed in Chapter 4.

This dissertation is structured as follows. In the next chapter, Chapter 2, a discussion of the history of family stress models and of the model to be used in the current study is presented, serving as a guide for the theoretical framework of the research questions. Chapter 3 consists of the literature review and contains a discussion of the studies concerning the main concepts presented in this work, which include a rationale behind the use of the non-categorical approach to understanding children with various neurodevelopmental disorders and the cognitive appraisal of the family impact of raising a child with a disability. Research pertaining to child characteristics of difficult behaviour and health complexity are presented, and research pertaining to parenting behaviours and parent attributions of typically-developing children and children with neurodisabilities are presented. In Chapter 4, the study goals and hypotheses are specified and the method section is detailed. In Chapter 5, the results of the data analyses which includes hierarchical multiple regressions and moderation analyses, are presented. In Chapter 6, the discussion and the study implications for families with a child with a neurodisability are presented along with the limitations, directions for future research and conclusion.

Chapter 2: Theoretical Framework

Early family stress models are contextualized in history and begin with that of Reuben Hill in 1949. His formula was developed based on the stress experienced by families that had a male figure (i.e., son, father, or husband) leave for World War II (McCubbin, 2012). This disruptive experience allowed Hill to observe how families dealt with the stress of the situation in a variety of ways, and how they attempted to remain functional during the war. His findings allowed Hill (1958) the opportunity to develop his ABCX family crisis formula, which has become a seminal model in family stress research, providing a framework for the development of subsequent family stress models (Rosino, 2016).

Since Reuben Hill's ABCX family crisis model (1958), family stress models have continued to evolve and be revised, with current models emphasizing how families experience a different type of crisis - the stress in providing care for a child with a developmental disability within the family. McCubbin and Patterson's (1983) Double ABCX model of family stress, was developed in order to make improvements to Hill's (1958) formula. It has been used to guide research that addresses family stress in raising a child with a developmental disability (e.g., Hall et al., 2012; Jones & Passey, 2004; Thompson, Hiebert-Murphy, & Trute, 2013).

Using McCubbin and Patterson's (1983) model as a basis, Perry (2004) developed a model of family stress, and it has subsequently been used in studies with families with a child with a disability (e.g., Minnes, Perry, & Weiss, 2015; Weiss, Cappadocia, MacMullin, Viecili, & Lunskey, 2012). The research questions and methodology of the present thesis were developed using Perry's (2004) model as a theoretical framework; why and how this model was used is presented in this chapter.

Origin of Family Stress Models

Hill (1949, 1958) developed a family stress model that accounted for the variability in family's response to crisis. His formula included the element of a crisis-precipitating event or stressor and these elements he labeled A, B, C and X:

A - the specific stressor event;

B - the family's available resources;

C - perceptions of the event; which may form

X - the crisis, in cases in which the stressors overwhelms the resources (Hill, 1958).

Hill developed this formula to explain the "crisis-proneness and freedom from crisis among families" (pg. 143; Hill, 1958). His formula was developed based on examples of hardships that occurred when the father or husband of the family was sent to war. This lead to stressors, such as changes in income and loss of a parenting figure, that lead the family to use their resources to deal with the crisis, either adequately or inadequately. The meaning or interpretation subscribed to the event by the family in combination with the stressors and resources, produced a crisis - if crisis-meeting resources were absent. The family was kept from crisis, and remained functional, if crisis-meeting resources were adequate.

Known as the father of family stress research, Hill's (1958) formula provided a basis upon which to describe the response to crisis by families (Boss, 2002; Weber, 2011). The formula also provided the opportunity for other researchers to expand upon his ideas and further develop a model of family response to crisis beyond what Hill had conceptualized. One such model was that of McCubbin and Patterson's (1983).

McCubbin and Patterson's (1983) Double ABCX Model

McCubbin and Patterson (1983) revised Hill's models to their Double ABCX model. An important revision was the change from Hill's (1958) linear formula that focused only on the pre-crisis response and did not account for the post-crisis response, to a model that included a variable/phase that depicted how families adapt post-crisis. McCubbin and Patterson's model is similar to Hill's in that they incorporated the variables associated with Hill's ABCX formula. In McCubbin and Patterson's model, the A in the Double ABCX model represents the *initial stressor*, similar to that of Hill's. However, the B was re-conceptualized from crisis-meeting resources to *existing resources*. This change was due to the order of variables in Hills' theoretical depiction in which the crisis follows the implementation of resources, and therefore resources conceptualized as existing is more accurate. Of note, McCubbin and Patterson also specified different types of resources, including psychological/individual, social/community, and intrafamilial/family resources. They also added a dimension to the C variable by including the *meaning or the family's interpretation of the event* in addition to the definition the family makes of the event. When in crisis, families can redefine the situation and give the crisis new meaning, which involves effort. That effort they make can play a role in facilitating coping and lead to subsequent adaptation. If a family can redefine a situation from that of a challenge to an opportunity for growth, then coping and adaptation may be facilitated (McCubbin & Patterson, 1983).

As with Hill (1958), the X in the McCubbin and Patterson's (1983) model was defined as *the crisis*. Their model then included a *post-crisis phase* that proceeded through a similar ABCX cycle again, which is why it is aptly named the Double ABCX model. In the *post-crisis phase* of their model, each variable, including stressors, resources and perceptions included additional *new*

stressors, new resources and new perceptions that were the result of the crisis situation and response. For example, resources included those that were present pre-crisis as well as new resources that the family had procured due to the crisis, such as increased self-sufficiency or interaction with a new community. They stated that coping began once the family entered the post-crisis phase of the model, and this was the major revision that they made to Hill's model. McCubbin and Patterson's model, which was developed based on families with typical children that were going through a crisis, has been implemented by those studying families with a child with a disability (e.g., Hall et al., 2012; Thompson, Hiebert-Murphy, & Trute, 2013). Their model was further modified by Perry (2004) to address the unique experience of families living with a child with a developmental disability.

Perry's Model of Family Stress

Perry (2004) developed a model of stress in families with children with a developmental disability based on revisions to McCubbin and Patterson's (1983) model (see Figure 1). Perry's model included four major components: *Stressors*, *resources*, *supports*, and *outcomes*. Each of these components were divided into two domains: *Stressors* included child characteristics and other life stressors; *resources* included individual personal resources and family system resources; *supports* included informal social support and formal support and services; and *outcomes* included negative and positive parental outcomes. As suggested by Perry (2004), the impact of the stressors may be mediated and/or moderated by the resources and support variables, and the outcome could be positive and/or negative.

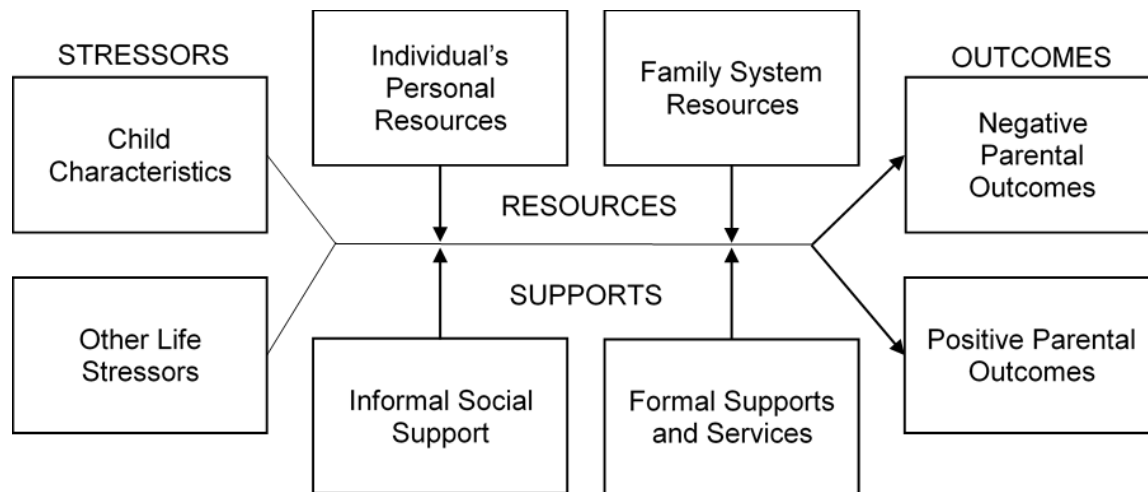


Figure 1. Perry's (2004) model of stress in families with a child with a developmental disability.

Perry's Model Components

Perry's (2004) model attempts to improve on McCubbin and Patterson's (1983) by better defining its component variables (i.e., ABCX) more specifically. The stressors component (A) pertained to ongoing stress on the life of the family with a child with a disability and included child characteristics and other life stressors. This conceptualization of stressors differed from McCubbin and Patterson (1983), who described the stressor as the initial stress-inducing event. Perry suggested that the researcher must distinguish between ongoing stress and objective variables, such as age or cognitive ability, for the stressors component of her model. In addition, she suggested that including parents' perceptions of child difficulty was relevant because their perception of difficulties was more telling than the child's objective characteristics. This suggested that parents raising children with more severe behaviour could be more positive in their perceptions than parents with less severe child behaviour. The stressors component also included other life stressors, such as those related to employment, illness in other family

members, financial problems, having other family members with developmental disabilities, and other stressors related to having a child with developmental disability.

The resources component of Perry's (2004) model also differed from McCubbin and Patterson's (1983) model. Perry's model divided McCubbin and Patterson, existing resources B variable into two categories: resources and supports. Her conceptualization of resources included the individual's personal resources and family system resources. The individual's personal resources included personality variables, cognitive coping strategies and beliefs, and demographic variables, such as education and employment. Family system resources included marital satisfaction and family functioning, as well as demographic variables that pertained to families, such as socioeconomic status and marital status. Perry suggested research in this area should examine whether these resources function in an additive way, and/or act as mediators and moderators of stress.

The supports component of the B variable in Perry's (2004) model also included two domains; informal social supports, and formal supports and services. Informal social support included emotional sustenance and/or tangible help from extended family members, friends, neighbors, social organizations, and religious communities. Perry acknowledged that there were considerable conceptual and measurement issues in studying support, such as determining the balance between quantity and quality of support, and how useful informal support was to the individual. In terms of formal supports and services, Perry suggested that professional or paraprofessional interventions directed at the child and/or family consisted of this type of support. Examples included education and treatment programs, as well as counselling, respite, support groups and others. She suggested future research should measure quantity, quality, effectiveness, suitability, and impact on parental levels of satisfaction of support.

In terms of the C variable, which is described in McCubbin and Patterson's (1983) model as the meaning or interpretation the family has of the crisis event, it is incorporated by Perry (2004) directly into the outcome part of her model rather than as its own entity. The outcomes component of Perry's model includes two domains; one that represents adaptation (i.e., positive parental outcome) and the other, crisis, represented by negative parental outcome. The outcomes may include factors that measure parents' meaning making of raising their child with a developmental disability. Importantly, a strength of this model is that it included positive outcomes, as historically, models have tended to focus on negative outcomes. Negative outcomes included parenting distress, and positive outcomes included aspects related to personal growth, such as advocacy efforts. Perry suggested measuring the negative and positive outcomes as two separate variables as they tend to co-occur. The crisis variable, X, was eliminated in Perry's model and instead two dichotomous outcomes were included, negative and positive parental outcomes.

The advantages of Perry's (2004) model include that (i) it was developed as a model for families with a child with a developmental disability, (ii) it's not specific to any type of disability, and is therefore (iii) applicable to a wider variety of families. The model also is relatively simple and this makes it more easily applicable to applied research and clinical practice. It does have some disadvantages, including that the constructs represented by the components can only be measured using individual report. Therefore, a mother may answer for her family as a unit, which may differ from a father's responses for his family. However, this is a common critique of family research and careful design of study methodology and data analysis is warranted.

Perry's Model as a Guide for the Current Study's Design

The research questions for the current study were developed based on Perry's (2004) model and motivated by the current open questions pertaining to raising a child with a neurodisability, including parenting and mothers' cognitive appraisal of the impact. Each of the variables from the current study may be categorized within Perry's components with the exception of supports, which was not included in this study.

The stressors component included child characteristics of child difficult behaviour and child health complexity. The parenting variables included in the current study are considered as part of the resources component that are part of the individual's personal resources, and include three types of parenting behaviours and two types of parent attributions. For the outcome component, the cognitive appraisal of the family impact of childhood disability was used as it tapped into how mothers made meaning from their situation. This construct had been explored by others to understand how families adapt to their child with a disability (Trute & Hiebert-Murphy, 2002). The cognitive appraisal of the family impact is conceptualized as negative and positive which aligns with Perry's (2004) model of including both negative and positive outcomes.

In the current study, Perry's (2004) model of stress in families with a child with a developmental disability served as the theoretical framework for the development of the research questions and methodology. As presented, a number of family stress models have been developed, used, and revised since the late 1940s, with Hill's (1958) formula and McCubbin and Patterson's (1983) models making significant contributions to the field. Their models have been progressed by other authors, including Perry (2004). The variables were chosen from each of the components of Perry's model; two variables are stressors (i.e., child health complexity and child

difficult behaviour), two are resources (i.e., parenting behaviours and parent attributions), and two are outcomes (i.e., positive and negative cognitive appraisal). The research questions were conceptualized based on the design of Perry's model, which allows for analysis of resources as predictors of the two outcome variables (i.e., positive and negative cognitive appraisal), and as moderators of the relationship between child difficult behaviour and cognitive appraisals.

Beginning with Hill (1958), family stress models have been developed to understand how families adapt to crises. Hill had the opportunity, although through unfortunate circumstances, to develop his seminal ABCX family crisis formula based on families in crisis during war. McCubbin and Patterson (1983) further revised Hill's models to develop the Double ABCX model, which changed Hill's linear formula to focus not only on the pre-crisis response but also the post-crisis response. Based on McCubbin and Patterson's model, Perry (2004) developed a model for families in a stressful situation, in which they were raising a child with a developmental disability. Perry defined the ABCX variables differently for her model and developed it to be specific to families raising a child with a developmental disability. Unlike previous models, Perry's model also allows for specific exploration of both positive outcomes and negative outcomes. As described in Perry's model, the current study's variables are represented by stressors, resources and outcomes. In the next chapter, these variables, which include the stressors of child health complexity and child difficult behaviour; the resources of parenting behaviours and parent attributions; and the outcomes of positive and negative cognitive appraisal, are contextualized within the current research questions.

Chapter 3: Review of the Literature

The following literature review begins by presenting the non-categorical approach to neurodisability, then continues with an explanation of the key outcome variable in this study, the cognitive appraisal of the family impact of childhood disability. Following discussion of the studies of cognitive appraisals, child characteristics of difficult behaviour and health complexity in children with a neurodisability are presented. Research pertinent to children with neurodisabilities regarding parenting factors, including parenting behaviours and attributions, is presented. Throughout the literature review, the pertinent research is presented and gaps in current knowledge are identified.

A Non-categorical Approach to Neurodisability

Research on children with neurodisabilities is often conducted with a sample defined by their diagnosis, such as autism spectrum disorder (ASD; e.g., Mandell, Novak and Zubritsky, 2005). However, researchers are increasingly starting to adopt a non-categorical approach to describe neurodisability, where children with a variety of disabilities are included in a particular study. In the same vein, research using a non-categorical approach examines issues that are common to children with various neurodevelopmental disorders, thereby being relevant to a greater number of individuals. The following section supports the use of a non-categorical approach in research and applied settings.

The non-categorical approach to studying children with various neurodevelopmental disorders postulates that individuals should be grouped and compared based on commonalities, such as the type of impairments they have, rather than by their specific diagnostic labels. Diagnoses are less useful to understanding the impact of the disability on the lives of those living with, and caring for a child with a neurodisability than is the nature of the impairment itself.

Given the considerable variability in function and in impairment *within* any diagnostic group (i.e., autism spectrum disorder), it is challenging to apply findings and to understand implications. Grouping or classifying children based on the complexity of their impairments allows for interpretation of findings across diagnoses.

Stein and Jessop (1989) stipulated that “greater variability within each diagnostic category is as great as or greater than the variability between these categories” (pg. 770). They argued that this variability was evident when one considered that the diagnostic label lacked descriptive information such as psychological and social parameters that the individual person with the disability may be living with. Historically, a number of studies (e.g., Stein & Jessop, 1989; Newacheck & Taylor, 1992; Perrin et al., 1993) set the tone for studying children with various types of neurodevelopmental disorders as one larger group. More recently published studies have also contributed to this scholarship (e.g., Etherington et al., 2016; Gillberg, 2010; Miller, et al., 2013; Miller et al., 2016).

Commonalities across diagnoses were demonstrated in 2006 study using the Participation and Activity Limitation Survey (PALS) sample in Canada (Miller et al., 2013). PALS is a population-based survey on children and adults in Canada with disabilities, which included individuals who were limited in performing everyday activities because of a condition or health problem. Using this sample, the authors compared diagnostic approaches to ascertain neurodevelopmental disorder and disabilities (NDD/D) with parent-reported functional limitations. The children had impairments in one of these areas of development: motor functioning, speech-language/communication, learning and cognition, social-emotional relating, or an impairment in vision or hearing, or an impairment related to an emotional, psychological or behavioural condition. Miller et al. (2013) established that from 174,810 children aged 5 to 14

years old, 73.5 percent of them were categorized as having an NDD/D. In their approach to ascertain NDD/D, the authors discovered that identifying the diagnosis did not necessarily result in being categorized as having a NDD/D in approximately 25 percent of cases. Children either had more functional limitations that were not associated with the specific diagnosis, or they were left out due to how parents reported the condition. When classifying these children as NDD/D based on functional characteristics and diagnosis, a substantial number shared functional characteristics, far more than when classified by individual disability type. The authors concluded that although diagnostic labels were informative and convenient, they did not provide the complete picture of the disability and could even be misleading when planning intervention.

In a study by Miller et al. (2016), functional impairments were more informative than diagnosis in predicting child and family well-being. Their study used the PALS 2006 Canadian data with a sample of 120,700 children with neurodevelopmental disabilities. They found that when the diagnosis of ASD was included as an independent variable in a model along with functional impairments, such as vision, hearing, and speech/communication, the effect of child diagnosis on the outcomes disappeared. Diagnosis thus exerted its influence on child and family outcomes through child functional characteristics. The authors concluded that functional status was a better guide than diagnostic label in the organization of health, rehabilitative and social services, and raised concerns about the use of diagnostic classification systems in determining service access and provision.

The effects on family functioning and parent stress are similar across samples of children with different disabilities. In a study of children with a variety of developmental disabilities, children were categorized into three groups by disability; intellectual disability, physical and sensory impairment, and other, which included learning disability, severe behaviour problems,

developmental delay, and speech disorders, the author investigated whether differences existed by disability within the areas of parental stress, family social support, and family functioning (Dyson, 1997). In support of the non-categorical approach, none of the groups were significantly different from the other on parent and family measures, and differences were not found between type of disability for these measures when reported by the father or the mother.

Given the evidence provided, it is both logical and fruitful to use the non-categorical approach to disability in the conceptualization, development and implementation of research. The approach is centered on the idea that children and adolescents can be grouped and compared based on their functional impairments rather than their diagnoses. This more inclusive approach allows for grouping of a wider variety and number of children with various neurodevelopmental and more rare genetic and/or metabolic diagnoses to be included in studies that consider questions pertaining to their health, rehabilitative and social service needs. The effects of caring for individuals with a disability are also similar across NDDs in terms of the effects on family functioning and parent stress.

In summary, a non-categorical approach was used in the present study. The participating families had a child with a neurodisability and these neurodisabilities included a range of disorders, and the children have a range of severity of impairment. This non-categorical approach was operationalized using the concept of child health complexity, which was measured using the About My Child (AMC-26; Rosenbaum et al., 2008). Complexity, as opposed to severity, refers to the “cumulative number ...of biological, psychological, social and environmental issues in a child’s life that directly ...impact their health and care and that of their families” (pp. 403, Brehaut et al., unpublished manuscript, as cited by Ritzema, Lach, Rosenbaum, & Nicholas, 2016). Measurement of complexity is a proxy for the child’s level of

impairment, a concept consistent with the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) definition of disability, which includes an umbrella term that includes impairments, activity limitations and participation restrictions and in which disability is an interaction between individual's with a health condition and personal and environmental factors (WHO, 2016). Therefore, rather than studying children with specific neurological conditions who would present with a range of impairments, I chose to study children with various neurological conditions in order to understand the role that complexity of their health played in the expression of positive and negative cognitive appraisal, rather than the diagnosis itself. In the next section, the cognitive appraisal of the family impact of childhood disability, the key concept of interest in this study, is described in detail as it served as an indicator of the positive and negative outcomes for these families.

The Cognitive Appraisal of the Family Impact of Childhood Neurodisability

Cognitive appraisal refers to the meaning that an individual attributes to an event (Lazarus & Folkman, 1984; Trute, Hiebert-Murphy, & Levine, 2007). Parents make both positive and negative cognitive appraisals of their experience of raising their child with a developmental disability (Trute & Hiebert-Murphy, 2002). An example of a father's positive cognitive appraisal is when he indicates that one of the consequences of having a child with a neurodisability in his family is that the experience has had an impact on his personal growth and has increased his sense of strength as a father. An example of a negative cognitive appraisal consists of a mother indicating that one of the consequences of having a child with a neurodisability is that there has been a reduction in time that the family is able to spend with friends.

Trute and Hiebert-Murphy (2002) developed the Family Impact of Childhood Disability scale (FICD) to evaluate parent cognitive appraisals. Much of the research on cognitive appraisals in families with a child with a disability has been undertaken by Trute and colleagues and their studies are discussed in this chapter. First, the background to the development of the FICD is explained; second, the relationship between cognitive appraisals and other family-related constructs, emotional well-being, parent stress and parent gender is presented.

Background to the Family Impact of Childhood Disability Scale (FICD)

The FICD (Trute & Hiebert-Murphy, 2002) was developed to gain an understanding of parents' appraisals of the effect of their child's developmental disability on their family. The questionnaire was developed based on a model referred to earlier, McCubbin and Patterson's (1983) ABCX model, in which C refers to the interpretation or meaning that an individual makes of an event. Work by Lazarus, Averill and Opton's (1974, as cited by Trute and Hiebert-Murphy, 2002) and Lazarus and Folkman (1984), in which they describe the cognitive appraisal of a situation, also framed the development of their questionnaire.

In its early development, Trute and Hiebert-Murphy (2002) expected the FICD to function as a unidimensional scale consisting of a discrepancy score that measured positive appraisal, in which the positive scale score was subtracted from the negative scale score. However, their research revealed that the positive and negative cognitive appraisals that parents reported should be treated separately, especially in consideration that the negative subscale predicted poor mental health, such as higher risk of depression in parents (Trute, 1995). The use of separate positive and negative subscales was also confirmed by factor analysis revealing two unique factors (Trute & Hiebert-Murphy, 2002). The authors decided to continue to calculate the discrepancy score in their research with the FICD, as well as calculate one positive and one

negative subscale score in their 2002 study (Trute & Hiebert-Murphy, 2002). By 2007, their study used the FICD with just the two subscales, one negative and one positive, with 10 items each (Trute, Hiebert-Murphy & Levine, 2007). They found that parents held both negative and positive cognitive appraisals simultaneously (Trute et al., 2007).

Next, the research pertaining to cognitive appraisals in families raising a child with a disability is discussed. For the older studies, the authors used the discrepancy score for the FICD; they combined the positive and negative subscale scores, and for the newer studies, two subscales, one positive and one negative, were used. The score used is indicated throughout the studies presented in the literature review when pertinent. Many studies regarding the relationships between cognitive appraisals and other constructs that are indicative of stress and well-being have been conducted, emphasizing the utility of the FICD in learning about the well-being of parents raising a child with a neurodisability. How cognitive appraisals relate with measures pertaining to the family, parenting stress, emotional well-being, and parent gender are presented in order to demonstrate the utility of the concept of cognitive appraisals in understanding families raising a child with a disability.

FICD as an Outcome Variable

In the literature reviewed here, the subscales of the FICD, the positive and negative cognitive appraisal of the family impact, are often investigated as predictor variables for various outcomes, such as family well-being, parenting stress and mothers' self-esteem. As mentioned above, Trute conceptualized the FICD as representing the C variable in McCubbin and Patterson's (1983) ABCX model. The outcomes that the FICD predicts, represent the X or crisis/adjustment (i.e., family adjustment). Whether the FICD is investigated as a predictor or outcome depends on the variables chosen to be investigated and whether they represent the A, B,

C or X in the model. Based on the variables chosen to be studied in this study, the FICD was studied as the C variable, however, unlike previous research, the predictors in the current study represent the B variable in the ABCX model. In this study, Perry's (2004) model was used as a framework which spurted from McCubbin and Patterson's (1983). In Perry's model, she included the same factors; B, which represents resources. In this study, the predictors are considered resources; i.e., parenting behaviours and parent attributions. The FICD subscales are represented by the C in the current study, which McCubbin and Patterson defined as the meaning or interpretation the family makes of the perturbing event, and Perry, who combined both of McCubbin and Patterson's C and X factors, considered C as a measure of adaptation and crisis, an outcome. Therefore, the proposed predictors, B, precede the outcome (C), the subscales of the FICD. Other predictors entered into the model represent the A in the model, and were included as control variables.

Cognitive Appraisals and the Relationships to Family-Related Measures

Cognitive appraisals are predictive of various family-related measures of well-being, such as family adjustment and family hardiness. The FICD has been shown to be a predictor over time and in cross-sectional studies, in samples of mothers and fathers, and in a sample with a low socioeconomic status. Three studies presented below demonstrated the predictive capacity of the FICD to family well-being.

Whether parents' cognitive appraisal scores were longitudinal predictors of family well-being was tested after a one-year period (Trute et al., 2007). Parents participated within 6 months of their child first entering disability services (time 1) and one year later (time 2). As in Trute and Hiebert-Murphy's (2002) study, Trute et al. (2007) also used a sample of parents caring for children with a variety of disabilities, including pervasive developmental disorders, Down

syndrome, cerebral palsy and other types of developmental delay. The children were a mean age of 4 years old at time 1. Both positive and negative cognitive appraisal, as well as self-esteem, predicted 35% of the variance in early family well-being as reported by mothers. The relationships to higher family well-being were as such: Higher positive cognitive appraisals, lower negative cognitive appraisals, and mothers' higher self-esteem predicted higher family well-being at the beginning of the study. Within the same study, fathers' cognitive appraisals were also investigated and they differed from mothers. Only lower negative cognitive appraisals and fathers' higher self-esteem, but not positive cognitive appraisals, were found to predict 25 percent of the variance in family well-being at the second time point (Trute et al., 2007). This suggested that fathers may arrive at appraising the positive impact of childhood disability on family well-being later than mothers. The results obtained for fathers were significant but the authors suggested that they be interpreted with caution due to the small sample size ($n = 49$). These results suggested that the FICD subscales were predictors of family well-being; early and higher family well-being were predicted by higher positive cognitive appraisals for mothers, and family well-being after one-year, was predicted by lower negative cognitive appraisals for mothers and fathers.

Whether cognitive appraisals were predictors of a family-related outcome, family adjustment, in mothers of children with a disability was investigated in another study by Trute, Benzies, Worthington, Reddon and Moore (2010). In terms of socioeconomic status, the 195 mothers that participated were from low income families. The children were approximately 8 years-old and had a variety of disabilities, including developmental disabilities and complex health conditions. Family adjustment was measured using the Brief Family Assessment Measure III General Scale (FAM-BF; Skinner, Steinhauser, & Santa-Barbara, 1995), a measure of family

functioning that includes measurement of the concepts of task accomplishment, role performance, communication, affective expression, involvement, control values and norms. Affect was measured using the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988), which is a measure of the mothers' frequency of positive and negative emotions in the previous week. A positivity ratio, which consisted of the positive affect score divided by the negative affect score, was used by Trute et al. (2010). The authors found evidence that positive and negative cognitive appraisals have different relationships to family adjustment. The positive and negative subscales of the FICD and the positivity ratio were entered simultaneously as predictors of family adjustment, and it was revealed that the positive cognitive appraisals and the positivity ratio explained 35 percent of the variance in family adjustment. Negative cognitive appraisals did not predict family adjustment. In comparison, the positive cognitive appraisals jointly with positivity, bring higher family adjustment (Trute et al., 2010). The authors state that the FICD is a unique measure of negative cognitive appraisals that is different from family adjustment, therefore useful as a separate tool to measure family outcomes. In addition, the positive cognitive appraisal subscale is useful as a predictor of family adjustment.

Other family outcomes, family hardiness and family functioning, were predicted by the cognitive appraisals that mothers form as well as their parenting morale (Benzies et al., 2011). The sample was the same as Trute et al.'s (2010), but additional data was available that was collected longitudinally over a one-year period. The authors investigated whether cognitive appraisals were predictive of family outcomes one-year after the cognitive appraisals were measured. Family hardiness referred to the family's resistance, and adaptation, to stress. Family adjustment referred to the Brief Family Assessment Measure III – General Scale (Skinner et al.,

1995) as described above. Parenting morale referred to the parents' enthusiasm, positive spirits and psychological energy for caring for a child with a disability. The authors found that mothers' higher positive cognitive appraisals and higher parenting morale at baseline predicted higher family adjustment and higher family hardiness one-year later. Negative cognitive appraisals were not predictive of these family-related measures.

In another study, the role of positive cognitive appraisal, parenting stress, and self-esteem on family adjustment for mothers and fathers with a child with a disability was investigated (Thompson, Hiebert-Murphy, & Trute, 2013). Positive cognitive appraisal also predicted mothers' family adjustment, and partially mediated the relationship between parenting stress and family adjustment. Lower parenting stress leads to higher positive cognitive appraisal, which leads to lower family adjustment (more positive adjustment). Self-esteem also partially mediated the relationship between parenting stress and family adjustment. For fathers, positive cognitive appraisal and self-esteem did not predict their perception of family adjustment. Fathers' parenting stress did predict family adjustment, with higher stress predicting poorer family adjustment. Fathers' self-esteem was a moderator of the relationship between parenting stress and family adjustment. When their reported parenting stress was low or moderate, fathers' self-esteem buffered (or lessened) the impact of parenting stress on family adjustment. When parenting stress was reported high, self-esteem no longer had a moderating effect. The findings of this study highlight the importance of increasing mothers' positive cognitive appraisals and that there are differences in mothers and fathers' experience of raising a child with a disability. The stress involved in parenting a child with a disability is affected by differing personal resources depending on parent gender and level of stress. Additional studies relating cognitive appraisals as predictors of parenting stress follow below.

Cognitive Appraisals and Parenting Stress

Whether cognitive appraisals preceded the family's coping response, was investigated using parenting stress as the outcome (Trute & Hiebert-Murphy, 2002). A positive finding would support the utility of the FICD as a research and clinical measure, as indicators of stress can help clinicians to better understand the family and provide appropriate support. Examples of a couple of studies in which parenting stress was predicted by cognitive appraisals are presented here.

In a longitudinal study pertaining to the development of the FICD by Trute and Hiebert-Murphy (2002), mothers and fathers completed the FICD and a measure of parenting stress. The sample consisted of 253 Canadian children with a primary diagnosis of developmental delay along with other impairments (i.e., a hearing or visual impairment, a serious physical disability, or Down syndrome). At time 1, the children were 5 years old, and at time 2, they were 12 years old. At time 1 and 2, the FICD was analyzed as one discrepancy score, but at time 1 parents completed the scale together and at time 2, the parents completed it separately. Parenting stress reported by mothers at time 2 was predicted by the FICD scores and marital adjustment at time 1. For fathers, the FICD score at time 1 was the sole predictor of their parenting stress at time 2. In addition, parenting stress was not found to be correlated among mothers and fathers at time 2. Although the discrepancy score of the FICD was used in the analyses of this study and both parents completed one questionnaire together at time 1, the authors took steps to ensure that the data was analyzable for conclusions to be drawn.

Within the Benzies et al. (2011) study described earlier, the authors investigated whether cognitive appraisals predicted parenting stress one-year later. Mothers' positive and negative cognitive appraisals and parenting morale were found to be significant predictors, accounting for 36 percent of the variance in parenting stress. The relationship was such that mothers' higher

negative cognitive appraisals and lower positive cognitive appraisals were related to higher parenting stress one-year later. The authors suggested that this measure can be used as an indicator of the stress mothers may experience after one-year.

From the research studies presented here, it can be concluded that cognitive appraisals are predictive of parenting stress occurring after a short and long period of time. Parenting stress was predicted by parents' prior FICD score, reported seven years earlier (Trute & Hiebert-Murphy, 2002). Positive and negative cognitive appraisals made a year prior predicted parenting stress for mothers (Benzies et al., 2011).

Cognitive Appraisals and Emotional Well-being

In order to check the utility of the FICD in predicting parents' well-being, the cognitive appraisals of parents raising a child with a disability were investigated as correlates with various measures of emotional well-being, including self-esteem, and depressive symptoms. Early work by Trute and Hiebert-Murphy (2002) with the FICD was conducted to investigate the links between cognitive appraisals, self-esteem, and depressive symptoms. In a longitudinal study, they conducted correlations with the FICD discrepancy score (i.e., negative cognitive appraisal score minus positive cognitive appraisal score). As explained above, at time 1 the FICD was completed by the parents in collaboration with each other, but separately for time 2. The FICD discrepancy score was related to mothers' self-esteem and depressive symptoms scores at time 1; the correlations for both self-esteem ($r = .23, p < .05$) and depressive symptoms ($r = .23, p < .05$) were significant but not strong. For fathers, the same result was not found, there were no significant relationships between the FICD discrepancy score and its' correlations with self-esteem and depressive symptoms. Further to this point, for time 2, the FICD scores were not related to either self-esteem or depressive symptoms in either parents. Self-esteem at time 1 was

not predictive of parenting stress at time 2, and depressive symptoms were not found as predictors of parenting stress. The authors suggested that these findings support the FICD as a unique measure of parents' cognitive appraisal of the family impact of childhood disability and not a measure of their psychological adjustment.

Whether parents' cognitive appraisals could be predictive of their emotional well-being, and self-esteem was investigated in Trute and colleagues' (2007) study. Using a longitudinal design, they tested whether positive and negative cognitive appraisals predicted self-esteem in mothers and fathers. For mothers, positive cognitive appraisals predicted their level of self-esteem a year later, and a direct relationship was found in which higher self-esteem related to higher positive cognitive appraisals. However, negative cognitive appraisals did not predict lower self-esteem for mothers. For fathers, the results differed; the positive cognitive appraisals did not predict self-esteem like it did for mothers. Similar to mothers, their self-esteem was not predicted by negative cognitive appraisals either.

In another study, the link to emotional well-being was investigated by checking whether positive and negative cognitive appraisals predicted maternal depressive symptoms (Benzies et al., 2011). Both subscales were not predictive of mothers' depressive symptoms one-year later. Therefore the relationship between parent well-being and cognitive appraisals was beginning to be established, given that in other previous research, there is a correlation between cognitive appraisal as a discrepancy score and depressive symptoms in Trute and Hiebert-Murphy (2002), but no predictive relationship between the appraisals and maternal depressive symptoms was found.

Cognitive Appraisals and Parent Gender

In order to investigate whether the FICD differed in terms of parent gender, mothers' and fathers' cognitive appraisals were explored (Trute & Hiebert-Murphy, 2002; Trute et al., 2007). In the longitudinal study by Trute and Hiebert-Murphy (2002), the mothers' and fathers' scores were similar for negative appraisals; they were significantly correlated. But for the positive appraisals, they were not correlated. Thus parents differed by gender in their positive cognitive appraisals, but not in their negative cognitive appraisal. In Trute et al. (2007) at time 1, mothers and fathers differed in their positive cognitive appraisals but did not differ in their negative cognitive appraisals, as was found in Trute and Hiebert-Murphy (2002). At time 2, the difference in parent gender for positive cognitive appraisals was no longer apparent as mothers and fathers made similar levels of positive cognitive appraisals. For negative cognitive appraisals, parents also did not differ from each other, and the amount was similar.

How mothers' and fathers' own positive and negative cognitive appraisals related also revealed differences in gender (Trute et al., 2007). Mothers' positive and negative cognitive appraisals were independent, or unrelated, to each other, whereas for fathers, they were inversely related, such that fathers' high positive cognitive appraisals were related to their low negative cognitive appraisals. This relationship was reported for time 1 only and was not found for time 2, suggesting that these relationships may change over time.

Gender differences among cognitive appraisals are apparent in the assessment of mothers and fathers' appraisals. There is conflicting evidence that cognitive appraisals stay consistent over time, although in one study Trute et al. (2007) found that parents' positive cognitive appraisal levels became similar when the child was older. In this study, the mothers were earlier in making positive cognitive appraisals than fathers, but over time, the amount of positive

cognitive appraisals converged with each other. This study took place over a one-year time period, and parents were approached shortly after entering their child into disability services at preschool age. In contrast, Trute and Hiebert-Murphy (2002) found that when the child was older, parents' amount of positive cognitive appraisals were different from each other. Perhaps by the time the child is a preteen, positive cognitive appraisals differ again, suggesting that variability in the amounts of positive appraisals mothers and fathers make may change over time. For negative cognitive appraisals, they were similar in amounts for mothers and fathers which is a result consistent in both studies (i.e., Trute & Hiebert-Murphy, 2002; Trute et al., 2007). The comparison of cognitive appraisals by parental gender over time shows that it is important to consider the type of appraisal separately as well as mothers' and fathers' responses separately. Their formation of appraisals differs at different stages of their child's life and this demonstrates that mothers and fathers' cognitive appraisals should be studied separately and should not be grouped together without first investigating whether they are significantly correlated.

Summary

In the preceding sections, the background and the research pertaining to the measurement of the cognitive appraisals of the family impact of childhood disability were presented. The research presented provided evidence that the cognitive appraisal of the family impact of childhood disability is an established measure to be used with families with a child with a disability. Links between different concepts have been established with the FICD, including to family-related measures, emotional well-being, and parenting stress. For instance, the FICD was found to be a predictor of family well-being - from the research presented, it is known that in mothers who report higher positive cognitive appraisals, lower negative cognitive appraisals, and higher self-esteem have higher family well-being (Trute et al., 2007). Differences among parent

gender have also been found, that warrant proceeding with caution in combining mothers and fathers in a sample and it is suggested that relationships between their scores are checked before deciding how to use their data.

Other important findings included that the cognitive appraisals that are positive and negative, predict different constructs. The different relationships between the positive and negative cognitive appraisals with other concepts indicate that the subscales should be treated differently and not combined in research. The FICD has also been used in complex analyses as a mediator – in which it was found that the positive cognitive appraisal also predicted mothers' family adjustment, and mediated the relationship between parenting stress and family adjustment (Thompson, Hiebert-Murphy, & Trute, 2013).

Despite the amount of research available, the cognitive appraisals of mothers raising a child with a neurodevelopmental disability have not been linked to the specific variables that are investigated in the current study. These included child characteristics – from the research reviewed here, the link between child-related predictors, like child characteristics, with the outcome of cognitive appraisal, have not been made. Similarly, the link between parenting factors, specifically parenting behaviours and parent attributions and cognitive appraisals was also not yet available. Continued research with the FICD as an outcome can uncover these relationships, and help to increase understanding of family's experiences in raising their child with a disability. The cognitive appraisals of parents are an important aspect of their lives, and in order to fully understand what parents are experiencing in caring for their child with a disability, it is important to consider some of the characteristics of children with neurodisability; child difficult behaviour and child health complexity.

Characteristics of Children with Neurodisability

Morris, Janssens, Tomlinson, Williams and Logan (2013) describe neurodisability as:

Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour. (pg. 1103)

This definition of neurodisability was obtained via a research study in which agreement with professionals, parents and colleagues were surveyed over three rounds (Morris et al., 2013). The authors' purpose in doing so was to obtain broad agreement among health professionals, as there is a lack of consistent use of terms used to describe individuals with neurological conditions and a lack of consensus about which conditions are included. The consensus-obtained definition allows for one broad group of health conditions to be grouped to facilitate research and clinical purposes (Morris et al., 2013). There are two characteristics of neurodisabilities explored in this study; these include child difficult behaviour and child health complexity.

Child Difficult Behaviour

Difficult behaviour in children includes a variety of behaviours that may be considered problematic or disruptive to the individual's well-being. Behaviours such as emotional symptoms, conduct problems, hyperactivity, inattention, and peer relationship problems are all considered difficult behaviour, and can range in frequency and severity (Goodman, 1997). In school-aged children with cerebral palsy, approximately one-third had concerning levels of

behavioural problems, of clinical or borderline level of severity. The behaviours that were most common to this group of children were peer problems, followed by emotional symptoms, hyperactivity, lack of prosocial behaviours and conduct problems (Brossard-Racine et al., 2012).

Individuals with neurodisabilities have a higher quantity of, and more severe level of behaviour problems than their typically-developing peers, over time (Baker et al., 2003). In typically-developing children and with developmental delays from 3 to 5 year-old and 9 to 11 years-old, children that were developmentally delayed displayed significantly higher amounts of difficult behaviour in comparison to the typically-developing children in both age groups (Woolfson & Grant, 2006). In young children with and without developmental delay from 3 to 5 years old, mothers and fathers with a child with developmental delay reported significantly higher behaviour problem scores, and these were more likely to be in the clinical range of severity for internalizing behaviour, externalizing behaviour, attention problems, aggression, somatic issues, and social withdrawal than what parents of children without developmental delay reported. Three year-old children with developmental delay were more likely to be at the clinical level of severity for behaviour in comparison to the children without a developmental delay. This difference continued to exist when the child was 4 years old (Baker et al., 2003). Behavioural problems in school-aged children with cerebral palsy also existed in adolescence (Brossard-Racine et al., 2012).

In families of children with a neurodisability with difficult behaviour, there is evidence that parents experience considerable stress and family functioning is negatively affected. In parents raising a child with high functioning autism spectrum disorder, parenting stress was higher than other parents whose child did not have that diagnosis (Rao & Beidel, 2009). The family functioning in families raising a child with a neurodisability was also affected by child

behaviour, and child behaviour had a detrimental effect on parents' health. In families with a child with cerebral palsy, higher levels of child behaviour problems were associated with lower levels of parent psychological and physical health. In turn, the psychological health and physical health of the parents predicted how well the family was functioning, with better health predicting better family functioning (Raina et al., 2005).

As reviewed above, children with neurodisability have behaviour problems that are present in higher quantity and higher in severity than in typically developing children. These behaviours are present early in childhood and continue into adolescence. The effects of these behaviours are detrimental to the family; parents' experience considerable stress and negative effects to their health, and family functioning is affected negatively. The child's difficult behaviour is one aspect of their neurodevelopmental disability, however, the child's health complexity, described next, is also an important factor to consider in understanding the experience of families raising their child with a neurodisability.

Child Health Complexity

In the present study, child health complexity was conceptualized as the "cumulative number ...of biological, psychological, social and environmental issues in a child's life that directly ...impact their health and care and that of their families" (pp. 403, Brehaut et al., unpublished manuscript, as cited by Ritzema, Lach, Rosenbaum, & Nicholas, 2016). In families with a child with a neurodisability, understanding the child's health complexity is important because it provides context to the family's situation and the kind of concerns and priorities they may have for receiving help (Ritzema et al., 2016). The construct of child health complexity differs from difficult behaviour as it focuses on parent concern for their child's functioning in a variety of domains, rather than a checklist of the presence and frequency of behaviours. There

are several domains to child health complexity and these include cognitive ability, communication ability, activities of daily living, internalizing and introverted behaviour, and externalizing and antisocial behaviour (Ritzema et al., 2016; Rosenbaum et al., 2008). Parents may or may not have concern for their child's functioning in each of these domains.

Significant relationships between the child's cognitive functioning, their level of adaptive behavior, and their behavioural difficulties indicate that child health complexity can be interpreted as an indicator of the child's level of disability. This aspect has been shown by relating child health complexity scores with other measures of child functioning. It has been shown that children with higher health complexity scores are more severely affected in cognitive and adaptive skills, and behaviour (Ritzema et al., 2016). In the cognitive and communication domains of health complexity, parents who reported more concerns than others, had lower cognitive scores on a measure of verbal and nonverbal intelligence (Ritzema et al., 2016). On a measure of adaptive behaviour, externalizing behaviour and difficult behaviour, such as conduct problems and hyperactivity, were positively correlated with the externalizing and antisocial behaviour domain of child health complexity. Likewise, the internalizing and introverted behaviour domain of child health complexity were also positively correlated with measures of internalizing behaviour on the same measures of adaptive behaviour and difficult behaviour (i.e., peer problems, emotional symptoms; Ritzema et al., 2016). These relationships suggest that child health complexity can serve as an indicator of the child's severity of disability in the areas of cognition, adaptive skills and behaviour.

In the current study, child health complexity was defined as described earlier: The "cumulative number ...of biological, psychological, social and environmental issues in a child's life that directly ...impact their health and care and that of their families" (pp. 403, Brehaut et al.,

unpublished manuscript, as cited by Ritzema et al., 2016). Child health complexity was considered as a factor that is focused on the mothers' concern for their child's functioning in a variety of domains, rather than focusing on the mere presence or absence of a particular symptom. As mentioned previously, this line of thinking is in agreement with the non-categorical approach to disability; it focuses on commonalities among the child's functioning and not individual symptoms, which is in line with the measure of child health complexity (i.e., AMC-26). If complexity is a significant factor in predicting the outcomes of cognitive appraisal, the non-categorical approach will be supported, meaning that it is not necessary to categorize children by specific diagnosis, but rather, by functioning because such conceptualization enables a greater number of individuals to benefit from the research study.

Parenting Factors

Parenting Behaviour

Parenting, or child-rearing has historically been understood as the influence that parents have on their child through habitual patterns of interaction (Holden & Miller, 1999; Maccoby & Martin, 1983). Radke-Yarrow, Zahn-Waxler and Chapman state that "In theories of child-rearing, parental behavior is assumed to have effects on children through a history of experiences. There is faith that, over time, parental influences lead to generalized behavior tendencies that have some durability" (pp. 223, as cited by Holden & Miller, 1999). Thus, a child's developmental outcome is affected by their parents' recurrent interactions with them. These stable patterns of child-rearing are responsible for the relationships between parenting practices and child outcomes (Holden & Miller, 1999). However, evidence exists that parenting does change over time, and may depend on the child's developmental stage (Holden & Miller, 1999; Roberts, Block & Block, 1984). For example, Roberts, Block and Block (1984) found

evidence for substantial continuity in some parenting practices over time, and significant changes in other parenting practices over time. Nevertheless, the effects of parental influence on child development have been widely established (e.g., Baumrind, 1971; Darling & Steinberg, 1993).

Differences in parenting behaviours among children. Differences in parenting between children with neurodisability and typically-developing children have been found that highlight the challenges present in parenting a child with high needs. Woolfson and Grant's (2006) study examined, whether the amounts of nurturing and restrictive parenting differed between typically-developing (TD) children and children with developmental disability (DD). The study was cross-sectional, and included four groups of children; two groups of 3 to 5 year-olds, one DD and one TD, and similarly, two groups of 9 to 11 year-olds. Healthy parenting characterized by high nurturance and high restrictiveness (i.e., authoritative) was used less often for children with developmental delay age 9 to 11 years, compared to the children in the younger age group with developmental delay. The opposite pattern was found for typically-developing children, in which parents used high nurturance and high restrictiveness less often when the child was younger, and more often when the child was older (Woolfson & Grant, 2006). However, the study was cross-sectional in nature, and therefore whether the same pattern would emerge had the same participants been followed over time, is unknown. The authors suggest that parents of children with developmental disabilities may find that using authoritative parenting is challenging due to characteristics of the child's disability and the demand on time and energy to achieve successful authoritative parenting being high (Woolfson & Grant, 2006).

Canadian Longitudinal Parenting Behaviour Research. The Canadian National Longitudinal Survey of Children and Youth (NLSCY) involved a collection of data in a large sample of children and their families from across Canada from 1994 to 2009, and was conducted

by Statistics Canada and Human Resources and Skills Development over 8 cycles (Statistics Canada, 2009). Although data were collected longitudinally, the analyses were cross-sectional in nature. In the NLSCY, the children were categorized as having a neurodevelopmental disability only (NDD; $n = 815$), NDD and externalizing behaviour ($n = 452$), externalizing behaviour only (EBP; $n = 1322$), and neither an NDD nor externalizing behaviour ($n = 11376$). The children with NDDs had a diagnosed condition and/or functional limitations, and children with externalizing behaviour were categorized as such if their scores were above the mean score on a child behaviour measure.

The use of parenting behaviours in children with neurodisabilities was investigated with the NLSCY data. The level of use of consistency, positive interaction, and ineffective/hostile parenting behaviours in children age from 4 to 11 years was investigated. For parenting characterized by consistency, children with an EBP and children with both NDD and EBP, experienced significantly lower amounts in comparison to children with neither condition or with an NDD (Garner et al., 2011; Arim et al., 2012; Arim et al., 2015). For hostile/ineffective parenting, it was used most often for children with both NDD and an EBP. Ineffective/hostile parenting was used by parents of children, in decreasing order, with both conditions, with an EBP, with an NDD, and with neither condition (Garner et al., 2011). For children with NDD, both or neither condition, girls received less hostile/ineffective parenting than boys, and the difference was largest by gender for children with an EBP (Arim et al., 2012). For positive interaction parenting, it was used least often by parents of children with an EBP in comparison to children with neither condition, after controlling for socio-demographic variables (Garner et al., 2011).

Child, parental and social context variables were investigated as predictors of consistency parenting. Consistency parenting behaviour was used more often with older children or if the child had siblings. It was used more frequently by non-biological parents, parents with a college education or higher, and parents with a higher household income. It was used more often when the parent reported lower depressive symptoms, lower family dysfunction and were receiving help from religious or spiritual leaders (Arim et al., 2012). Hostile/ineffective parenting was higher in families in which the child was younger, and the parent was male and a biological parent. It was used more frequently by parents that reported higher depressive symptoms, higher family dysfunction, and higher social support, and that were using magazines and books for help. For children with an NDD, parents used less ineffective parenting when they were also receiving help from community or social services personnel. Their level of use was close to children with neither condition, which was the lowest among the conditions (Arim et al., 2012). Further, child's poorer psychosocial outcomes were significantly correlated with ineffective parenting, such that poorer scores on indicators of psychosocial functioning (i.e., peer relationships, general self-esteem, prosocial behaviour, anxiety-emotional problems) were correlated with higher ineffective parenting. For children with both an NDD and an EBP, the higher use of hostile/ineffective parenting was predictive of lower levels of peer relationships in the children, and for all groups of children in the NLSCY, it was predictive of lower general self-esteem (Arim et al., 2015).

The relationships to the use of ineffective parenting with problem behaviour in children has been established in other countries as well. An example of the relationship between ineffective parenting discipline practices and child problem behaviour in children with neurodisability was evident in another cross-sectional study, conducted in Japan. The use of

parenting over-reactivity was linked to children with higher amounts of difficult behaviour (Suzuki et al., 2015). Over-reactivity was defined as harsh or punitive parenting involving anger, meanness and irritability (Arnold et al., 1993). The children were from 3 to 18 years old and had a variety of disabilities including autism spectrum disorder, attention deficit hyperactivity disorder, learning disability, intellectual disability or a combination of more than one of these (Suzuki et al., 2015).

In the preceding section, a number of studies (Arim et al., 2012; Arim et al., 2015; Garner et al., 2011; Woolfson & Grant, 2006) pertaining to parenting behaviours in typically-developing children and children with a neurodisability were discussed. As demonstrated by the research presented, there are differences in the parenting behaviours used by parents of children who are typically-developing and children with various health conditions. In the study by Woolfson and Grant (2006), the use of healthy parenting characterized by high nurturance and high restrictiveness differed by age and condition of the child. It was used more often in groups of younger children with developmental delay and older typically-developing children. A wealth of data from the studies using the Canadian National Longitudinal Survey of Children and Youth (NLSCY; Arim et al., 2012; Arim et al., 2015; Garner et al., 2011), was used to analyze parenting behaviours, in regards to the child's health condition, as well as demographic, social and family-related variables. Among the results from the NLSCY analyses, most importantly it was revealed that children with the presence of an externalizing behaviour receive lower quality parenting in comparison to children without one (Arim et al., 2012; Arim et al., 2015; Garner et al., 2011). Although research related to child outcomes and parenting behaviours was found, research about the relationships between parenting behaviours and cognitive appraisal of the family impact, was not found in the published literature reviewed. Other findings regarding

family-related variables are available and parenting behaviours were linked to family dysfunction, which was lower in families in which parents reported using parenting consistency and higher in families in which parents were using ineffective parenting (Arim et al., 2012). Continued research into the relationship between parenting behaviour among children with a NDD and the family-related variables, including cognitive appraisal, is needed in order to understand whether the parents' parenting behaviour can affect how they appraise the family impact of raising their child. Another aspect of scholarship examines parenting attributions and the research pertaining to parent attributions in parents and children at-risk and in children with neurodevelopmental disability is presented next in order to understand how parent attributions influence parenting.

Parent Attributions

Human interaction with others is influenced by the individual's inferring of a cause as to why things happen as they do, such as why individuals behave a certain way (Bugental & Happaney, 2002). For example, an individual may think that their partner is being uncommunicative because they are sick, whereas another may think it is because they are angry. Individuals make attributions of cause about their own behaviour and events (Bugental & Happaney, 2002).

In a review of the theoretical underpinnings and research pertaining to attributions Bugental, Johnston, New and Silvester (1998) state that the attributions that parents make have important implications for their emotional and behavioural responses, and family relationship quality. Research pertaining to parent attributions is focused on the attributions that parents make about their own actions, and about their child's social behavior and interactions (Bugental et al., 1998). Attributions vary across different contexts, such that parents vary their attributions

depending on the setting and the individual, and their interpretation of the interaction or behaviour. Individuals also rely on their own history in making attributions, and because history differs among individuals, differences in attributions and reactions are expected.

Parents make attributions of control over caregiving outcomes. A successful interaction between a parent and child may be deemed by the parent as due to their own control over that event, or as due to their child's control over that event. The attributions that parents make within their relationship with their child facilitates their ability to respond to their child (Bugental & Happaney, 2002). For example, a child that is crying may be inferred to be doing so for a few reasons: hunger, frustration, or pain or the parent may believe the child is intentionally trying to annoy the parent. This situation may elicit a variety of responses from the parent, depending on what he or she attributes the crying behaviour to. Responses may include frustration, anger, affection, sympathy, or other positive or negative responses.

The majority of studies discussed below have used a test that measures parent attributions (Parent Attribution Test, PAT; Bugental, 2004; Bugental, Blue & Cruzcosa, 1989), in which attributions that parents make are described in terms of two dimensions: one which identifies that causes for the success or failure of an event are due to the self, or adult, and one in which the causes for success or failure of an event are due to the child. These two dimensions are then combined to create a measure of balance of power. Balance of power is perceived as low if the child is perceived as having more control over an event than the parent. High balance of power occurs when the adult perceived themselves as having more control over success or failure of an event than the child.

Parent attributions in parents and children facing adversity. The attributions that parents make are affected by their own cognitive notions of the caregiving relationship and that

of their child's characteristics from a very early age (Bugental & Happaney, 2004). Families at risk for child maltreatment were recruited to investigate mothers' attributions of their newborn child's behaviour at the time of birth and one year later. The PAT (Bugental et al., 1989) was used to assess mothers' parent attributions of causes for negative caregiving outcomes described in a vignette. Their scores were deemed to be high or low on attributions on two dimensions; for the child as a cause for the negative caregiving outcome, and for the adult (themselves) as the cause for the negative caregiving outcome. The relationships of the parent attributions to the child's mild medical risk, determined by their low Apgar score at birth or earlier than expected birth (but not premature), and to maternal characteristics of harsh parenting, depressive symptoms, and safety neglect, were investigated.

Mothers whose infants were at higher medical risk, and reported a low perceived balance of power (high power attributed to the child and low power attributed to the self) reported the highest use of harsh parenting after one year. Similarly, mothers with a perceived low balance of power and high-risk infants also had the highest level of safety neglect (i.e., high child accidental injury and household hazards) and the highest levels of depressive symptoms, at one-year follow-up. These results suggested that the attributions that parents made sensitized them to respond towards their child's behaviour as a potential threat. In addition, it is possible that mothers who perceived low power made low investment in providing protective care to their child. Due to the presence of these attributions at birth, the authors suggested that they originate in the parents' own personal history, and are not a result of prior experience with their child (Bugental & Happaney, 2004; Grusec & Mammone, 1995).

The role of parent and child characteristics in making parent attributions was also evident in young and pre-adolescent children and their mothers (Bugental et al., 1989). The parents and

children in this study were unique in that the children were classified as ‘difficult’ and mothers were chosen to participate due to their history of being at risk for, or committing child abuse. Parent attributions in mothers who had sought counseling for child abuse were investigated and were divided into two groups: those that had been abusive to two or more of their children, and other mothers that had not been abusive but were seeking help. The mothers all had two or more children between the ages of 3 and 13 years. The study involved interacting with their own pairs of children and involved completing a jigsaw puzzle over a short time period of several minutes as well as several questionnaires. In each sibling pair, one child was deemed to be more ‘difficult’ than the other by the mother.

The authors investigated the relationships between mothers’ perceived control over failure, as well as their reports of adult attribution of control over failure (ACF), and attributions of child control over failure (CCF) in the two groups of mothers. Mothers with low levels of perceived control over failure were more likely to belong to the group that was abusive towards one or more of their children. Adult attributions of control over failure (ACF) were inversely related to abusiveness, meaning that the more the mothers attributed failure to themselves for caregiving, the more likely that they were in the abusive group. The attributions of child control over failure were not significant predictors of mothers’ membership to the abusive or not group. There was also a significant relationship between being an older mother and belonging to the abusive group (Bugental et al., 1989).

Higher use of maternal coerciveness, a caregiving style consisting of using force or threats, was also predicted by low perceived control over failure, and similarly, higher ACF and lower CCF was predicted by lower coerciveness. This relationship was found to be more likely

with the one child in the sibling pair that mothers had deemed as ‘more difficult’ than the other (Bugental et al., 1989).

Thus, the findings of this study reveal that abusive mothers with low perceived control over caregiving failure, were less likely than non-abusive mothers to believe that they can act to prevent negative caregiving outcomes. They were also more likely to believe that their child had control over caregiving outcomes. These findings indicate that different adults will have different reactions to children if they believe that the behaviour of the child is intentional versus non-intentional, such as a reaction to the environment, or behaviour related to tiredness or hunger. Parents who perceived themselves as having low power were expected to respond more negatively than other parents (Bugental et al., 1989).

Similar results regarding fathers’ parent attributions for interactions with their own school-aged children have been found (Bugental & Happaney, 2000). In this study, parents completed tasks in which they were primed to compare themselves with their children in order to induce a situation of social stress or threat. For example, parents were asked to judge whether they or one of their children were nicer, sadder, friendlier, etc., than themselves. This priming task was done in order to induce negative affect. Fathers who completed the priming task and who reported low perceived balance of power (i.e., ratio of high control over failure attributed to child, and low control over failure attributed to parent) were more likely to provide negative feedback about their child’s performance on a maze and drawing task than fathers who were primed but perceived themselves as having a high balance of power. Low power fathers gave higher amounts of verbal derogation and a lower performance evaluation of their child’s performance. When fathers were not primed, there was no significant difference in the amount of verbal derogation and level of performance evaluation in high versus low perceived power

balance parents. However, it was noted that children responded to their father in a significantly shorter conversation than the children whose fathers used a non-derogatory style of conversation (Bugental & Happaney, 2000).

The parent attributions of parents facing adversity, in that their child was at-risk or the parent was at-risk or was abusive, were presented here. Parent attributions are evident in mothers as early as birth, and those characterized by low balance of power, were associated with more negative outcomes for infants at-risk and their mothers, such as higher safety neglect and increased depressive symptoms (Bugental & Happaney, 2004). In abusive mothers raising a ‘difficult’ child, attributions were of parental low control and high perceived power of the children (Bugental et al., 1989). Fathers who believe themselves to be of low power were more negative in their feedback towards their child’s performance on a task (Bugental & Happaney, 2000). Taken together, parents who made attributions characterized by low adult control and high child control, or low balance of power, were reacting negatively and providing adverse environments for their child. A link between parent attributions to another variable in this study, harsh parenting, showed that parents with low balance of power used harsher parenting with their child. How parent attributions relate to children with a neurodevelopmental disability experience is described in the next section.

Parent attributions for children with neurodisabilities. Different relationship patterns among families raising a child with a disability have been found in terms of parent attributions. Johnston and Freeman (1997) have researched the attributions of parents of children who have attention-deficit-hyperactivity disorder (ADHD). Although Johnston and Freeman did not use Bugental’s PAT scale (1989), the insight into attributions with children with a disability is informative. Their scale consisted of 10 items in which attributions of cause for the child’s

behaviour included measures of: locus (something about child versus other people or the situation), control (within child's control or not within control) and stability (one time versus will happen again in future). The mothers also reported the responsibility they felt towards their child's behaviour and their reaction to the behaviour. Ratings were made based on examples of their child's compliant and non-compliant behaviour during a laboratory task.

Parents with a child with ADHD viewed their child's behaviours, which included overactive-inattentive and oppositional-defiant behaviour, as internally caused by the child, less controllable, and more stable in comparison to parents with children without behaviour disorders (Johnston & Freeman, 1997). Parents took less responsibility for their child's behaviours than parents of children without behaviour disorders. The authors concluded that parents were making attributions consistent with the characteristics of the children's chronic disorder, and not blaming the child for their own behaviour. This suggested that the presence of a disorder may serve to prevent parents from making more harmful attributions of blame to the child.

Johnston et al. (2000) investigated the attributions of two groups; one consisted of mothers with a child with ADHD that were medicated and another group of mothers whose children were not yet medicated. Mothers with medicated children rated their children's compliant and non-compliant behaviour differently. The cause of medicated children's compliant behaviour was seen as more global and more internal, and mothers reported less responsibility and more positive feelings towards their child's behaviour compared to the non-medicated group. For non-compliant behaviour, mothers in the medicated child group indicated that their child's behaviour was less internal, global, and stable than mothers in the non-medicated group.

In terms of attributions about the child's ADHD symptoms, mothers reported the symptoms as less global and less stable, but more controllable by the child. For oppositional

behaviour, mothers rated it as less global and less stable, but more controllable in comparison to children that were not medicated. Mothers with children in the medicated group reacted less negatively to oppositional behaviour compared to the not medicated group. The authors also investigated mothers' attributions for prosocial behaviours, and for those who had children in the medicated condition, mothers rated their child's behaviours as more global and stable than in the not medicated condition. The authors suggest that mothers' attributions are more adaptive when their child is medicated – they see positive behaviour as more dispositional, enduring and pervasive (Johnston et al., 2000). They hypothesize that parents may be able to respond more positively to their child. However, oppositional behaviour was seen as more controllable by the child, and perhaps demonstrated that parents may react more harshly to behaviour when child displays it, on medication.

In another study of parent attributions in children with moderate to severe intellectual disability conducted by Chavira, Lopez, Blacher and Shapiro (2000), similar results were found to that of Johnston and Freeman (1997) and Johnston et al. (2000); mothers did not attribute responsibility to child behaviour that was seen as part of their disability. Children ranged in age from 3 to 19 years and families were mostly of Mexican origin. Mothers viewed their child as responsible for their own problem behaviour if they perceived it as a behavioural excess, such as acting out behaviours, which included temper tantrums, self-injury and aggression towards others. They did not view their child as responsible for their behaviour nor react with negative emotion if it was viewed as a behavioural deficit (absence of behaviour that was expected), such as behaviour related to communication, walking or toilet training. This difference, in which it was more likely for mothers to attribute responsibility for behavioural excess versus behavioural

deficit, was significant. This demonstrated that parent attributions were indeed affected by the different types of behaviours that the child displayed.

The type of behaviour that their child displayed predicted mothers' negative emotional reactions to that behaviour. Behavioural excesses were responded to with more negativity in comparison to behavioural deficits. Mothers' own behavioural reactions were investigated as well, and when mothers attributed high ratings of responsibility to the child for their behaviour, they were more likely to respond with aggressive behaviour, such as harsh talking, yelling, hitting or spanking, towards their child (Chavira et al., 2000). The authors investigated whether this relationship stood with child-related factors co-varied out of the analysis, and it was revealed that parents' attributions alone were predictors of their aggressive behaviour.

In parents of children with autism spectrum disorder, mothers made differing attributions based on the type of child behaviour. This study was in a sample of 59 mothers with children with autism spectrum disorder age 2 to 9 years. The attributions were measured using the Parental Attribution Questionnaire (Whittingham, Sofronoff, & Sheffield, 2006), which was designed by the authors specifically for their study. The parents rated their agreement with attributional statements in three scenarios in which the child's behaviour was good, bad/misbehaviour, or demonstrated autism spectrum disorder-related behaviour (ASD-related). For autism spectrum disorder-related behaviour, the parent was not given any specific type of behaviour to consider, but prompted to consider behaviour that they felt was behaviour characteristic of autism or Asperger's to them. The attributions were for parent or child as the cause of the behaviour, and for the parent-related and child-related causes, the parent was asked to rate locus (internal or not), stability (persisting over time) and controllability (degree to which can control). Parents rated their child's ASD-related behaviour and their misbehavior as being

less controllable by the child and less controllable by the parent than good behaviour. The parent also did not rate themselves as a cause of these behaviours, but did so for positive behaviour. The parents also rated their child's good behaviour, misbehavior and ASD-related behaviour as all influenced by internal characteristics of their child. The authors suggest that parents may be less likely to attempt to change their child's behaviours because they attribute the behaviour as caused by the child, and less controllable by the child or the parent (Whittingham, Sofronoff, Sheffield, & Sanders, 2008).

The parent attributions of parents with a child with a neurodisability that were discussed above highlight that parents make different attributions about their child's behaviour when they have a disability. Research pertaining to parent attributions made by parents of a child with ADHD demonstrated that parents made attributions that were consistent with the characteristics of the children's chronic disorder, blaming neither the child nor themselves for their behaviour (Johnston & Freeman, 1997). This was also evident in a study of children with ADHD who were medicated, mothers reported less responsibility and more positive feelings towards their child's behaviour compared to the non-medicated group. Mothers' attributions are more adaptive when their child is medicated, and they saw positive behaviour as more dispositional, enduring and pervasive (Johnston et al., 2000). In addition, similar results were found in a study with a wide age range of children with disabilities in which mothers did not view their child as responsible for their behaviour nor react with negative emotion if it was viewed as a behavioural deficit (Chavira et al., 2000). In parents with a child with an autism spectrum disorder, the attributions of child-caused and parent-caused behaviours differ depending on the behaviour, with children seen as less controllable over their ASD-related behaviour and misbehaviour (Whittingham et al., 2008). The results of these studies demonstrated more favorable reactions from parents when

they deemed their child's behaviour being related to other factors, and not under the individual child's control. From the research reviewed here, the link between parent attributions and children with a disability is apparent, however, the link to family-related variables in families raising a child with a neurodisability has not yet been established. Further research regarding the family, such as how cognitive appraisals relate to parent attributions, will help us better understand the role that attribution plays and whether it should be a target for psychosocial intervention.

Chapter 4: Study Goals and Hypotheses

The overall aim of the present study was to learn about the experiences of families with a child with a neurodisability and to gather new knowledge to develop intervention for improving family outcomes. The specific research questions were to investigate whether parenting factors were predictive of, and moderated mothers' formation of positive and negative cognitive appraisals of the family impact of caring for their child with a neurodisability.

Hypotheses 1 and 2: Predictors of Positive and Negative Cognitive Appraisals

The first research question pertained to whether certain factors predict mothers' positive and negative cognitive appraisals of the family impact of child neurodisability. These factors include child characteristic variables and parenting variables. The variables pertaining to child characteristics are child difficult behaviour and child health complexity. The parenting variables include three parenting behaviours: (a) positive interaction, (b) consistency, and (c) hostile/ineffective; and two parent attributions: (a) adult control over failure, and (b) child control over failure. The two outcome variables are positive cognitive appraisal and negative cognitive appraisal. Due to the exploratory nature of this study, the directionality of the relationships between the predictors and outcomes were not hypothesized.

For Hypothesis 1, it was hypothesized that the following predicted positive cognitive appraisal: child difficult behaviour, child health complexity, positive interaction, consistency, hostile/ineffective parenting, adult control over failure and child control over failure.

For Hypothesis 2, it was hypothesized that the following predicted negative cognitive appraisal: child difficult behaviour, child health complexity, positive interaction parenting,

consistency parenting, hostile/ineffective parenting, parent attribution of adult control over failure and child control over failure.

Hypotheses 3 and 4: Moderators of the Relationship between Child Difficult Behaviour and Cognitive Appraisals

The second research question addressed whether the relationships between the child's difficult behaviour and mothers' cognitive appraisals changed, or were moderated, depending on parenting factors (i.e., parenting behaviours and parent attributions). For example, does the relationship between the child's difficult behaviour and mothers' negative cognitive appraisals change depending on their level of hostile/ineffective parenting behaviour? The impact of an independent variable, child difficult behaviour, on a dependent variable, mothers' negative cognitive appraisals, may differ depending on a third variable, a moderator, hostile/ineffective parenting (See Figure 2). It is possible that the relationship between the child's difficult behaviour and mothers' negative cognitive appraisals is changed by a high level of hostile/ineffective parenting. This example and the hypotheses stipulated for the current study entail the use of a moderation model.

A moderation model was used to investigate the subsequent hypotheses in order to hypothesize about the conditions under which a relationship differs. The parenting variables act as moderators in the subsequent hypotheses. Each parenting variable was individually tested as a moderator between the relationship between child difficult behaviour and negative cognitive appraisal, and as a moderator between the relationship between child difficult behaviour and positive cognitive appraisal.

Hypotheses 3 and 4 were devised for each type of cognitive appraisals; one set for negative cognitive appraisals and one for positive cognitive appraisals. For each set of hypotheses, five moderation analyses were specified, one for each parenting variable. Due to the exploratory nature of this study, the direction in which the moderator variables would change the relationship between child difficult behaviour and mothers' cognitive appraisals were not hypothesized.

For Hypothesis 3, it was predicted that the following variables would change the direct relationship between child difficult behaviour and mothers' negative cognitive appraisal: mothers' level of parenting behaviours of positive interaction, consistency and hostile/ineffective parenting, and the parent attributions of adult control over failure and child control over failure. Five moderations were tested to investigate Hypothesis 3, one moderation for each of the five parenting variables.

For Hypothesis 4, it was predicted that the following variables would change the inverse relationship between child difficult behaviour and mothers' positive cognitive appraisal: mothers' level of parenting behaviours of positive interaction, consistency and hostile/ineffective, and the parent attributions of adult control over failure and child control over failure. Five moderations were tested to investigate Hypothesis 4, one moderation for each of the five parenting variables.

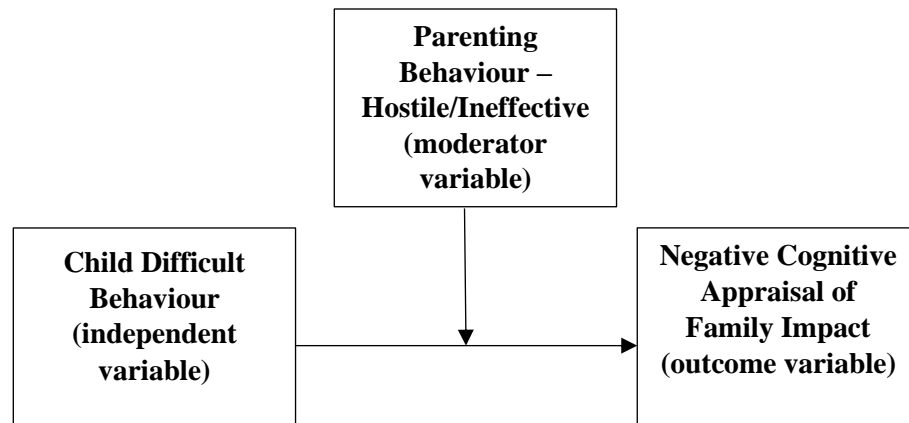


Figure 2. Diagram of a moderation model.

Operationalization of Variables

Hypotheses 1 and 2: Predictors of Cognitive Appraisals

The predictor variables in Hypotheses 1 and 2 were child health complexity and child difficult behaviour, as well as the parenting variables. As in Hypotheses 1 and 2, child health complexity was operationalized using the About My Child, 26 item version (Rosenbaum et al., 2008) questionnaire and child difficult behaviour was operationalized by the Strength and Difficulties Questionnaire – Total Difficulties subscale (Goodman, 1997). The parenting behaviours of positive interaction, consistency and hostile/ineffective were operationalized using the scales of the Parenting Your Child Scale (National Longitudinal Survey of Children and Youth, 1994), and parent attributions of adult control over failure and child control over failure, were operationalized using the Parent Attribution Test (Bugental, 2004). The outcome or dependent variables were the positive and negative cognitive appraisal of family impact and were operationalized using the Family Impact of Childhood Disability Scale – Positive Family Impact subscale and Negative Family Impact subscale (Trute, Hiebert-Murphy, Benzies, & Levine, 2009).

Hypotheses 3 and 4: Moderators between Child Difficult Behaviour and Cognitive Appraisals

The independent variable for Hypotheses 3 and 4, was child difficult behaviour, and was operationalized by the Strength and Difficulties Questionnaire – Total Difficulties subscale (Goodman, 1997). The moderator variables were the parenting behaviours and parent attributions. The parenting behaviours of positive interaction, consistency and hostile/ineffective were operationalized by the scales of the Parenting Your Child Scale (National Longitudinal Survey of Children and Youth, 1994), and parent attributions of adult control over failure and child control over failure were operationalized by the Parent Attribution Test (Bugental, 2004). The outcome or dependent variables were the positive and negative cognitive appraisal of family impact and were operationalized with the Family Impact of Childhood Disability Scale – Positive Family Impact subscale and Negative Family Impact subscale (Trute, Hiebert-Murphy, Benzies, & Levine, 2009).

Method

This study was undertaken as a secondary data analysis of the Parenting Matters! study. See Appendix A for details of ethical approval.

Recruitment and Selection Criteria

In the larger Parenting Matters! study, potential participants were notified about the study by their family health care or service provider, and/or by advertisement. Participants were approached if their child met the age criteria (4 to 12 years old) and had received a diagnosis indicative of a neurodevelopmental disorder. In order to respect the emotional distress in receiving a diagnosis, participants were only approached if their child had been previously

diagnosed over 6 months ago. Participants were excluded from participation if they did not have at least a Grade 5 level of reading ability. Only mothers from the larger Parenting Matters! study were included in the current study and fathers were excluded. Children who did not meet the criteria for diagnosis of a neurodisability nor meet the age criteria were excluded. Some children that were recruited by Parenting Matters! had diagnoses that were deemed secondary to other types of diagnoses, and were not included. For example, the excluded children had diagnoses of attention-deficit-hyperactivity-disorder or a specific learning disability as their primary diagnosis. The primary diagnoses of the children included in the sample severely affected their functioning; for example, 74.5% of the sample reported that the child's ability to move around at home, school or in the community was impaired.

Participants were approached in major health centers servicing families with a child with a neurodevelopmental disorder in cities across Canada. In Montreal, Quebec, participants were recruited from the Montreal Children's Hospital, Miriam Home and Services, West Montreal Readaptation Centre, Shriner's Hospital for Children, Jewish Rehabilitation Hospital, and Mackay Rehabilitation Centre. In Ontario, the participants were recruited from the Hospital for Sick Children (Toronto), Holland Bloorview Kids Rehabilitation Hospital (Toronto), Surrey Place Centre (Toronto), McMaster Children's Hospital (Hamilton), Erinoak Kids Centre (Mississauga), and Grandview Children's Centre (Oshawa). In Alberta, participants were recruited from Alberta Children's Hospital in Calgary, and in Edmonton, Stollery Children's Hospital and Glenrose Rehabilitation Hospital. For the included sample, the children were referred to the study by pediatric hospitals (43.9%), rehabilitation hospitals (36.2%) and other locations (19.9%). The location from which the participant was recruited was recorded and is indicated in Table 1.

Table 1

Percentage of Sample from Each Service Centre in Each Province

Service Center	% (N=196)
Quebec	
Montreal Children's Hospital	3.7
Shriner's Hospital	2
Mackay Rehabilitation Centre	0.5
Ontario	
Hospital for Sick Children	36.7
Holland Bloorview Kids Rehabilitation Hospital	35.3
Surrey Place Centre	6.6
McMaster Children's Hospital	3.1
Erinoak Kids Centre	6.1
Grandview Children's Centre	2
Alberta	
Alberta Children's Hospital	2
Stollery Children's Hospital	1
Glenrose Rehabilitation Hospital	1

Participants

A total of 629 parents were approached for participation in the Parenting Matters! study. Two-hundred sixty-four parents completed all the necessary questionnaires, a response rate of 42 percent. The remaining 365 participants (58%) did not complete questionnaires after providing consent for participation. The 365 participants were attempted to be contacted a maximum of three times in order to encourage them to participate. No identifying data was kept on record to analyze any differences between the participants who participated and those who did not, therefore, no comment can be made regarding any differences between these two groups. The 264 completed participants consisted of 212 mothers and 52 fathers. Eleven participants were

excluded because the child did not meet the criteria for diagnosis of a neurodisability and another four participants did not meet the age criteria. For example, some children that participated had diagnoses that were not included in the final analysis, such as attention-deficit-hyperactivity-disorder, specific learning disabilities. The 52 fathers that participated were not included in the data analysis for the current study. Two parents from one family, both female, completed information about their child, therefore one of the mothers' data was excluded to prevent duplicate reporting. Taking into account the excluded children, fathers, and mother, the remaining participant sample size was 196. The participants came from three provinces; 4.1% were from Alberta, 6.1% were from Quebec, and 89.8% were from Ontario.

The data collected from the mother of the child with neurodisability (ND) were used for the current study and included biological mothers (93.9%), adoptive mothers (1.5%), step-mothers (1%), foster mothers (1%), common law female partners (1%), and other (.5%). Two participants (1%) did not indicate the type of relationship to their child.

The 196 children included in the study were ages 4 to 12 years old ($M = 8.10$ years, $SD = 2.42$ years) and consisted of 72 females (36.7%) and 124 males (63.3%). The mothers were 27 to 70 years old ($M = 42.5$, $SD = 7.18$ years). Each child had one primary diagnosis, which was decided by consensus by two of the investigators (Drs. Anton Miller and Peter Rosenbaum), both who are developmental pediatricians. The children with NDs had diagnoses of autism spectrum disorder, cerebral palsy, epilepsy, global developmental delay, or had multiple impairments. Children with multiple impairments included those that had at least two areas in which they were functionally impaired, such as physical and cognitive impairments and children with cerebral dysgenesis with uncertain functional prognosis. Children with multiple impairments also included a subset with a ND - not otherwise specified. The primary diagnoses of the children in

descending order included cerebral palsy, autism spectrum disorder, global developmental delay (GDD), epilepsy and multiple impairment. See Table 2 for the details of the child's age and type of neurodisability.

Table 2

Child Age and Type of Neurodisability Presented as a Percentage of the Sample

Child characteristics	n	%
Age		
4-5	38	19.4
6-8	64	32.6
9-12	94	48
Type of neurodisability		
Cerebral Palsy	73	37.2
Autism Spectrum Disorder	51	26
Global Developmental Delay	36	18.4
Epilepsy	19	9.7
Multiple Impairment	17	8.7

In terms of education, children were at a variety of stages, and some mothers reported that their child attended more than one setting. The data collected did not allow for discerning which type of education the child spent most of their time in. The majority of the children in the sample attended elementary school in a regular classroom (48.5%). An approximately even amount of children attended either a regular program with assistance in the classroom, or a special education program (30.1% and 26.5%, respectively). Some children attended regular school with withdrawal assistance programming, in which extra aid was provided outside the classroom (11.2%). Special education school was attended by 17.9% of the children. For children that were below elementary school age, 3.1% attended preschool, and 4.6% attended daycare. A few children attended home school (1.5%) and some, did not attend school yet

(2.6%). Another 13.8% of the children attended school classified as 'other'. Mothers who indicated 'other' for their child's education included children receiving intensive behavioral intervention or occupational therapy for the majority of the educational hours during the week, children attending private schools, and other children were attending school that differed from the standard categories offered in the education options provided on the study checklist.

Data for the family composition, household income, community size, parent education and employment were collected as well. The families consisted of single (16.8%, $n = 33$), two parent (80.1%, $n = 157$) or 'other' (3.1%, $n = 6$) type of families. The number of children per family was as follows: 23% had 1 child ($n = 45$), 45.9% had 2 children ($n = 90$), 17.9% had 3 children ($n = 35$), 4.6% had 4 children ($n = 9$), and an additional 5% ($n = 10$) had 5 to 9 children. Twenty of the families had 2 children with a ND (10.2%), 4 of the families had 3 children with a ND (2%), 1 family had 5 children with a ND (.5%), and the remaining 171 children or 87.2% of the sample, had one child with a ND. In terms of birth order, 115 or 58.7% of the children with a ND were first-born, 46 or 23.5% were second-born, and 22 or 11.2% were born as a third-child, and the remaining were fourth-born to sixth-born ($n = 13$, 6.6%). Time since disclosure of the diagnosis was not recorded, however, the child's age at diagnosis was gathered. The child's age at diagnosis was from 1 to 2 years old for 18.9% of families, 2 to 3 years old for 12.2% of the families, 3 to 5 years old for 18.4% of the families and for children 6 years or older, 4.1%. Approximately one-third of children were younger than 1 year old (28.6%), 3.1% were diagnosed before birth, 13.8% were diagnosed immediately at birth, and 1% of families did not indicate when their child received a diagnosis.

The majority of families spoke English at home (93.9%), and 6.1% also reported that they spoke French, while 21.4% spoke other languages which varied greatly. The majority of parents were married or common-law partners.

The families lived in a variety of communities, with the majority of families living in large metropolitan cities with over 1 million people (41.3%), medium metropolitan cities (17.3%), and small metropolitan cities with a population under 250,000 (19.4%). Other families lived in non-metropolitan, urbanized communities with populations from 20,000 to 49,999 (7.7%); 9.2 percent lived in non-metropolitan, less urbanized communities with less than 20,000 people, and 4.6 percent lived in rural communities (less than 2500 people). For the household income levels, see Table 3 for the percentage of the sample stratified by household income.

Table 3

Family Characteristics Presented as a Percentage of the Sample

Family characteristics	% (N = 196)
Languages spoken	
English	93.9
French	6.1
Other	21.4
Marital Status	
Married or common-law	82.1
Separated, divorced, widowed or single	17.8
Household Income	
Less than \$89,999	50.1
More than \$90,000	44.4
Breakdown of income:	
Less than \$10,000	3.1
\$10,000 to 19,999	5.1
\$20,000 to 29,999	5.6
\$30,000 to 39,999	6.6
\$40,000 to 49,999	5.1
\$50,000 to 59,999	4.6
\$60,000 to 69,999	8.2
\$70,000 to 79,999	7.7
\$80,000 to 89,999	4.1
\$90,000 to 99,999	5.6
\$100,000 to 109,999	8.2
More than \$110,000	30.6
Not indicated	5.6

The majority of mothers and their partners completed university or had completed college or technical training. See Table 4 for details regarding the mothers' and partners' education. The main activities that mothers spent the majority of their time in was caring for the family (73.5%), full-time paid work (39.3%), part-time paid work (14.8%), attending school (7.1%), looking for

work (4.1%), recovering from illness/disability (3.6%), and retired (2%). Close to 9.7 percent of the mothers engaged in activities other than the options provided, such as full or part-time self-employment, advocacy, or volunteering, and others stated that they were looking for work due to relocation, or had recently resigned.

Table 4

Parents' Level of Education Attained Presented as a Percentage of the Sample

Level of Education Attained	% (N = 196)
Mother's Education	
Completed university	46.4
Completed college or technical training	30.6
Completed high school	5.1
Some university	5.6
Some college or technical training	8.7
Some high school	3.1
Not indicated	.5
Partner's Education	
Completed university	33.7
Completed college or technical training	24
Completed high school	7.1
Completed elementary school	.5
Some university	4.6
Some college or technical training	8.2
Some high school	5.6
Not indicated	16.3

Procedure

Families were recruited for the study by their family health care or service provider, and/or by advertisement. A list of interested families was given to the research assistants by the service provider. Parents were also able to contact the study coordinators to participate on their own will. A member of the research team subsequently contacted the family by telephone.

Informed consent, inclusion criteria, the purpose and study procedures were explained. Once it was confirmed that the family met inclusion/exclusion criteria, participants were assured that participation was optional, and contact information was collected.

Data collection proceeded thereafter. Participants had the choice to receive the questionnaires in either two packets in which the questionnaires were divided into equal parts, or one packet, depending on the preference of the participant. If the participant chose to receive two packets, the first packet was mailed to the family immediately and the second packet was mailed one month following study enrollment. This format was recommended to the research team by their parent advisory group.

Questionnaires were completed either on paper or online. Parents had access to a research assistant in each city (i.e., Montreal, Toronto, Hamilton, Calgary, Edmonton), and parents were offered to meet with the research assistant to help complete the questionnaires, in the parent's home or in a local public area. The research team members collected and stored the raw data at each health center while the study was ongoing. These were eventually sent to McGill University where a password protected de-identified dataset was created at the Centre For Research on Children and Families. Families were given reminders by telephone to return their questionnaires two weeks after receiving them, and if needed, one month after receiving them. If no questionnaires were received, they were contacted one subsequent time after that. Then, each family received a gift certificate to a local store as compensation for participating.

Measures: Children

Child characteristics. Two scales from two distinct questionnaires are described below. One scale is a measure of child difficult behaviour and is entitled the Strength and Difficulties

Questionnaire (SDQ; Goodman, 1997). The other scale is a measure of child health complexity and is entitled About My Child, 26 item version (AMC-26; Rosenbaum et al., 2008).

Child difficult behaviour. The Strength and Difficulties Questionnaire (SDQ; Goodman, 1997) is a measure of both positive and negative child behaviour attributes and consists of 25 items. It is available for children age 2 to 17, has been used as a clinical and research tool throughout the world, and is available in over 50 languages. It is composed of five subscales: emotional symptoms, conduct problems, hyperactivity/impulsivity, peer relationship problems, and prosocial behaviours, with five items each. The scores from the following four subscales: emotional symptoms, conduct problems, hyperactivity/impulsivity, and peer relationship problems, are summed to obtain a total difficulties score. The prosocial behaviours subscale is not used to calculate the total difficulties score. The Strength and Difficulties Questionnaire - Total Difficulties subscale (SDQ-TD) was used in the current study. The child's parent or caregiver was asked to respond to the items based on a 3-point Likert scale that included *not true*, *somewhat true*, and *completely true*. Examples of items include statements such as, "My child is helpful if someone is crying". For the current study, two versions of the SDQ were used depending on the age of the child, and there is one version for children from 4 to 10 years old, and another for children from 11 to 17 years old. Items that differed for the version for older children were designed to be age-appropriate and are very similar to the items in the version for younger children. For example, for an item about sharing, the difference between the questionnaires for younger versus older children is in referring to sharing toys versus sharing electronics. Thus, the different versions of the questionnaires tap into similar concepts.

The SDQ has been widely used and its' reliability and the validity is well established. The SDQ was evaluated in the United States with 9,878 children and adolescents that

participated in the 2001 National Health Survey in order to obtain data regarding mental health, impairment and service use in the population (Bourdon, Goodman, Rae, Simpson, & Koretz, 2005). The survey is designed to gather data from a civilian, noninstitutionalized sample. Children from each age and gender were equally represented and 92% of respondents were parents and 4.4% were grandparents. Internal consistency was reported with Cronbach's alpha and was excellent for the Total Difficulties scale (0.83), and good to excellent for four subscales (0.63-0.77), however, fair for peer problems (0.46).

Goodman, the author of the SDQ, has completed a number of similar surveys using the SDQ since 1997, up until the most recent published survey in 2011 (Goodman & Goodman, 2011). In the United Kingdom, Goodman (1997) conducted a study in which the SDQ was tested as to whether it distinguished between a clinical and non-clinical sample, as well as to compare it to a Rutter questionnaire, which was a long-established parent report screener of child behavioural problems. The receiver operating characteristic (ROC) curves, in which the sensitivity and specificity of the two questionnaires are plotted, and the area under the curve closest to 1.0 indicated high discrimination and 0.5 indicating discrimination no better than chance were used. The ROC statistic was 0.87 (95% confidence interval = 0.83-0.91) for the SDQ and 0.87 (95% confidence interval = 0.83-0.91) for the Rutter questionnaire, indicating high discrimination among clinical and non-clinical samples.

The SDQ has also been validated for samples of children and adolescents with disabilities. In children and adolescents with intellectual disability, Emerson (2005) checked the reliability and validity of the SDQ for child, parent and teachers in a sample of 98, 11 to 15 year-old children with an intellectual disability that were extracted from a larger population of 4449 children in Great Britain. Cronbach's alpha was also calculated in a sample of 4074 typical

children. The children with intellectual disability were also categorized, if applicable, in addition to an intellectual disability, as having an emotional disorder, hyperkinetic disorder, conduct disorder or other disorder, such as pervasive developmental disorder. For the children with intellectual disability, the internal consistency for the five subscales and total score for the SDQ were acceptable, although peer problems was lower than expected in comparison to the typical sample. The Cronbach's alphas ranged from 0.56 to 0.71 when excluding the peer problems subscale which was 0.30. The highest Cronbach alpha was for total difficulties at 0.71. For the typical children, the Cronbach's alphas were similar, ranging from 0.41 to 0.78 for the subscales and total score, with the peer problems subscale producing the lowest alpha and the total difficulties score, the highest. The SDQ is sensitive to samples with different diagnoses; those with an intellectual disability scored higher on specific subscales compared to typical children, and in comparison to those with an intellectual disability and an emotional disorder, or conduct disorder, or hyperkinesia (hyperactivity). Consistency among different reporters was also investigated. For children with intellectual disability, their parents' and teachers' scores were higher than the children's own self-report scores. Parents' scores were higher for the subscales of total difficulties, peer problems and hyperactivity, and teachers' scores were higher for the subscales of peer problems and prosocial behaviour.

Child health complexity. The About My Child, 26 item version (AMC-26; Rosenbaum et al., 2008; see Appendix B) is a measure of child health complexity and was designed as a tool to gather information regarding the child's functional needs and the family's priorities in caring for their child. The AMC-26 includes nine subdomains related to their child's functioning: physical function, activities of daily living, behaviour, mood, thinking and learning abilities, ability to communicate, social skills with children, social skills with adults, and participation in

activities outside of school. The parent is prompted to respond to the scale items with the following statement: “Compared to other children of the same age, I am concerned about my child’s...” and then an item follows, such as: “ability to tell people what he/she wants”. The parent indicates whether or not this is a concern that he or she has for their child’s functioning, and if so, he or she rates the degree to which their child’s functional limitation impacts the child’s ability to participate in everyday activities. The degree of impact that the limitation has on the child’s ability to participate is rated on a 4-point Likert scale that includes 0 - *not at all*, 1 - *a little*, 2 - *somewhat* and 3 - *a lot*. The scale yields two scores, child health complexity and the overall mean degree of impact. The child health complexity score is calculated by tallying the number of items for which the parent asserts a concern (indicates “yes” as an answer). The overall degree of impact is calculated by adding the degree of impact indicated and calculating the mean. For the current study, child health complexity scores (AMC-26 COM) were used, and a higher score indicates greater child health complexity.

The reliability and validity of the AMC-26 was established in a recent study with 258 parents with a child with a NDD (Ritzema et al., 2016). A four-factor solution was discovered, and Cronbach’s alpha for four subscales ranged from .74 to .85. In the current study, there was a significant correlation between child health complexity and the sum of the degree of impact ($r = .90, p < .01$). Child health complexity was also significantly correlated with the mean degree of impact although the correlation was lower ($r = .39, p < .01$). Significant correlational relationships were found with child health complexity and the degree of impact score in the AMC-26, therefore only the child health complexity score was used for the current study. Support for the use of the child health complexity variable alone has been provided by Ritzema and colleagues (2016).

Measures: Parenting

Parenting was measured with two questionnaires; each one taps into different aspects of parenting, namely parenting behaviours and parent attributions, and are described in detail below.

Parenting behaviour. The Parenting Your Child Scales (PYC; NLSCY, 1994) were adapted from Strayhorn and Weidman's Parent Practices Scale (1988) for the NLSCY and were used in the current study. The PYC scales include the Consistency (PYC-CON), Positive Interaction (PYC-PI) and Hostile/Ineffective scales (PYC-H/I) as measures of parenting behaviour (see Appendix C). The parent was asked to respond to 17 items on a 5-point Likert scale which ranged from 0 to 4 and pertained to frequency of behaviour occurrence. For the PYC-PI scale, choices from 0 to 4 were *never, about once a week or less, a few times a week, one or two times per day, many times each day*. For the PYC-CON and PYC-H/I scales, choices were also from 0 to 4, however the descriptors were different from the PYC-PI scale (i.e., *never, less than half the time, about half the time, more than half the time, all the time*). Parents also had the option to indicate *don't know* for each item. The PYC-CON scale consists of five items, and includes statements that measure the frequency of parents' use of punishment, and frequency of obedience to commands and discipline. A higher score on the PYC-CON scale indicates a greater amount of consistency of use of parenting behaviours and scores range from 0 to 20. The PYC-PI scale consists of five items and statements are focused on frequency of giving verbal praise, amount of time spent in play, and time spent together engaged in preferred activities. The PYC-PI scale's scores range from 0 to 20 and higher scores indicate a greater amount of positive interaction. The remaining seven items pertain to the PYC-H/I scale and parents were asked to respond to items that measure the proportion of praise and disapproval, use of anger while

punishing the child, and frequency of parents' perceived problems with managing their child.

The PYC-H/I scale ranges in score from 0 to 28, and a higher score indicates the use of a greater amount of hostile or ineffective parenting.

As to the reliability and validity of the parenting behaviour scales, the NLSCY study is a Canadian study that was conducted to determine the various risk and protective factors for children and youth, from birth to 17 years, longitudinally and by cross-section. Data collection occurred every two years for eight cycles from 1994 to 2009, and included tens of thousands of children. The NLSCY included a number of child and parent measures amongst others, including the PYC scales. The factor structure and reliability of the three PYC scales were checked for cycle 4 of the study and from a sample of 21, 777 parents who completed the questionnaire about their child. Cronbach's alphas was calculated for each parenting scale and for children ages 2 to 11 years old were all at least acceptable, at 0.78 for PYC-PI, 0.66 for PYC-CON, and 0.70 for PYC-H/I (Statistics Canada, 2001). In another study analyzing the NLSCY data that included the PYC scales, the children were divided into four groups; one group was identified as having a neurodevelopmental disability, one group was identified as having externalizing behaviour problems, another group was identified as having both a neurodevelopmental disability and externalizing behaviour problems, and the remaining group was identified as having neither condition. The children were from cycle 1 of the NLSCY study, and were 4 to 11 years old. Internal consistency for the PYC scales was calculated as one group for the four groups of children and the alphas all reached at least acceptable levels, at 0.87, 0.62, and 0.84 for the PYC-PI, PYC-CON and PYC-H/I scales, respectively (Garner et al., 2011). In cycle 8 of the NLSCY, children from ages 2 to 7 years for which their parents completed the PYC scales had internal consistency scores that varied by age, from 2 to 3, 4 to 5, and 6 to 7 years. The mean ordinal

alphas for the three age groups were also acceptable at 0.68 for PYC-PI (range: 0.677 to 0.682), 0.63 for PYC-CON (range: 0.520 to 0.723), and 0.64 for PYC-H/I (range: 0.607 to 0.672) (Statistics Canada, 2009).

Parent attributions. The Parent Attribution Test (PAT; Bugental, 2004) provides a measure of the parent's perceived causes of failure over caregiving a child (see Appendix C). The test was designed in order to obtain parent's attributions of failure and success, which they can attribute to themselves, or to the child that they are caring for. Only the questions pertaining to items measuring attributions of failure scale were used in the current study (part 2 of the questionnaire) due to poor psychometric properties of the success scale (Bugental, 2004). The parent was introduced to a hypothetical situation in which he or she takes care of a neighbor's child, and then was prompted to respond to items that tap into failure in doing so. The items pertain to the perceived balance of power or control within the caregiver-child relationship. The parents were asked to rate how important possible causes were for an unsuccessful afternoon caring for a child belonging to a neighbor. A rating scale from 1 to 7 was provided from *not at all important* to *very important* with higher scores corresponding to higher importance. For example in response to the item, "the child's disposition is negative", a rating of "very important" by the parent can be interpreted as the parent attributing the child's disposition as an important reason for the unsuccessful experience. This item is an indicator of Child Control over Failure (CCF), and a high rating indicates that for this specific item, the parent perceives that the child has high control over failure.

The PAT was developed with the intention to include additional subscales based on control over success rather than solely control over failure, however, the author suggested that although available, items and their corresponding subscale scores not be used due to lack of

support for any factor solutions (Bugental, 2004). The success subscale, similar to the failure subscale, asked mothers to rate how important possible causes were for a successful afternoon caring for a hypothetical child.

The PAT can be interpreted by analyzing scores from its' two subscales (Adult Control over Failure (ACF) and Child Control over Failure (CCF)); or by analyzing the data as a continuous score (the Perceived Control over Failure score (PCF)). The PAT yields the ACF and CCF mean scores, which can then be combined to create one continuous score, the Perceived Control over Failure score (PCF) by subtracting the ACF from CCF. A parent with a high CCF score and a low ACF score is considered to have a low balance of control over failure (low PCF). In contrast, an individual with a low CCF score and a high ACF score is considered to have a high balance of control over failure (high CCF).

The reliability and validity of the PAT tested with mothers and undergraduate students by Bugental (2004). The PCF score was used to calculate the test-retest reliability. The PCF scale of the PAT was administered to 57 mothers, one week apart, and a reliability coefficient of .63 was obtained. A version of the PAT for undergraduate students was also administered one week apart with 55 students and the reliability coefficient was .61 for the PCF.

The author also investigated the stability of responses obtained from a test-retest over a 2-month interval, with 30 mothers from the general community. Stability was calculated using the total score (PCF) rather than calculating inter-item consistency, which according to the author, is a better measure of reliability for the PAT because it is a complex composite measure (Martorell & Bugental, 2006). Mothers were categorized as low or high ACF, and low or high CCF based on the median split to check stability over time. Eighty percent of mothers were consistent in their responses for the ACF subscale, significantly greater than chance ($p < .001$,

contingency coefficient = .58). For the CCF subscale, 80 percent of mothers were consistent in their responses, and this was significant at the $p < .05$ level (contingency coefficient = .55).

Martorell and Bugental (2006) used the PAT in their study of mothers and provided support for the independence of the two subscales (ACF and CCF) which were not significantly related to each other ($r = .15$).

For the current study, internal consistency was calculated using four components of the PAT. The four components of the PAT are measured by three items each and consist of the following: (a) causes controllable by adults (ACF-plus), (b) causes not controllable by adults (ACF-minus), (c) causes controllable by child (CCF-plus), and (d) causes not controllable by child (CCF-minus). According to Martorell and Bugental (2006), the four components of the PAT measure four different constructs and are representative of a complex measure, therefore not amenable to analysis of reliability and validity as a composite score in which the four components are combined. The internal consistency (Cronbach's alpha, α) for the PAT was calculated using the four component scales and was as follows: ACF-plus .73, ACF-minus .88, CCF-plus .75 and CCF-minus, .74.

Measures: Outcome

The measure that was used to obtain the two outcome variables: positive cognitive appraisal and negative cognitive appraisal was the Family Impact of Child Disability Scale (FICD; Trute, Hiebert-Murphy, Benzies, & Levine, 2009), described next.

Cognitive appraisal of the family impact of childhood disability. The Family Impact of Child Disability Scale (FICD; see Appendix E; Trute, Hiebert-Murphy, Benzies, & Levine, 2009) is a 20-item scale that measures the parent's assessment of the meaning and emotional

impact that their child with a disability has on their immediate family. It consists of two subscales, positive family impact (PFI) and negative family impact (NFI), which each consist of 10 items. Parents were introduced to the measure by the following question: “In your view, what have been the family consequences of having a child with disability in your family?” followed by a statement such as, “There has been disruptions to our daily schedules”, an example of a negative family impact (NFI) item. The parent must choose one of four responses, which range from *not at all* to a *substantial degree*. The positive family impact subscale (PFI) includes statements such as: “Family members are becoming selfless”. The FICD was scored by calculating the total scores for each subscale separately, yielding one score for the positive subscale and one score for the negative subscale. A higher score indicates greater degree of impact, and scores for both the PFI and NFI range from 0 to 40. The authors recommended using each subscale score separately in any further analysis, therefore two separate scores, one for each subscale were used in the analyses in the current study.

In past studies using the FICD, reliability and validity were established with two samples of parents of children with a disability in Manitoba and Alberta, Canada (Trute, Benzies, & Levine, 2009). For these samples, the FICD was administered as an in-person interview and over the telephone. The subscales of the FICD were not confounded by social desirability response bias for these samples. The reliability findings for the FICD include strong internal consistency for both subscales as assessed by Cronbach’s alpha averaged for the two samples (PFI: alpha = .84, NFI: alpha = .88). Test-retest reliability was also strong and it was tested after a two-week interval (PFI: $r(52) = .95$, NFI: $r(52) = .92$). It was also strong after a four-week interval (PFI: $r(51) = .77$, NFI: $r(51) = .86$).

Chapter 5: Results

The current study was part of the Parenting Matters! study and data were entered by research assistants and graduate students of the Centre for Research on Children and Families in the School of Social Work at McGill University. Data cleaning proceeded by checking if the mean and standard deviation values had any discrepancies that could indicate errors in data entry. It was also ensured that all data fell within the minimum and maximum score range for responses to all measures. Descriptive statistics were computed and assumptions of normality were checked for all variables. Then, the data analyses which consisted of two hierarchical multiple regressions for Hypotheses 1 and 2, and moderations for Hypotheses 3 and 4, were conducted.

Descriptive Statistics

Descriptive statistics are indicated in Table 5 for all observed variables. The number of participants for which data were available per subscale (n), the mean (\bar{X}), the standard deviation (SD) and the range were calculated. The reliability of each measure was calculated via Cronbach's alpha (α) for internal consistency and is presented in Table 5. Cronbach's alpha ranges from .6 to .7 are acceptable, .8 to .9 are excellent and below .5 are poor (Field, 2009). The internal consistency for the majority of the scales used in the current study were acceptable or excellent. Cronbach's alpha for the parenting behaviour scale, consistency, was nearly acceptable, at .57 and was deemed adequate to be included in the analyses (N. Hall, personal communication, April 26, 2016).

Table 5

Psychometric Properties for Observed Variables

Variables	<i>n</i>	<i>X</i>	<i>SD</i>	<i>α</i>	Range
AMC- 26					
Child health complexity (COM)	196	12.99	5.48	.85	[0, 26.00]
SDQ					
Child Total Difficulties (TD)	195	13.89	6.60	.83	[0, 34.00]
PAT					
Adult control over failure (ACF)	190	4.25	0.68		[2.00, 7.00]
ACF-plus				.73	
ACF-minus				.88	
Child control over failure (CCF)	194	3.78	0.61		[1.67, 6.00]
CCF-plus				.75	
CCF-minus				.74	
PYC					
Consistency (CON)	176	14.75	3.42	.57	[5.00, 20.00]
Positive Interaction (PI)	193	14.77	3.08	.77	[5.00, 20.00]
Hostile/Ineffective (H/I)	186	10.45	5.40	.82	[0, 25.00]
FICD					
Positive cognitive appraisal (PFI)	193	2.94	0.59	.83	[1.20, 4.00]
Negative cognitive appraisal (NFI)	193	2.82	0.79	.91	[1.00, 4.00]

Note. AMC-26 = About My Child; SDQ = Strength and Difficulties Questionnaire; PAT = Parent Attribution Test; PYC = Parenting Your Child Scale; FICD = Family Impact of Childhood Disability Scale.

Sample Size and Missing Data

The sample size available for the current study was 196 participants. For the hierarchical multiple regressions with nine predictor variables, the sample size was adequate (i.e., $50 + 8m = 112$, where m equals the number of predictor variables; Tabachnick & Fidell, 2007).

Bootstrapping was conducted for the moderation analyses, which set the sample at 1000.

For some of the variables, there were participants for which data were missing. For the child characteristics variables, one participant had data missing for the SDQ-TD scale. For the

parenting behaviour variables, the sums were calculated if 80% of the items were answered, and if not, the sum was considered missing. The parenting consistency scale had 20 participants with missing data, the hostile/ineffective parenting scale had 10 participants with missing data, and the positive interaction parenting scale had three participants with missing data. Little's MCAR test was run on the PYC-PI scale (positive interaction parenting) as 10% of the values were considered missing and in order to ensure that missing values were occurring at random. Little's Missing Completely at Random (MCAR) test was not significant ($\chi^2 = 49.48$, $df = 40$, $p = .15$, *ns*) and this indicated favorably that data was missing completely at random. For the parent attribution variables, PAT-ACF (adult control over failure) had six participants, and PAT-CCF (child control over failure) had two participants for which data was missing. The missing data reduced the sample size available for the analyses, and is reported for each analysis.

Assumptions of Normality

Histograms and probability-probability (P-P plots) were plotted to examine the assumption of normality for each measured variable. The skewness and kurtosis statistics were analyzed to check whether the normality assumptions were violated. The *z*-score cut-off for skewness and kurtosis was set at 1.96 (Field, 2009). Upon visual examination of the histograms with an overlay of a normal curve, the majority of variables did not appear to differ from a normal distribution. In Figure 3, an example of one of the histograms for one variable, child difficult behaviour as measured by the Strength and Difficulties Questionnaire, Total Difficulties subscale (Goodman, 1997), is shown with the overlay of a normal curve. This data was deemed to approximate a normal distribution. The P-P plots for each variable, which is a plot of a cumulative probability of a variable against the cumulative probability of a normal distribution, were plotted and examined as well and were satisfactory.

For the parent attribution variables, PAT-ACF and PAT-CCF, the kurtosis values were high, at 2.52 and 2.27. This was rectified by removing outliers which brought the kurtosis values within an acceptable range, just below 1.96. The parenting behaviour variables (PYC-CON, PYC-PI and PYC-H/I), did not have problematic skewness or kurtosis values. The outcome variables, positive and negative cognitive appraisal of family impact (FICD-PFI, FICD-NFI) did not have problematic skewness or kurtosis values.

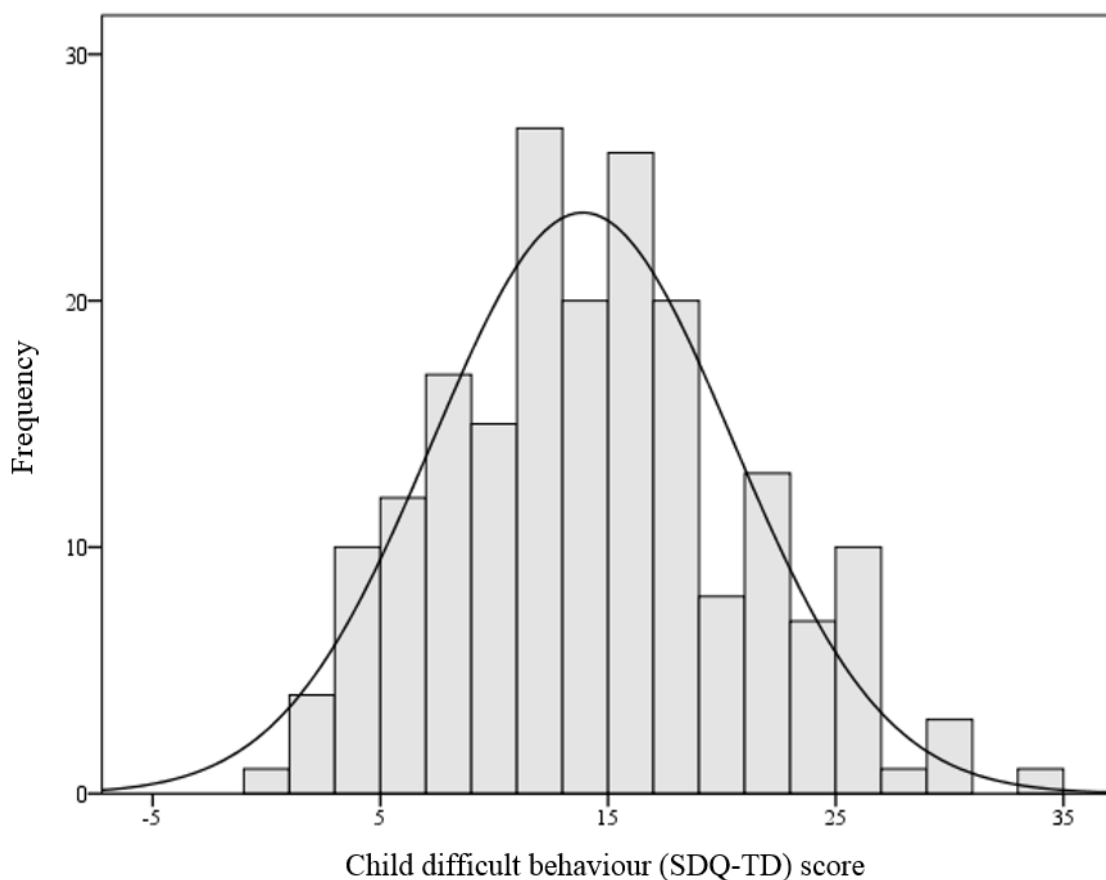


Figure 3. Histogram with overlay of normal curve for child difficult behaviour

Outliers

For each variable, the presence of outliers was verified by examining the box-and-whiskers plots of the data. Regarding child characteristic measures, the child difficult behaviour (SDQ-TD) variable had one outlier, which was changed to reflect a value that was two standard deviations (*SD*) above the mean (Field, 2009). There were no outliers for the child health complexity (AMC-26 COM) measure.

For the parenting behaviour measures, there was one outlier for the positive interaction parenting variable, one outlier for the hostile/ineffective parenting variable, and none for the consistency parenting scale. The outlier for the positive interaction parenting variable was altered to reflect three *SDs* above the mean, and the outlier in the hostile/ineffective variable was left as is because it was within three *SDs* of the mean (Field, 2009).

The parent attribution variables were plotted on a box-and-whiskers plot and numerous outliers were revealed; the adult control over failure variable (PAT-ACF) had 10 outliers, and the child control over failure variable (PAT-CCF) had nine outliers. It was decided to rectify the most severe outlying cases only, two each from the adult control over failure variable and the child control over failure variable; one from each end of the distribution for both subscales were altered to reflect three *SDs* from the mean (Field, 2009).

For the cognitive appraisal of the family impact variables, the positive family impact variable (FICD-PFI) had one outlier which was changed to two *SDs* below the mean from three *SDs* below the mean, and there were no outliers for the negative family impact (FICD-NFI) subscale (Field, 2009).

Linearity and Multicollinearity

Inspection of scatterplots revealed linear relationships among the predictors, moderators, and outcome variables with none deemed problematic. The relationships among pairs of variables, including demographic variables, predictor variables, moderator variables, and outcome variables, were assessed for multicollinearity as indicated by high correlations (above 0.90) (Tabachnick & Fidell, 2007). All correlations were lower than 0.60 and some of the relationships were significant. The two predictors measuring child characteristics, AMC-26 COM (child health complexity) and SDQ-TD (child difficult behaviour), were significantly correlated (see Table 6). See Table 6 below for the zero-order (Pearson r) correlations among each of the predictor, moderator, outcome and demographic variables.

Table 6

Zero-Order Correlations Among Variables

	1	2	3	4	5	6	7	8	9	10
1. Household Income	-									
2. Age at Diagnosis	.05	-								
3. AMC-26 COM	-.25***	-.01**	-							
4. SDQ-TD	-.12	.22**	.56***	-						
5. PAT-ACF	-.10	.02	-.14	-.09	-					
6. PAT-CCF	-.11	-.12	-.16*	-.13	.19*	-				
7. PYC-PI	-.10**	-.10	.03	-.02	.06	-.09	-			
8. PYC-CON	.09	-.14*	-.05	-.05	.17*	-.10	.01	-		
9. PYC-H/I	.19**	.16*	.12	.41**	-.08	.14	-.28***	-.17*	-	
10. FICD-PFI	-.19*	-.31***	-.04	-.18*	-.17*	.11	.20**	-.01	-.20**	-
11. FICD-NFI	-.16*	-.04	.44**	.37**	-.04	-.04	-.07	-.04	.19**	.11

Notes. AMC-26 COM = About My Child, child health complexity; SDQ-TD = Strength and Difficulties Questionnaire, child total difficulties; PAT = Parent Attribution Test, adult control over failure (ACF), child control over failure (CCF); PYC = Parenting Your Child Scale, positive interaction (PI), consistency (CON), hostile/ineffective (H/I); FICD = Family Impact of Childhood Disability Scale, positive family impact (PFI), negative family impact (NFI).

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

Hierarchical Multiple Regressions

Two hierarchical multiple regressions were conducted using IBM Statistics SPSS, Version 22 software. One hierarchical multiple regression was to test Hypothesis 1 with positive cognitive appraisal as the outcome and a second hierarchical multiple regression was to test Hypothesis 2 with negative cognitive appraisal as the outcome.

Hypothesis 1

A hierarchical multiple regression was conducted in order to test Hypothesis 1 in which it was predicted that the following would predict positive cognitive appraisal: child difficult behaviour, child health complexity, positive interaction, consistency, hostile/ineffective parenting, adult control over failure and child control over failure. The demographic variables that were significantly correlated with positive cognitive appraisal were entered into the hierarchical multiple regression in step 1 (i.e., household income and child's age at diagnosis). Only the predictor variables from those specified in the hypothesis that correlated significantly with the outcome, positive cognitive appraisal, were entered into the hierarchical multiple regression (see Table 6 for significant correlations). In step 2, child difficult behaviour was entered, and in step 3, the variables entered were parenting behaviours - positive interaction and hostile/ineffective parenting, and the parent attribution of adult control over failure.

The *F* ratios indicating significance at each step of the hierarchical multiple regression were significant for step 1 and 3, and step 2 was not significant (see Table 7). In step 1, household income ($t(164) = -2.39, p < .05$) and child's age at diagnosis ($t(164) = -4.15, p < .001$) were significant predictors of positive cognitive appraisal, accounting for 11.7% of the variance. In step 2, child difficult behaviour was added as a predictor and was not significant ($t(163) = -1.52, ns$). Household income and child's age at diagnosis remained significant predictors of

positive cognitive appraisal. In step 3, parenting behaviours of positive interaction and hostile/ineffective, and parent attribution of adult control over failure were added as predictors. The parenting behaviour of positive interaction was close to reaching significance ($t(160) = 1.94$, $p = .054$), and hostile/ineffective did not reach significance ($t(160) = -1.35$, ns). The parent attribution – adult control over failure reached significance ($t(160) = -2.65$, $p < .01$), and the demographic variables, household income and child's age at diagnosis remained significant predictors of positive cognitive appraisal. Together, these variables accounted for 17.8% of the variance in positive cognitive appraisal. Lower household income, lower child's age at diagnosis, and lower adult control over failure predicted higher positive cognitive appraisal. This result is contrary to the hypothesis, in which it was predicted that higher, rather than lower, adult control over failure would be a predictor of higher positive cognitive appraisal.

Table 7

Hierarchical Regression Analysis Summary for Positive Cognitive Appraisal (FICD - PFI) as Outcome

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Step 1									
Household Income	-.03	.01	-.17*	-.03	.01	-.19*	-.02	.01	-.15*
Age at Diagnosis	-.11	.03	-.30**	-.10	.03	-.28**	-.09	.03	-.25**
Step 2									
SDQ - TD				-.01	.01	-.07	-.01	.01	-.07
Step 3									
PYC - PI							.03	.01	.15
PYC - H/I							-.01	.01	-.11
PAT - ACF							-.17	.06	-.19**
R^2		.12			.12			.18	
<i>F</i> for change in R^2		12.01***			8.84			6.98**	

Notes: $N = 167$; SDQ-TD = Strength and Difficulties Questionnaire, Child total difficulties; PYC = Parenting Your Child Scale, positive interaction (PI), hostile/ineffective (H/I); PAT = Parent Attribution Test, Adult control over failure (ACF); FICD = Family Impact of Childhood Disability Scale, positive family impact (PFI).

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

Hypothesis 2

A second hierarchical multiple regression was conducted in order to test Hypothesis 2 in which it was predicted that the following variables would predict negative cognitive appraisal: child difficult behaviour, child health complexity, positive interaction, consistency, and hostile/ineffective parenting behaviours, and parent attribution of adult control over failure and child control over failure.

Household income significantly correlated with negative cognitive appraisal and was entered into the hierarchical multiple regression in step 1. Only the predictor variables from those specified in the hypothesis that correlated significantly with the outcome, negative cognitive appraisal, were entered into the hierarchical multiple regression (see Table 6 for significant correlations). In step 2, child difficult behaviour and child health complexity were entered, and in step 3, the variable entered was parenting behaviours - hostile/ineffective parenting.

The F ratios indicating significance at each step were significant for each step (see Table 8). In step 1, household income ($t(172) = -2.18, p < .05$) was a significant predictor of negative cognitive appraisal, accounting for 2.1% of the variance. In step 2, child difficult behaviour ($t(170) = 2.46, p < .05$) and child health complexity ($t(170) = 3.79, p < .001$) were added as predictors and were significant. Lower household income did not remain a significant predictor of higher negative cognitive appraisal once the child characteristic variables were entered. In step 3, parenting behaviour - hostile/ineffective ($t(169) = 1.39, ns$) was entered but was not a significant predictor of negative cognitive appraisal. In step 3, and the child's difficult behaviour did not remain significant ($t(169) = 1.63, ns$) but child health complexity ($t(169) = 3.95, p < .001$) remained a significant predictor of negative cognitive appraisal. Taken together, child

health complexity accounted for 21.8% of the variance in negative cognitive appraisal within the context of the demographic, child characteristic and parenting variables. Higher child health complexity predicted mothers' higher negative cognitive appraisals. This result is in agreement with the hypothesis, in which it was predicted that higher health complexity would be a predictor of higher negative cognitive appraisal.

Table 8

Hierarchical Regression Analysis Summary for Negative Cognitive Appraisal (FICD - NFI) as Outcome

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Step 1									
Household Income	-.04	.02	-.16*	-.01	.02	-.06	-.02	.02	-.09
Step 2									
AMC-26 COM				.04	.01	.32***	.05	.01	.33***
SDQ - TD				.02	.01	.20*	.02	.01	.15
Step 3									
PYC – H/I							.02	.01	.11
R^2		.02			.21			.22	
<i>F</i> for change in R^2		4.74*			21.99***			1.93***	

Notes: $N = 174$; AMC-26 COM = About My Child, child health complexity; SDQ-TD = Strength and Difficulties Questionnaire, Child total difficulties; PYC = Parenting Your Child Scale, hostile/ineffective (H/I); FICD = Family Impact of Childhood Disability Scale, negative family impact (NFI).

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

Moderation Analyses

For the moderation analyses, the IBM Statistics SPSS software, Version 22 was used with the SPSS PROCESS macro (Hayes, 2013) which included the following options to accurately conduct the analysis. Mean centering of variables and the derivation of confidence intervals were used in order to accurately interpret the results (Hayes, 2013). For the moderation analyses, a causal relationship between the predictor, X , and the outcome, Y , is presumed to

exist. To test moderation, a hierarchical multiple regression is conducted in which a predictor, the outcome, and the interaction between the predictor, X and the moderator, M, is entered into the analysis. Moderation is confirmed when the interaction between the predictor and moderator is found to be significant (Field, 2013).

Hypothesis 3

For Hypothesis 3, five moderation analyses were conducted to investigate whether positive interaction, consistency and hostile/ineffective parenting, and the parent attribution of adult control over failure and child control over failure changed the direct relationship between child difficult behaviour and mothers' negative cognitive appraisal.

Parenting behaviour: Positive interaction. The parenting behaviour of positive interaction was tested to investigate whether it moderated the relationship between child difficult behaviour and negative cognitive appraisal. The overall model was significant ($F(4, 185) = 13.90, R^2 = .23, p < .001$) for positive interaction parenting and child difficult behaviour and the interaction was entered as a predictor to test moderation. However, positive interaction parenting did not predict negative cognitive appraisal, and the interaction between positive interaction parenting and child difficult behaviour was not significant (see Table 9). Therefore the parenting behaviour of positive interaction was not a moderator of the relationship of child difficult behaviour to negative cognitive appraisal.

Parenting behaviour: Consistency. The overall model, with parenting behaviour of consistency entered with child difficult behaviour and their interaction was significant ($F(4, 169) = 14.57, R^2 = .26, p < .001$). However, the parenting behaviour of consistency did not predict negative cognitive appraisal nor was the interaction significant (see Table 9). Therefore the

parenting behaviour of consistency was not a moderator of the relationship between child difficult behaviour and negative cognitive appraisal.

Table 9

Testing Parenting Behaviours as Moderators between Child Difficult Behaviour and Negative Cognitive Appraisal of Family Impact

Moderations tested	<i>b</i>	<i>SE b</i>	95%CI	<i>t</i>	<i>p</i>
<i>Outcome FICD-NFI</i>					
Moderator: PYC-PI (centered)	-.02	.02	-.05, .01	-1.17	.24
Predictors: SDQ-TD (centered)	.02	.01	.00, .04	2.22	.03*
Interaction: SDQ-TD x PYC-PI	-.01	.01	-.03, .01	-.69	.49
<i>Outcome FICD-NFI</i>					
Moderator: PYC-CON (centered)	-.00	.02	-.04, .03	-.24	.81
Predictors: SDQ-TD (centered)	.03	.02	-.04, .03	2.69	.02*
Interaction: SDQ-TD x PYC- CON	.00	.00	-.01, .01	.19	.85
<i>Outcome FICD-NFI</i>					
Moderator: PYC-H/I (centered)	.01	.01	-.01, .03	.98	.32
Predictors: SDQ-TD (centered)	.02	.01	.00, .04	2.04	.00***
Interaction: SDQ-TD x PYC- H/I	.00	.00	-.02, .00	1.14	.26

Notes. CI = confidence interval; SDQ-TD = Strength and Difficulties Questionnaire, child total difficulties; PYC = Parenting Your Child Scale, positive interaction (PI), consistency (CON), hostile/ineffective (H/I); FICD = Family Impact of Childhood Disability Scale, negative family impact (NFI).

* $p < .05$, *** $p < .001$.

Parenting behaviour: Hostile/ineffective. The overall model was significant for hostile/ineffective parenting and the child difficult behaviour variable entered as predictors along

with their interaction ($F(4, 180) = 15.57, R^2 = .25, p < .001$). Hostile/ineffective parenting did not predict negative cognitive appraisal ($b = .01, t(185) = .98, p = .32$). The interaction between hostile/ineffective parenting and child difficult behaviour was not significant. Therefore the parenting behaviour - hostile/ineffective did not moderate the relationship between child difficult behaviour and negative cognitive appraisal.

Parent attribution: Adult control over failure. The parent attribution of adult control over failure was investigated as a moderator of the relationship between child difficult behaviour and negative cognitive appraisal. The overall model with parent attribution – adult control over failure entered as a predictor along with the child difficult behaviour and their interaction was significant ($F(4, 182) = 12.48, R^2 = .21, p < .001$). However, the interaction between parent attribution – adult control over failure and child difficult behaviour did not predict negative cognitive appraisal (see Table 10). Therefore the parent attribution of adult control over failure was not a moderator of the relationship of child difficult behaviour to negative cognitive appraisal.

Parent attribution: Child control over failure. The parent attribution of child control over failure was investigated as a moderator of the relationship between child difficult behaviour and negative cognitive appraisal. The overall model with parent attribution of child control over failure and child difficult behaviour entered as a predictor and their interaction was significant ($F(4, 186) = 12.58, R^2 = .21, p < .001$). The interaction of parent attribution of child control over failure with child difficult behaviour did not predict negative cognitive appraisal (see Table 10). Parent attribution of child control over failure was not a moderator of the relationship of child difficult behaviour to negative cognitive appraisal.

Following from the results obtained, this indicates that Hypothesis 3 was not supported as neither the parenting behaviours nor the parent attributions were found to be moderators of the relationship between child difficult behaviour and negative cognitive appraisal of family impact. The variables did not change the relationship by acting as moderators that change the relationship between child difficult behaviour and negative cognitive appraisal.

Table 10

Testing Parent Attributions as Moderators between Child Difficult Behaviour and Negative Cognitive Appraisal of Family Impact

Moderations tested	<i>b</i>	<i>SE b</i>	95%CI	<i>t</i>	<i>p</i>
<i>Outcome FICD-NFI</i>					
Moderator: PAT-ACF (centered)	.02	.09	-.16, .20	.22	.83
Predictors:					
SDQ-TD (centered)	.02	.01	.00, .04	2.15	.03*
Interaction: SDQ-TD x PAT-ACF	.00	.01	-.02, .03	.30	.76
<i>Outcome FICD-NFI</i>					
Moderator: PAT-CCF (centered)	.06	.11	-.15, .27	.58	.56
Predictors:					
SDQ-TD (centered)	.02	.01	.00, .04	2.27	.02*
Interaction: SDQ-TD x PAT-CCF	-.01	.02	-.04, .02	-.48	.63

Notes. CI = confidence interval; SDQ-TD = Strength and Difficulties Questionnaire, child total difficulties; PAT = Parent Attribution Test, adult control over failure (ACF), child control over failure (CCF); FICD = Family Impact of Childhood Disability Scale, negative family impact (NFI).

* $p < .05$, *** $p < .001$.

Hypothesis 4

For Hypothesis 4, it was predicted that the following variables would moderate the inverse relationship between child difficult behaviour and mothers' positive cognitive appraisal:

parenting behaviours of positive interaction, consistency and hostile/ineffective, and the parent attributions of adult control over failure and child control over failure.

Parenting behaviour: Positive interaction. The overall model, in which child difficult behaviour and the parenting behaviour of positive interaction, PYC-PI, were entered as predictors of and positive cognitive appraisal was significant ($F(3, 188) = 5.54, R^2 = .072, p = .001$). To test whether positive interaction parenting changed the relationship between child difficult behaviour and positive cognitive appraisal, the interaction was interpreted and needed to be significant, but was not ($b = .0001, t(188) = .072, p = .94$). Therefore, positive interaction parenting was not a moderator of the relationship of child difficult behaviour and positive cognitive appraisal (see Table 11).

Parenting behaviour: Consistency. The overall model, in which child difficult behaviour and the parenting behaviour of consistency, PYC-CON, were entered as predictors of and positive cognitive appraisal was not significant ($F(3, 183) = 1.57, R^2 = .029, p = .20$). The interaction between consistency parenting and child difficult behaviour did not predict and positive cognitive appraisal ($b = -.003, t(183) = -.26, p = .80$) and therefore the parenting behaviour of consistency was not a moderator of the relationship between child difficult behaviour and positive cognitive appraisal (see Table 11).

Parenting behaviour: Hostile/ineffective. The overall model, in which child difficult behaviour and the parenting behaviour of hostile/ineffective, PYC-H/I, were entered as predictors of and positive cognitive appraisal was significant ($F(3, 186) = 2.95, R^2 = .049, p < .05$). To test whether hostile/ineffective parenting changed the relationship between child difficult behaviour and positive cognitive appraisal, the interaction was not significant ($b =$

.0005, $t(186) = .33$, $p = .74$). Hostile/ineffective parenting behaviour was not a moderator of the relationship between child difficult behaviour and positive cognitive appraisal (see Table 11).

Table 11

Testing Parenting Behaviours as Moderators between Child Difficult Behaviour and Positive Cognitive Appraisal of Family Impact

Moderations tested	<i>b</i>	<i>SE b</i>	95%CI	<i>t</i>	<i>p</i>
<i>Outcome FICD-PFI</i>					
Moderator: PYC-PI (centered)	.04	.01	.01, .07	2.92	.004**
Predictor: SDQ-TD (centered)	-.02	.01	-.03, -.00	-2.49	.014*
Interaction: SDQ-TD x PYC-PI	.00	.00	-.00, .00	.07	.94
<i>Outcome FICD-PFI</i>					
Moderator: PYC-CON (centered)	-.00	.01	-.03, .02	-.26	.80
Predictor: SDQ-TD (centered)	-.02	.01	-.03, -.00	-2.01	.03*
Interaction: SDQ-TD x PYC-CON	.00	.00	-.00, .01	.42	.67
<i>Outcome FICD-PFI</i>					
Moderator: PYC-H/I (centered)	-.02	.01	-.04, .00	-1.86	.06
Predictor: SDQ-TD (centered)	-.01	.01	-.02, .01	-1.13	.26
Interaction: SDQ-TD x PYC-H/I	.00	.00	-.00, .00	.33	.74

Notes. CI = confidence interval; SDQ-TD = Strength and Difficulties Questionnaire, child total difficulties; PYC = Parenting Your Child Scale, positive interaction (PI), consistency (CON), hostile/ineffective (H/I); FICD = Family Impact of Childhood Disability Scale, positive family impact (PFI).

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

Parent attribution: Adult control over failure. The overall model, in which child difficult behaviour and the parent attribution of adult control over failure, PAT-ACF, were entered as predictors of and positive cognitive appraisal was significant ($F(3, 183) = 3.39$, $R^2 = .049$, $p < .05$). The interaction between parent attribution of adult control over failure and child difficult behaviour ($b = -.10$, $t(183) = -1.51$, $p = .13$) did not predict positive cognitive appraisal

of family impact, therefore, it was not a moderator of the relationship between child difficult behaviour and positive cognitive appraisal (see Table 12).

Parent attribution: Child control over failure. The overall model, in which child difficult behaviour and the parent attribution of child control over failure, PAT-CCF, were entered as predictors of and positive cognitive appraisal was significant ($F(3, 187) = 3.41, R^2 = .054, p < .05$). Although child difficult behaviour was a significant predictor of and positive cognitive appraisal ($b = -.02, t(187) = -2.22, p < .05$), the parent attribution of child control over failure interaction with child difficult behaviour did not predict positive cognitive appraisal of family impact (see Table 12). Therefore, it was not a moderator of the relationship between child difficult behaviour and positive cognitive appraisal.

Following from the results obtained, Hypothesis 4 was not supported. The parenting behaviours, positive interaction, consistency, and hostile/ineffective as well as the parent attributions of adult control over failure and child control over failure were not moderators and therefore did not change the relationship between child difficult behaviour and positive cognitive appraisal of family impact as hypothesized.

Table 12

Testing the Effects of Parent Attributions as Moderators between Child Difficult Behaviour and Positive Cognitive Appraisal of Family Impact

Moderations tested	<i>b</i>	<i>SE b</i>	95%CI	<i>t</i>	<i>p</i>
<i>Outcome FICD-PFI</i>					
Moderator: PAT-ACF (centered)	-.10	.06	-.22, .03	-1.51	.13
Predictor: SDQ-TD (centered)	-.02	.01	-.03, -.00	-2.49	.01*
Interaction: SDQ-TD x PAT-ACF	-.01	.01	-.03, .01	-.70	.48
<i>Outcome FICD-PFI</i>					
Moderator: PAT-CCF (centered)	.10	.08	-.06, .26	1.23	.22
Predictor: SDQ-TD (centered)	-.02	.01	-.03, -.00	-2.22	.03*
Interaction: SDQ-TD x PAT-CCF	-.02	.01	-.04, .01	-1.29	.19

Notes. CI = confidence interval; SDQ-TD = Strength and Difficulties Questionnaire, child total difficulties; PAT = Parent Attribution Test, adult control over failure (ACF), child control over failure (CCF); FICD = Family Impact of Childhood Disability Scale, positive family impact (PFI).

* $p < .05$.

Chapter 6: Discussion

Despite the many challenges faced by families with a child with a neurodisability, they manage to be resilient and experience positive outcomes among negative outcomes. Resilience is an individual's ability to attain positive outcomes despite adversity (Luthar, 2006). Increasing the understanding of the impact that childhood disability has on the family would provide greater insight into the family's resilience. One concept, the cognitive appraisal of the family impact, is the meaning that an individual attributes to a stressful event. When mothers make appraisals, they are taking into account the consequences of raising a child with a neurodisability in terms of positive and negative aspects. Thus, the overall aim of the present study was to learn about the positive and negative family impact of raising a child with a neurodisability and to gather new knowledge to develop intervention for improving family outcomes. The first research question pertained to whether certain factors predict mothers' positive and negative cognitive appraisals of the family impact of child neurodisability, namely, parenting factors. The second research question addressed whether the relationships between the child's difficult behaviour and mothers' cognitive appraisals changed, or were moderated, depending on parenting factors (i.e., parenting behaviours and parent attributions).

Within the context of raising a child with a neurodisability, discovering which factors predict that a mother makes positive and negative cognitive appraisals, and discovering which factors moderate the relationship between the child's difficult behaviour and mothers' cognitive appraisals is useful. The knowledge obtained from investigating these relationships can be used to inform the development of interventions which aim to increase positive cognitive appraisals and decrease negative cognitive appraisals. The discussion of the current study follows next and within it, the research questions, their associated hypotheses and results drawn from the analyses,

will be addressed. Then, the implications of this study will be discussed within the larger context of practice and research.

Discussion of Research Questions

The first research question was to investigate whether specific factors predicted mothers' positive and negative cognitive appraisals of the family impact of child neurodisability (outcomes). These factors were the child characteristics (stressors): Child difficult behaviour and child health complexity; and the parenting factors (resources): Parenting behaviours (consistency, positive interaction, hostile/ineffective) and parent attributions (adult control over failure, child control over failure). Demographic variables were considered control factors and these included household income and the child's age at the time of receiving the diagnosis. The second research question was to investigate whether the relationship between the child's difficult behaviour and mothers' cognitive appraisals changed (or was moderated) depending on the parenting variables; parenting behaviours and parent attributions. This research question serves the purpose of discovering whether mothers who use certain amounts of parenting behaviours, or certain amounts of parent attributions, experience changes in the relationship that the child's difficult behaviour has with their cognitive appraisals. For example, if a mother uses a high amount of consistent parenting, does the relationship between the negative cognitive appraisals she makes and her child's difficult behaviour change by decreasing (or weakening)? The results relating to the research questions are discussed below.

Predictors of Mothers' Positive Cognitive Appraisals

The first research question pertained to the investigation of predictors of mothers' positive cognitive appraisals. It was hypothesized that the following factors predicted mothers'

formation of positive cognitive appraisals: Child difficult behaviour, child health complexity, parenting behaviours of consistency, positive interaction, hostile/ineffective behaviour, parent attributions of adult control over failure, and child control over failure. The predicted directions of the relationships were not specified due to the exploratory nature of the study.

The results of the analyses were as follows. Three predictors were found, one of the measured variables and two demographic variables. The key result that was discovered from investigating this hypothesis was that one of the measured variables, the parent attribution of adult control over failure, was a significant predictor of positive cognitive appraisals, and that an inverse relationship was found. Two demographic variables; household income and child age at diagnosis, were significant and the relationship between each of these two predictors and positive cognitive appraisal was inverse (i.e., higher household income, lower positive cognitive appraisal; higher child age at diagnosis, lower positive cognitive appraisal). The parenting behaviour of positive interaction was also close to reaching significance. Each of the predictors are discussed in turn within the current research context in the section below.

Parent attribution of adult control over failure. This was the key result found from investigating Hypothesis 1: One of the measured variables hypothesized to be a significant predictor with the outcome variable was found to be significant. A *lower* parent attribution of adult control over failure was a predictor of a higher positive cognitive appraisal. Mothers who attributed lower control to themselves (i.e., lower adult control over failure) than other mothers, made higher positive cognitive appraisals.

The meaning behind mothers' low attributions of adult control over failure can be interpreted by referring to Bugental's (1989) Parent Attribution Test, in which respondents were asked to rate the importance they assign to potential causes of failure in a hypothetical caregiving

situation in which the caregiver and the child did not get along well. Mothers who make lower attributions of failure to control a hypothetical child's behaviour may, by extension, make the same level of attributions of control over failure of their own child with a neurodisability.

Therefore, in an unsuccessful experience with parenting their own child, mothers may be less likely to attribute failure to themselves. In examining the items of the PAT scale, mothers with low adult attributions of control over failure were less likely to indicate that their enjoyment of children, their approach with the child, their ability to get along with children in general, their mood, how they felt that day, and the type of day they felt they were having, as reasons for unsuccessfully caring for the child in comparison to other mothers. They did not rate these items as important possible causes for an afternoon in which the caregiver and child did not get along well.

What are potential reasons that mothers' lower adult control over failure predicted higher positive cognitive appraisal?

In considering previous research reviewed earlier, in children with ADHD, parents took less responsibility for their child's behaviours in comparison to parents with children without behaviour disorders, when they viewed their child's behaviour as less controllable, stable, and internally caused by the child. They found that parents made attributions consistent with the characteristics of the children's chronic disorder and the parent did not blame the child for their behaviours, but saw them as symptoms of an underlying disorder (Johnston & Freeman, 1997). The mothers in the current study may have also treated these behaviours as symptoms of the underlying disorder, therefore, taking less responsibility for their child's behaviour, leading them to make low attributions of adult control over failure.

However, in Chavira, Lopez, Blacher and Shapiro (2000), parent attributions were indeed affected by the different types of behaviours that the child displayed. Therefore in the current study, the low adult attribution over failure could be due to how the parents viewed “unsuccessful” interactions. In Chavira et al., mothers did not attribute responsibility to child behaviour that was seen as part of their disability, in that if their behaviour was considered a deficit, such as behaviour related to communication, walking or toilet training, they did not view their child as responsible nor react with negative emotion. Mothers viewed their child as responsible for their own problem behaviour if they perceived it as a behavioural excess, such as acting out behaviours, which included temper tantrums, self-injury and aggression towards others. This difference, in which it was more likely for mothers to attribute responsibility for behavioural excess versus behavioural deficit, was significant. This demonstrated that there are differences. It is possible that in this study, we do not know which type of behaviours parents may have been picturing in answering the PAT scale, and it is possible that based on the low adult attribution of control over failure, they were picturing behavioural deficits. The results of the current study are in line with other work; in Whittingham et al. (2006) the parents were prompted to consider behaviour that they felt was behaviour characteristic of autism or Asperger’s. Parents rated their child’s ASD-related behaviour and their misbehavior as being less controllable by the parent than good behaviour. The parent also did not rate themselves as a cause of these behaviours, but did so for positive behaviour.

Another possibility for low adult control over failure may be due to the children taking medication. Mothers of medicated children reported less responsibility and more positive feelings towards their child’s behaviour (Johnston et al., 2000). Although the data regarding

medications for the children studied in the current study is not available, it is possible that they were taking medication, given their neurodisability.

Making lower adult attributions of control over failure is an indicator of strength for mothers – they make higher positive cognitive appraisals. It is possible that these mothers see past their child's neurodisability and see them for who they are as individuals. Parents with low adult control over failure appreciate their child, are open to their child's neurodisability (i.e., are not trying to “fix it”), and are not trying to control it. It is possible that they understand their child well, and see the child for who they are, not just their behaviour. They see beyond the disability. How this view plays out is that the actions that are characteristic of the parent in an interaction are such that they are much less directive, less controlling, and not trying to force the child to be a certain way.

Perhaps intervention that could help parents to appreciate the child for his or her personality, identity, and individuality would be helpful. There are certain intervention types that open parents up to meeting their children where they are and seeing them for who they are.

The Early Start Denver Model (Rogers & Dawson, 2009) is an intervention for children with autism that has as its core features naturalistic applied behavioral analytic strategies, but is sensitive to normal developmental sequence. It entails deep parental involvement, a focus on interpersonal exchange and positive affect, and shared engagement with joint activities. It involves a positive, affect-based relationship using a play-based approach.

Similarly, Watch, Wait and Wonder (Cohen et al., 1999), is another intervention that can be used to help foster the relationship between child and parent. This program is child-led, uses spontaneous infant activity to enhance maternal sensitivity and responsiveness, and increases the

quality of the parent-child attachment. In this program, parents work through developmental and relational struggles through playing, and parents are taught to reflect about the child's inner world of feelings, thoughts and desires.

Child's age at diagnosis. In families whose child was diagnosed at a younger age relative to other children who received a diagnosis at an older age, the mothers made higher amounts of positive cognitive appraisals. There are a few possible reasons for this result that can be examined by looking at the process of receiving a diagnosis. The majority of parents want to know their child's diagnosis as early as possible. Parents often suspect that there may be a medical problem with their child before receiving a diagnosis, and finding it out as soon as possible lessened their uncertainty and suspicion sooner (Seligman & Darling, 2009). A quote from one mother exemplifies the stress in not knowing;

To me, not knowing was worse than knowing. Until the tests were completed, I didn't know if our child would live a normal life, live his life with a serious disability, or not live at all. All I know was that I was scared (Freedman, 2001, p 39).

When this waiting period is shorter, such that the child may receive a diagnosis at birth or soon after, these feelings that are related to the stressful period, occur for a shorter period as well.

Parents have also expressed that the adjustment to the child's diagnosis was easier for them when they were aware of it from the beginning of their child's life (Seligman & Darling, 2009). The initial reaction to diagnosis is often negative; their hopes and expectations are challenged when their child receives a diagnosis (Poslawsky, Naber, Van Daalen, & Van Egeland, 2013). What follows is a process of redefinition characterized by intense grief for the child that was hoped for (Seligman & Darling, 2009). Mothers and fathers grieve the loss of

dreams for their child that began at birth, and grieve the hope they had for themselves for their own lives, when the child was to become independent. The grief is chronic – it is an adaptive, dynamic and recurrent process, with a gradual letting go of dreams and construction of a new reality as the child grows and develops (Brown, 2016). By having had relatively more time to process and adjust to their child's diagnosis, it is possible that mothers have dealt with the grief longer than others, and therefore are more able to make positive cognitive appraisals as compared to other mothers.

When the diagnosis is received later in the child's life, Seligman and Darling (2009) suggest that the sense of loss may be even greater due to the child having already been defined and experienced as normal. Furthermore, some parents still feel a sense of meaninglessness and powerlessness until they have completely understood the nature of their child's disability and have enrolled their child in treatment. Thus, the importance of receiving a diagnosis early reduces parent worry and stress, and gives them time to immediately begin the grieving and redefinition process, and enroll their child into treatment. By taking all of these positive steps, it allows the parent to eventually come to terms with the positive family impact that the child has had on their lives. Therefore, it is potentially for these reasons (i.e., more time to adjust, shorter waiting period, less time spent in uncertainty) that a younger child's age at diagnosis is related to a higher positive cognitive appraisal.

Household income. A *lower* household income contributed to mothers' higher positive cognitive appraisals. This demographic variable was a control variable and reached significance. One possible reason that families with lower household income make more positive cognitive appraisals than others is because they possess the strengths that families characterized by resilience do. In a study by Orthner, Jones-Sanpei and Williamson (2004), the strengths of low

income families were examined, their resilience was demonstrated through some of the assets they had managed to procure. For example, unemployed single-parent households were most often covered (83%) in comparison to two-parent households with 20 hours of work or less. Those with no employment were just as likely as those working full-time to pay their bills on time (60% to 62%) and were more likely to have savings (46% versus 43%).

In addition, the positive cognitive appraisal subscale of the FICD likely taps into the relationship assets of the family. The positive cognitive appraisal of family impact subscale asks the parent to rate the degree that family members have become more tolerant, more accepting of differences, and how they do more for each other as a family (Trute & Hiebert-Murphy, 2002). McCubbin and McCubbin (1996) reported that economically disadvantaged families often demonstrate high levels of warmth, affection, and emotional support for one another. In a review of family research and conceptual literature, other prominent factors in resilient families included a positive outlook, family communication, family member accord, shared time and recreation, maintaining routines and rituals, access to support networks, and financial management (Black & Lobo, 2008). It is possible that factors like these are present in families with a child with a neurodisability and are related to positive cognitive appraisals.

Families with a child with a neurodisability have likely become closer and tighter-knit due to the adversity they face. In a qualitative study of families with a child with a physical or intellectual disability, family togetherness, cohesion and cooperation was reported as an important factor in strengthening the family's functioning (Taanila, Järvelin, & Kokkonen, 1999). Therefore, it is possible that through their ability to be resilient, the families in this study with a low household income were better able to interpret their situation in a positive manner and find positive meaning in their life.

One must consider reasons that those with a higher household income relate to a lower positive cognitive appraisal. Families with a higher household income are likely experiencing different issues than those with a lower household income. These issues may include stress around maintaining a certain lifestyle. Perhaps they are less willing to adapt to their situation. For example, the parents may both be trying to maintain full-time work to be able to pay for their expenses, some of which may be unnecessary, regardless of the need to spend time on therapy and the child's medical appointments. Making time for these appointments interferes with a regular working day, making it harder to maintain full-time work. In addition, there is an association between those with a high income and their reduced ability to enhance and prolong their own positive emotional experiences, meaning that the positive experiences that they do experience are harder for them to enjoy (Quoidbach, Dunn, Petrides, & Mikolajczak, 2010). It is possible that these phenomena occur in families with a child with a disability with higher household incomes, and may be associated with the mother's ratings of lower positive cognitive appraisals in comparison to others.

Positive interaction parenting behaviour. An additional variable that was tested as a predictor of positive cognitive appraisal, the parenting behaviour of positive interaction, almost reached significance, and was considered a trend. Perhaps parents who are optimistic are more likely to appraise a positive family impact of childhood disability. If an individual is more positive in their disposition, perhaps they are more likely to make positive appraisals as well. In a study with parents of typical children, the parents used positive parenting, which involved warmth, affection, monitoring, and positive engagement, and it was promoted by their optimism (Castro-Schilo et al., 2013). Dispositional optimism is a relatively stable, generalized tendency of individuals to expect positive outcomes in life (Scheier & Carver, 1985). The influence of

optimism on physical, psychological, and social adjustment is attributed to better coping strategies of individuals who are optimistic (Carver, Scheier, & Weintraub, 1989). Optimists tend to rely on active, problem-focused coping when faced with stressful life events, whereas pessimists tend to give up when goal pursuit becomes too stressful (Nes & Sergerstrom, 2006; Scheier & Carver, 1992). These findings suggest that individuals with higher levels of optimism should have better skills for dealing with the stresses and challenges of parenting.

In addition, optimistic parents remain warm and affectionate toward their children despite experiencing high demographic risks, whereas demographic risk decreased positive parenting for those with lower levels of optimism (Kochanska, Aksan, Penney & Boldt, 2007). It is perhaps this optimism that is present in the mothers taking care of their child with a neurodisability in this study. The mothers are using higher levels of positive interaction parenting behaviour and this is associated to a higher positive cognitive appraisal which is close to reaching significance.

Predictors of Mothers' Negative Cognitive Appraisals

It was hypothesized that the following factors predicted mothers' formation of negative cognitive appraisals: child difficult behaviour, child health complexity, parenting behaviours of consistency, positive interaction, and hostile/ineffective behaviour, parent attributions of adult control over failure, and child control over failure. The results of this analysis were as follows: only one predictor was significant in predicting negative cognitive appraisals; child health complexity. Higher child health complexity predicted lower negative cognitive appraisals. Child health complexity accounted for a substantial amount of the variance, 21.8 percent, which is just over one-fifth of the variance for the outcome of negative cognitive appraisal. This result suggests that child health complexity is a major contributor to mothers' negative cognitive appraisal.

As presented in the literature review, it has been shown that children with higher health complexity scores are more severely affected in cognitive and adaptive skills, and behaviour (Ritzema et al., 2016). Although health complexity as measured in the current study has not yet been linked to parent stress, other studies investigating the links between severity and stress have been found. For example, in parents with a child with an autism spectrum disorder, higher severity of symptoms was significantly and positively associated with higher stress due to their child's condition (Benson, 2006). In mothers of children with cerebral palsy, mothers' stress was higher when their child's cerebral palsy was mild or severe in comparison to mothers with a child with no condition (Britner, Morog, Pianta, & Marvin, 2003). Trute et al. (2010) suggest that the negative cognitive appraisal subscale is an indicator of the overall level of parent stress. To further support this notion, in Benzies et al.'s (2011) study, negative cognitive appraisal related to parenting stress such that higher parenting stress was related to higher negative cognitive appraisals. It is possible that in the current study, the higher negative cognitive appraisals are predicted by higher child health complexity due to the stress that a higher health complexity poses.

Children with higher health complexity have greater needs. These needs center around various aspects of the child's functioning, including needing aid to toilet and dress independently. The AMC-26 (Rosenbaum et al., 2008) is a measure of health complexity and mothers' concerns were related to the child's deficits in functioning, such as lack of understanding others and presence of aggression. Other concerns surrounded the child's participation in activities outside of school, social skills with adults and other children, thinking, learning, behaviour, mood and the ability to communicate.

These needs consume more attention from the parents – there is an increased burden for these parents in comparison to others with children with lower health complexity. These families may be making a great effort to meet the needs of their child, living almost as if they are in a survival mode. Perhaps the routine and rhythm of the home is centered on the child, leaving little time and effort for anyone or anything else.

In considering the burden of care on these mothers and their families, it emphasizes the importance of meeting their needs with provision of services from government. In Ontario, there is an initiative for families to benefit from new research findings to be translated to therapy and intervention for the child, called the Province of Ontario Neurodevelopmental Disorders Network (POND). Other institutions provide services for families, such as the Child and Parent Resource Institute (CPRI) run by the province of Ontario as well, which provides outpatient and inpatient services to children with a complex presentation of neurodisability and/or a mental health issue.

The importance of using the non-categorical approach to neurodisability is exemplified in the relationship between child health complexity as a predictor of negative cognitive appraisal as it highlights the importance of focusing on need rather than the diagnosis that the child has received. As health complexity increases across a variety of neurodisabilities, it relates to higher negative cognitive appraisal, suggesting functional characteristics are more important than diagnostic label. This finding highlights the importance of serving populations based on need, not just by their label, in which some children with a specific diagnostic label may be in need of help whereas others may not be. Servicing by complexity is useful and fruitful for those receiving services, as it allows for a focus on functional characteristics, such as child health complexity, and this result supports the non-categorical approach of neurodisability to research

and practice, as well as in the continued development of intervention and in allocating funding (Miller et al., 2016).

Therefore, child health complexity has an impact on the negative cognitive appraisals that mothers make. A focus of a policy goal would be to help mothers to reduce their concerns regarding child health complexity, especially because negative cognitive appraisal has been found to be associated with emotional well-being in mothers. Parents' cognitive appraisals, using the FICD discrepancy score in which negative cognitive appraisal score minus positive cognitive appraisal score, were related to mothers' self-esteem and depressive symptoms (Trute & Hiebert-Murphy, 2002). A focus on reducing concerns with child health complexity should be a goal for policy that would aim to help the mother in her appraisals of the negative impact.

The Role of Parenting Factors for Mothers

The second goal of this study was to investigate for whom the relationship between the child's difficult behaviour and mothers' cognitive appraisals changes, depending on the parenting variables: parenting behaviours and parent attributions. In other words, does the effect of difficult behaviour on mothers' cognitive appraisal of the negative impact, become lessened if she used a certain type of parenting?

This goal was obtained by investigating whether parenting behaviours and parent attributions were moderators of the relationship between child difficult behaviour with positive, and negative cognitive appraisal of family impact of raising a child with a neurodisability, through the third and fourth hypotheses. The hypotheses were not supported; none of the parenting behaviours (i.e., consistency, positive interaction and hostile/ineffective) nor the parent attributions (i.e., adult control over failure and child control over failure) were found to moderate

the relationship between child difficult behaviour and both types of cognitive appraisals. In considering the findings with Perry's (2004) model parenting behaviours and attributions were conceptualized as a resource. However, the findings of the current study suggest that these aspects of parenting fail to make a difference in the relationship between child difficult behaviour and cognitive appraisal.

It is possible that there are other factors that impact that relationship; alternatively, parenting behaviours and parent attributions may play a moderating role on some other outcome or relationship, but not in this one. In addition, there may be other factors not examined in this study that alter this key relationship between child difficult behavior and the positive and negative cognitive appraisal of the impact on the family that may be considered resources.

As discussed in the literature review, a variable related to emotional well-being was predicted by positive cognitive appraisals, the variable of self-esteem. For mothers, positive cognitive appraisals predicted their level of self-esteem a year later, and a direct relationship was found in which higher self-esteem related to higher positive cognitive appraisals (Trute et al., 2007). The relationships between cognitive appraisals and self-esteem suggest that emotional well-being is important to consider in investigating family outcomes.

It is possible that factors related to emotional well-being, such as indicators of mental health, are potential moderators of the relationship between the child's difficult behaviour and cognitive appraisal. In Benzies et al., (2011) emotional well-being was investigated in terms of mothers' depressive symptoms, but was not predicted by either type of cognitive appraisals. Despite the lack of prediction, it is possible that depressive symptoms could be a moderator.

There have been links found between parents' health and their child's difficult behaviour, Raina et al. (2005) found that higher levels of child behaviour problems were associated with lower levels of parent psychological and physical health, and in turn, the psychological health and physical health of the parents predicted how well the family was functioning, with better health predicting better family functioning. Perhaps investigating parents' health, including their emotional well-being, could be fruitful in discovering the factors that change the strength of the relationship between child difficult behaviour and cognitive appraisal of the family impact.

Other facets related to emotional well-being include the ability to practice mindfulness, which is the observation and acting with awareness to the present moment. Indeed, in a mindfulness-based stress reduction program, participants reported decreased stress and increased wellbeing and mindfulness following completion of the program in comparison to the beginning of the program (Carmody & Baer, 2008). The potential for mindfulness to reduce stress in families with a child with neurodisability has also been found (Lunsky et al., 2017). Parents who had children with an autism spectrum disorder or other developmental disability had reduced psychological distress after practicing a mindfulness-based intervention for 6 weeks. Future research in looking at mindfulness as a potential moderator between the relationship between child difficult behaviour and cognitive appraisals may reveal improvements in family impact as well.

Conclusion

This study was undertaken with the goal to gain knowledge about the positive and negative cognitive appraisal of the family impact of disability. This study examined whether and how parenting, and more specifically parenting behaviours and attributions, had anything to do

with positive and negative cognitive appraisal among families raising a child with a neurodisability.

Statement of Original Contribution. The major original contributions of this study pertain to the findings that predictors were found for both of the outcomes of positive and negative cognitive appraisals, and that moderators were not found. The parent attribution of adult control over failure, household income and child age at diagnosis were significant predictors of positive cognitive appraisals (i.e., higher adult control over failure, lower positive cognitive appraisal; higher household income, lower positive cognitive appraisal; higher child age at diagnosis, lower positive cognitive appraisal). Child health complexity was a major and significant predictor of negative cognitive appraisal (i.e., higher child health complexity, higher negative cognitive appraisal). The importance of using the non-categorical approach to neurodisability is exemplified in the relationship between child health complexity as a predictor of negative cognitive appraisal as it highlights the importance of focusing on need rather than diagnosis. Finally, parenting behaviours and parent attributions were not moderators of the relationship between child difficult behaviour with positive, and negative cognitive appraisal of family impact of raising a child with a neurodisability. Despite this result, it indicates that it is possible there are other factors not examined in this study that impact that relationship; alternatively, parenting behaviours and parent attributions may play a moderating role on some other outcome or relationship, and this provides direction for future research.

Limitations. There were some limitations that must be acknowledged in the current study. The sample that participated in this study was obtained via convenience sampling. Mothers were approached by a health professional, or responded to an advertisement at the center from which they were receiving services. Due to this non-random sampling, the sample is

unique as it consists of families that were receiving services from the health center. This means that the families that were not frequenting the center did not have access to the opportunity to participate. Those without the access to the service centers may not be receiving the same support as other families, and therefore may differ from other families that are receiving the support.

Given the requirements of participation within the larger Parenting Matters! study which consisted of completing two packets of questionnaires that inquired about many personal details about the family; these participants were also most likely highly motivated to participate. A highly motivated sample may differ from the broader population, as they are willing to expend the time and effort to participate. This willingness may be due to the family possessing more resources than others, in which they may be experiencing less stress. Finally, the majority of parents were highly educated, married, and had a household income of \$80,000 or more, indicating that caution must be taken in generalizing to other demographic groups. Therefore, given that convenience sampling was used and that families were likely highly motivated and affluent, researchers are cautioned in generalizing the results to other populations of families raising a child with a neurodisability.

One challenge that is faced in conducting research with individuals with a disability that is present in the current study is the lack of availability of measures developed specifically for individuals with a disability. In disability studies, the authors may use measures that were developed for typically-developing children (e.g., Arim et al., 2012). Measures pertaining specifically to families with a child with a neurodisability could yield different results. The parenting behaviour measure in the current study was not developed originally for parents of children with a disability, but had been tested with children with a disability (e.g., Garner et al.,

2011), and was deemed a reliable and valid measure. It would be interesting to see if measures that were specific to parenting a child with a disability would capture a different experience from parenting a typical child. However, despite this drawback, significant findings were found with the use of the Parent Attribution Test (PAT; Bugental, 2004), the remaining variables other than the parenting variables, were measured with measures developed for children with a disability.

Implications. The current study has implications for the theoretical model on which it was based, Perry's (2004) model of family stress. In terms of resources, it was discovered that certain variables serve as resources to families, including income level and time of diagnosis as resources that indicate a higher positive rather than lower positive cognitive appraisal of the family impact. These variables were investigated as control variables, and it is possible that other demographic variables may be shown to be resources as well. These may include variables such as number of children in family. For example, the presence of an older sibling in the family may predict cognitive appraisal.

In terms of sample characteristics, in discovering that families with a lower household income make higher positive cognitive appraisals, the importance of accessing a samples with various levels of income for research is highlighted. This result inspires us to learn from these families and how they adapt to caring for a child with a neurodisability. This result also has clinical implications – one must take income into account to understand a family's situation well, not make assumptions regarding resources they have available and especially regarding their cognitive appraisal of family impact.

The results suggest that obtaining a diagnosis as early as possible is beneficial for families. Early diagnosis, even prenatally and at birth, is possible for some neurodisabilities, but for others, the symptoms of the neurodisability are only apparent later on in the child's

development. For those disorders, such as autism spectrum disorder, early identification is not only important in order to begin intervention, but also, as seen in the current study, helpful for appraisal of a higher positive family impact. Research has focused on the importance of early identification and intervention, (e.g., Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). Working further to lower the age of diagnosis for some disorders that are not identifiable prenatally or at birth, adds benefits to families that may not have been originally accounted for.

Support for the construct of child health complexity as measured by the AMC-26 (Rosenbaum et al., 2008), which has been used in a few studies to date, was obtained in this study. It is a quick, easy to understand measure that provides an aspect to the child's health that may be overlooked. In understanding parent's concerns, a better picture is available from which to understand the family's needs and from which to base service such as those described earlier available in Ontario.

In terms of implications for research, the significant findings provide support for the use of the non-categorical approach to neurodisability. The children in this study had a variety of neurodisabilities, and the results pertained to them, and indicate that, despite the differences between them, there are enough commonalities among them, that the mothers share in their perception of the cognitive appraisal of the family impact. Therefore, the use of the non-categorical approach within the area of cognitive appraisal in continued research is supported.

Directions for Future Research. Opportunities for future research are provided following from the results of this study. In this study, the predictors for the outcome of positive cognitive appraisal they accounted for 17.8 percent of the variance, and the predictors for the outcome of negative cognitive appraisal accounted for a substantial amount of the variance, 21.8 percent. This result suggests that child health complexity is a major contributor to mothers'

negative cognitive appraisal. For both outcomes, exploring any additional predictors to account for the remaining percent of the variance can be a goal of future research. By exploring predictors of both the positive and negative cognitive appraisal of mothers and other family members, the family impact can be further understood. Knowing which parents will fare better than others based on these predictors can be helpful in clinical practice, in which it can be predicted that one parent may appraise the impact less negatively than another. Therefore knowing how to prioritize one parents' needs for services over another is possible, thus allowing for service provision to those most in need.

In addition, although none of the parenting factors within the current study were moderators of the relationship between the child's difficult behaviour and the cognitive appraisals, additional research to find moderators is warranted. A moderating variable may help in determining how to intervene. For example, because mothers with a child with a neurodisability with high health complexity make more negative cognitive appraisals than those with lower health complexity, finding out what variable can change the relationship between child health complexity and negative cognitive appraisal may be useful. Perhaps additional respite time could affect that relationship, and if that information can be given to mothers and that service could be provided, mothers could potentially be enabled to reduce the negative impact that they appraise. Another possibility is to look at the effect of attachment on the relationship between children with neurodisability and cognitive appraisal. Specific aspects of attachment, such as reactions after separation, differ in children with neurodisability from that of typically-developing children. Factors such as cognitive skill level and complexity of their health have been found to be linked to these differences (Grzadzinski, Luyster, Spencer & Lord, 2014).

Investigating attachment as a moderator between the child's difficult behaviour and cognitive appraisal may indicate areas for intervention.

In terms of Perry's (2004) theory, parenting factors were tested as resources between the child's characteristic of difficult behaviour and the outcome of cognitive appraisal. The parenting factors were not found to be resources between this relationship, however, this indicates that other variables, as shown in the model, including family system resources, internal personal resources, as well as formal and informal support may be studied as potential moderators between the relationship of child characteristics and cognitive appraisals. It would be fruitful to verify whether different types, quality and quantity of support play a role in this relationship, such as from professionals and/or from friends and family.

In future research, consideration of using a different parenting behaviour measure, specifically a different measure from the Parenting Your Child (NLSCY, 1994) may yield different results. The PYC contains few items per parenting type (consistency, hostile/ineffective and positive interaction), leading to possibly lower variability in responding which could affect its' ability to result in a predictor or moderator variable. In addition, it is possible that parents may answer differently if using a questionnaire about parenting that is specifically developed for parenting behaviours for a child with a neurodisability, as this questionnaire was developed based on parenting behaviours used for typically-developing children.

One challenge present in all family research is the necessity to use multiple family members to obtain the perspective of the family. From the results of this study, it is clear that in taking into account the family impact that the child's neurodisability has had on the family, mothers do not consider their own parenting as part of the family impact. This is most likely because the mother is asked to consider other family members, such as the father, in the FICD.

However, within the literature review covering cognitive appraisals that was presented, there were differences in the relationships that mothers and fathers had with their positive and negative cognitive appraisals. This also suggests that obtaining separate perceptions from individual parents and verifying their similarity and differences in the analyses is important in conducting future research with families and for measurement of the cognitive appraisal of family impact. An idea for future research is to test a complex model in which the perspectives of multiple family members can be included simultaneously. The inclusion of stressors pertaining to a sibling, and how this enacts upon their cognitive appraisals of the family impact, while taking into account the relationship between their mother and their sibling with a neurodisability, would be fruitful and provide an increasingly realistic perspective of the life of these families, thus contributing to realizing their needs. Therefore, future research into the lives of families with a child with a neurodisability may strive to include a large sample of fathers, grandparents or siblings, in order to truly understand their unique experience.

Finally, one of the most relevant findings includes that using the non-categorical approach has proved to be fruitful in the current study and has the benefit of allowing findings to be applicable to a wide range of families with a child with a variety of neurodisabilities. The continued use of a non-categorical approach with individuals with a neurodisability and their families should continue in future research.

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Appendix A

Ethics Approval Procedure

Ethics Approval

This study was undertaken as a secondary data analysis study and received ethics approval as part of the Parenting Matters! study. The primary investigators for the CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada study were Dr. Lucyna Lach (McGill University), Dr. Peter Rosenbaum (McMaster University) and Dr. Dafna Kohen (Statistics Canada). A separate Research Ethics Board (REB) application was submitted to McGill University Ethics Review Committee in order to obtain approval with Sara Quirke as a secondary researcher for the purpose of the current project.

Appendix B

About My Child (AMC-26; Rosenbaum et al., 2008)

B. About My Child

Our Concerns about Our Child's Function

- Please fill in every row by ticking either "yes" or "no" on each line

Compared to other children of the same age, I am concerned about my child's:		If YES, does this impact on their ability to participate in everyday activities?
1. Ability to move around at home, school and community	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
2. Ability to use their hands and arms to do the things they want to do	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Daily Activities such as		
3. Feeding / eating	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
4. Toileting	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
5. Dressing/undressing	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
6. Sleeping	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
7. Seeing	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
8. Hearing	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot

Compared to other children of the same age, I am concerned about my child's:		If YES, does this impact on their ability to participate in everyday activities?
Ability to communicate		
9. Ability to understand other people	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
10. Ability to tell people what they want	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
11. Clarity of speech/language	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Behaviour: My child is often...		
12. Aggressive toward others	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
13. Overactive and too 'busy'	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
14. Too quiet and shy	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Mood: My child is often...		
15. Irritable and cranky	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
16. Anxious and worried	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
17. Sad and moody	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot

Compared to other children of the same age, I am concerned about my child's:		If YES, does this impact on their ability to participate in everyday activities?
Thinking and learning abilities: My child has...		
18. Trouble to learn new things	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
19. Trouble to remember things they know	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
20. Trouble to say what they mean	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Social skills with children: My child is often...		
21. Shy	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
22. Slow to make friends	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
23. Aggressive	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Social skills with adults: My child is often...		
24. Rude	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
Participation in activities outside of school		
25. My child is a loner	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot

Compared to other children of the same age, I am concerned about my child's:		If YES, does this impact on their ability to participate in everyday activities?
Participation in activities outside of school		
26. My child doesn't want to do outside activities	<input type="checkbox"/> Yes → <input type="checkbox"/> No (go to next question)	<input type="checkbox"/> not at all <input type="checkbox"/> a little <input type="checkbox"/> somewhat <input type="checkbox"/> a lot
<p>Are there any other functional/behavioural problems which worry you? Please describe these in your own words.</p>		

Appendix C

Parenting Your Child Scale (PYC; NLSCY, 1994)

The following questions have to do with things that your child does and ways that you react to him/her.

[illegible]

Part B

Now, we know that when parents spend time together with their children, some of the time things go well and some of the time they don't go well. For the following questions, I would like you to tell me what proportion of the time things turn out in different ways.

	Never	Less than half the time	About half the time	More than half the time	All the time	Don't know
1. Of all the times that you talk to your child about [his/her] behaviour, what proportion is praise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Of all the times that you talk to [him/her] about [his/her] behaviour, what proportion is disapproval?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. When you give your child a command or order to do something, what proportion of the time do you make sure that [he/she] does it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. If you tell [him/her] that [he/she] will get punished if [he/she] doesn't stop doing something, and [he/she] keeps doing it, how often will you punish [him/her]?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. How often does [he/she] get away with things that you feel should have been punished?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. How often do you get angry when you punish your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How often do you think that the kind of punishment you give [him/her] depends on your mood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. How often do you feel you are having problems managing [him/her] in general?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. How often is [he/she] able to get out of a punishment when [he/she] really sets [his/her] mind to it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. How often when you discipline [him/her], does [he/she] ignore the punishment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. How often do you have to discipline [him/her] repeatedly for the same thing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* Positive interaction A1, A2, A3, A5, A6

* Hostile/ineffective A4, B1*, B2, B6, B7, B8, B11

* Consistency B3, B4, B5*, B9*, B10*

Appendix D

Parent Attribution Test (PAT; Bugental, 2004)

In this questionnaire, we want to know how important you believe different factors might be as potential causes of successful and unsuccessful interaction with children. We are interested in discovering the way people think about children--there are no right or wrong answers.

Example: If you were teaching a child an outdoor game and he or she caught on very quickly, how important do you believe these possible causes would be?

Place a circle around a number. Pick one of the bigger numbers if you think this factor is important, and a smaller number if you think it is not important.

		Not at all import- ant						Very import- ant
a.	How good he or she is in sports in general.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
b.	How good a teacher you are.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
c.	How easy the game is.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

Answer the following questions by making ratings in the same way as shown above.

- Suppose you took care of a neighbour's child one afternoon, and the two of you had a really good time together. How important do you believe the following factors would be as reasons for such an experience?

	Not at all import- ant							Very import- ant
a. Whether or not this was a "good day" for the child, e.g., whether there was a TV show he/she particularly wanted to see (or some other special thing to do).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	
b. How lucky you were in just having everything work out well.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	
c. How much the child enjoys being with adults.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	
d. How pleasant a disposition the child had.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	
e. How well the neighbor had set things up for you in advance.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	
f. Whether the child was rested.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	

The next question asks about BAD experiences with children. Reasons for good interactions are not necessarily the same as those for unsuccessful ones. So please think about this situation without regard for the way you answered the first question.

2. Suppose you took care of a neighbour's child one afternoon, and the two of you did not get along well. How important do you believe the following factors would be as possible reasons for such an experience?

	Not at all import- ant						Very import- ant
a. How unpleasant a disposition the child had.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
b. Whether the child was tired or not feeling well.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
c. Whether or not you really enjoy children that much.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
d. Whether or not this was a bad day for the child, e.g., whether there was nothing good on TV, whether it was raining and he or she couldn't go outside.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
e. Whether you used the wrong approach for this child.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
f. The extent to which the child was stubborn and resisted your efforts.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
g. How you get along with children in general.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
h. What kind of mood you were in that day.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
i. How hungry the child was.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
j. How little effort the child made to take an interest in what you said or did.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
k. The extent to which you were not feeling well that day.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
l. Whether or not this was a bad day for you in general.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

Appendix E

Family Impact of Childhood Disability Scale (FICD;

Trute, Hiebert-Murphy, Benzies, & Levine, 2009).

In your view, what have been the family consequences of having a child with disability in your family?

		Not at all	Mild degree	Moderate degree	Substantial degree
1.	There have been extraordinary time demands created in looking after the needs of the child with disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2.	There has been unwelcome disruption to "normal" family routines.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3.	The experience has made us more spiritual.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4.	It has led to additional financial costs.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5.	Family members do more for each other than they do for themselves.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6.	Having a child with disability has led to an improved relationship with spouse.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7.	It has led to limitations in social contacts outside the home.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8.	The experience has made us come to terms with what should be valued in life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9.	Chronic stress in the family has been a consequence.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10.	This experience has helped me appreciate how every child has a unique personality and special talents.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11.	We have had to postpone or cancel major holidays.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12.	Family members have become more tolerant of differences in other people and generally more accepting of physical or mental differences between people.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13.	It has led to a reduction in time parents could spend with their friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14.	The child's disability has led to positive personal growth, or more strength as a person in mother and/or father.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15.	Because of the situation, parents have hesitated to phone friends and acquaintances.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16.	The experience has made family members more aware of other people's needs and struggles which are based on a disability.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17.	The situation has led to tension with spouse.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18.	The experience has taught me that there are many special pleasures from a child with disabilities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19.	Because of the circumstances of the child's disability, there has been a postponement of major purchases.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20.	Raising a disabled child has made life more meaningful for	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

family members.

Other comments?

Appendix F

Strength and Difficulties Questionnaire (SDQ; Goodman, 1997).

Strengths and Difficulties Questionnaire**P or T⁴⁻¹⁰**

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

Child's name

Male/Female

Date of birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children, for example toys, treats, pencils	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often loses temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, prefers to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally well behaved, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries or often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, depressed or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often offers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets along better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Good attention span, sees work through to the end	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature

Date

Parent / Teacher / Other (Please specify):

Thank you very much for your help