

THE EXPERIENCE OF SOUTH ASIAN IMMIGRANT AND CANADIAN MOTHERS OF
CHILDREN WITH A DEVELOPMENTAL DISABILITY: A MIXED METHODS STUDY

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Abstract

Purpose: To explore the similarities and differences between the experiences of South Asian immigrant and Canadian mothers raising a child with developmental disabilities using the Perry (2004) model. **Research questions:** 1) Is there a significant difference between the two groups on any of the *impact* (negative, positive), *stressor* (child's age, adaptive skills, maladaptive behaviors, financial burden, other life stressors), *personal* (self-efficacy, mental health problems, coping) and *family resource* (family hardiness, marital satisfaction), or *social support* variables? 2) Are there different predictors of negative (e.g., stress) and positive impact (positive changes in mother) in the two groups? 3) How do mothers articulate their experiences and does their interview data support these findings? **Method:** I used a correlational embedded mixed method design. Quantitative questionnaire data completed by 56 Canadian (CA) and 51 South Asian immigrant (SA) mothers was the primary and semi-structured interview data from a sub sample was a secondary source of data. SA mothers were from five countries, spoke 11 languages, and immigrated an average of 13.5 years ago. **Results:** Children of CA mothers had significantly more adaptive skills according to a parent report measure. SA mothers reported experiencing significantly higher levels of negative and positive impact, more severe levels of mental health issues, more frequent use of positive coping skills, and greater helpfulness of social supports. Child's adaptive skills and maladaptive behaviour predicted negative impact in CA and SA mothers. In CA mothers, their mental health issues also predicted higher levels of negative impact. Positive impact was predicted by positive coping and family hardiness in CA mothers, and by mental health problems and positive coping in SA mothers. Overall, results show a mostly similar experience in both groups. However, interview data from SA mothers revealed a mix of medical and traditional explanation of disability, prevalence of social stigma

about disability, influence of immigration, value of family, and religion as a coping mechanism.

This is the first study to make a comparison between the experiences of South Asian immigrant and Canadian mothers who have a child with disability in Ontario. It has several important implications for culturally sensitive service provision.

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The Experience of South Asian Immigrant and Canadian Mothers of Children with a
Developmental Disability: A Mixed Methods Study

Introduction

The diagnosis of a developmental disability (DD) in a child may have a considerable impact on the family of the child. The process of diagnosis is often long and complex for many families, and there can be uncertainty surrounding their child's diagnosis, treatment and prognosis (Lauchlan & Boyle, 2007; Most, Fidler, Laforce-Booth, & Kelly, 2006; O'Brien, 2007). It has also been reported that some parents experience significant distress, and go through cycles of grief, acceptance and readjustment of their expectations for their child at various developmental stages (Bingham, Correa & Herber, 2012; Lutz, Patterson & Klein, 2012). However, clinical observations and research in the past five decades suggests that there is a great degree of variability in this impact.

Researchers have used various models to study factors that contribute to this variability in parent outcomes (Hill, 1949; Lazarus & Folkman, 1984; McCubbin & Patterson, 1983; Perry, 2004). Until approximately the turn of the 21st century, most of the quantitative research in the area of parent outcomes focused solely on negative outcomes such as stress and depression (Blacher & Baker, 2002; Blacher, Begum, George, Marcoulides, & Baker, 2013). During the mid 1990s, researchers who conducted qualitative studies of parents' experiences started reporting benefits and positive outcomes such as increased tolerance and personal maturity (Patterson et al., 1993), in addition to challenges. Since then, positive outcomes have been increasingly studied using various measurement approaches, both qualitative and quantitative. However, factors associated with variability in positive outcomes, such as stressors, resources, and supports, have received attention only recently. In particular, the role of the family's culture has

only been addressed in a small number of studies. The overarching goal of this dissertation is to contribute to the expanding literature regarding positive and negative outcomes in mothers of children with DD, using mixed methods, with a particular focus on the role of culture in maternal experiences, particularly in the South Asian and Canadian cultures.

Developmental Disabilities is the classifying term often used for a group of life-long disabilities attributable to mental and/or physical impairments that are manifested before the age of 18 years. This includes childhood disorders such as Intellectual Disability (ID)/Mental Retardation (MR), Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), medical diagnoses such as Cerebral Palsy (CP), and syndromes such as Down Syndrome, Fetal Alcohol Syndrome etc. For the purposes of this study, I refer to this whole group of disorders as DD, except when reporting results of particular studies that target one or more specific disorders from this group. The children involved in the current study have any one or more of these diagnoses.

Even though both parents may be affected by their child's challenges, mothers have been reported in the research literature to be the primary caregivers for most children and have been described as being involved closely with children's day-to-day upbringing. Although in the current study I focus on maternal experiences, I use both 'mother'/'maternal' and 'parent'/'parental' when presenting the existing literature in the following sections depending on the participants in the studies being reported. However, when referring to the current study, I use the terms 'mother' or 'maternal' since the research participants are mothers.

In the following sections of this manuscript, I will present a comprehensive model of parental outcomes by Perry (2004), followed by a thorough review of the current literature examining the eight components of this model. Next, I will examine this model through a

cultural lens, by presenting literature looking at the role culture plays in the experience of disability, with a focus on the experience of South Asian and Canadian parents (especially mothers) of children with DD. Finally, I will present the main research questions, followed by the methodology used, description of participants, results of this study and will end by discussing how the results of this study contribute to the existing research in this field and delineating study limitations.

A Comprehensive Model of Parental Outcome

In the past, a number of models have used a resource imbalance perspective to understand the stress that the family experiences when raising a child with a disability. The Double ABCX model (McCubbin & Patterson, 1983) of family adaptation is the most well known example of this type of model. According to the ABCX model, when a family experiences a *stressor* (A, an event that has the ability to change the family system), based on the *existing supports* (B, community and familial support, SES, etc.) and the family's *perception of the stressor* (C, what the problem means to the family), the members of the family experience a certain level of *crisis* (X). Minnes (1988) applied this model to study the relationship between stressors, coping and adaptation in families of children with a DD. Even though this model has since been studied and used extensively to study family outcomes in the field of DD, the outcomes in this model are studied in terms of "bonadaptation" and "maladaptation", which are seen as two ends of a continuum. That is, positive outcomes are, by definition, low levels of negative outcomes. This model does not allow for the examination of positive outcomes as separate from, but coexisting with, negative outcomes, as suggested by an ever increasing body of literature (Blacher & McIntyre, 2006; Lloyd & Hastings, 2009; Perry, 2004; Phelps, Hodgson, McCammon & Lamson, 2009; Phelps, McCammon, Wuensch & Golden, 2009). In addition, the

B factor of this model incorporates many different resources and supports that may usefully be examined by further delineating them.

The most comprehensive model that can be used to explain how rearing a child with DD affects a parent's functioning was proposed by Perry (2004) and is shown in Figure 1. The author reviewed various sources of family stress and coping literature to develop the model and tested it on a sample of 61 parents of children with autism (Perry, 1990). It includes four major components: Stressors, Resources, Supports, and Outcomes, each of which fall into two domains. The two domains of *Outcomes* are negative parental outcomes (e.g., stress, depression) and positive parental outcomes (e.g., increase in tolerance, belief in self). Note that, in this model, positive and negative outcomes are independent. Parents may have high positive outcomes even when simultaneously experiencing a high degree of parenting distress (negative outcome) and other domains in the model may be related differently to the two outcomes. *Stressors* fall into the parent's perception of child characteristics (e.g., level of functioning, behaviour problems and so on), and other life stressors that any family may experience (e.g., immigration and financial issues). The potential impact of these stressors on outcomes may be moderated or mediated by the availability of Resources and Supports. *Resources* are described as being within the family including the individual parent's personal resources (e.g., beliefs, positive appraisal) and the family system resources (e.g., marital status). *Supports* are portrayed as coming from outside the family including informal social support (e.g., from extended family and friends) and formal supports and services (e.g., professional interventions for the child and/or family). Thus, according to this model, parents experience positive and/or negative outcomes as a result of the interplay of all the other factors in the equation.

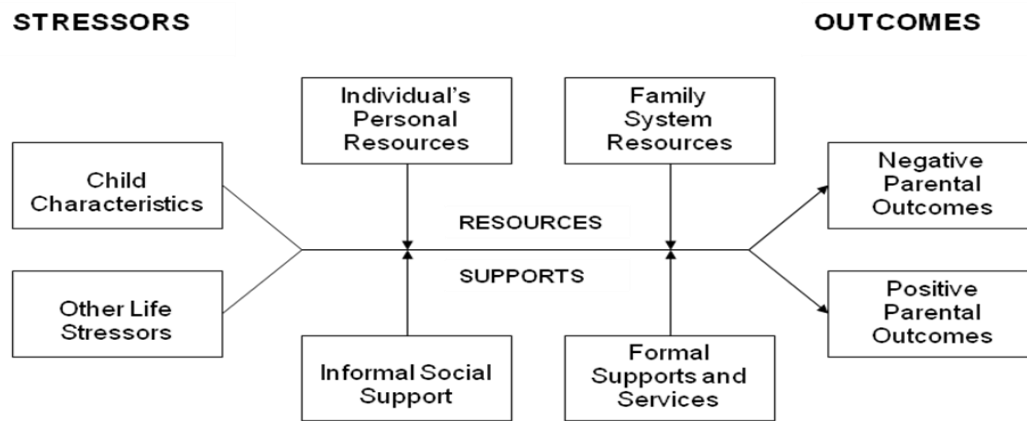


Figure 1. Perry (2004) Model of stress in families of children with DD.

In the following sections, I describe the literature for each of the components of this model, as related to parental/maternal outcomes, and as conceptualized for this study.

Negative Impact on Parents

For over half a century, the focus of research has been on negative impacts of children with a disability on their families (Blacher & Baker, 2002; Blacher et al., 2013; Kasari & Sigman, 1997). Perceived negative impact is the degree to which a parent experiences negative financial, social, emotional, and physical burdens of raising a child with a disability (Bishop, Richler, Cain, & Lord, 2007). Parents of children with a DD experience substantial emotional demands that are associated with caring for their children because of the lifelong nature of this disability.

Negative impact has been conceptualized and measured quantitatively by researchers in various different forms such as higher levels of stress, depression, burden, and divorce. It has most commonly been conceptualized in terms of parenting stress. Perry (2004) reported four

different conceptualizations of stress that are prevalent in the literature. First, stress related to raising a child with DD has been understood in terms of a grieving process involving a direct physiological and psychological reaction that parents might experience as part of grieving for the loss of their ideal child by going through stages of shock, denial, anger, bargaining, working through and acceptance (Perry & Condillac, 2003; Siegel, 1997). Secondly, stress has been studied as a direct reaction to “stressful life events”, such as getting a DD diagnosis for their child, on the mental and physical health of parents. However, this event does not influence the parents in isolation since parents have reported both extremely negative and positive outcomes (Perry, 2004; Wilgosh & Scorgie, 2000).

The third prevalent conceptualization of stress as a result of “daily hassles” is based on the fact that children with DD need constant care, supervision and support until an older age than their typically developing peers or siblings. In addition, teaching children with DD requires systematic repetition and practice of developmentally progressive skills, while their typically developing peers learn most of these skills experientially. Therefore, parents might experience higher strain on their time and resources, thereby creating distress and emotional strain (Floyd & Phillippe, 1993; Honey, Hastings & McConachie, 2005). In addition, parents’ understanding and explanation of their child’s diagnosis, their perceptions of their child’s disability, as well as their worry and plan for their child’s future, all form an important part of this negative impact (Bingham et al., 2012; Lauchlan & Boyle, 2007)

One of the most often used measures for parenting stress, the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crinc, 1983), includes items about daily hassles and how their child’s challenges affect their family and social interactions. On the other hand, measures such as the Family Impact of Childhood Disability (FICD; Trute & Hiebert-Murphy,

2002; Trute, Hiebert-Murphy and Levine, 2007) include statements about parents' perception of the impact of their child's disability on their family. I use both of these measures in the current study.

The fourth approach to conceptualizing stress is based on a "resource imbalance" approach that suggests that a person (e.g., parent of a child with DD) experiences stress when he/she does not have sufficient personal and family resources and supports to help him/her cope with the demands created by the pileup of stressors. This approach has been used most often to understand outcomes in parents of children with DD in recent years (Manning, Wainwright, & Bennet, 2011; Minnes, 1988; Paynter, Riley, Beamish, Davies, & Milford, 2013), especially in the form of the Double ABCX Model (McCubbin & Patterson, 1983) discussed above. However, Perry (2004) further clarified and expanded this general approach by separating parent outcome into negative and positive impact on parents of children with DD. These two distinct forms of outcome are considered the result of dealing with stressors that are directly related to their child and pileup of other life stressors and are influenced by the level of resources present within the family as well as supports received from outside the family. In the current study, I use this approach to conceptualize parent outcomes.

The majority of the negative impact literature has been quantitative in nature, with few qualitative studies. In one qualitative study, using a grounded theory approach, Altieri and Von Kluge (2009) conducted semi-structured interviews with 52 parents of children with autism in order to explore their struggles and successes in coping with the diagnosis of autism and raising their child. Six common themes emerged from the qualitative thematic analysis of the parents' description about their experiences: (a) distress around regression in skills or delays in development of skills (b) questions and confusion that resulted from their child's behavioural

presentation and the multiple false diagnoses given to their child, (c) feelings of loss and devastation, (d) loss of informal social support from friends and family, (e) lack of clarity around best treatment for their child, doing research on finding solutions for their child's behaviour and advocating for immediate services, and (f) personal growth of parents. In the current study, I conduct semi-structured interviews with mothers of children with a DD and add to this small pool of qualitative literature on negative impact on mothers. In addition, Altieri and Von Kluge (2009) reported that, in spite of the difficulties they experienced, almost every parent also described significant positive experiences as a result of raising a child with autism such as an increased appreciation of life, increased tolerance of differences between individuals, changes in priorities, and learning to cope with difficult situations.

In a mixed methods study by Myers, Mackintosh, and Goin-Kochel (2009), 493 parents of children with autism from across the USA, Canada, Australia, New Zealand, England, and Ireland completed an online questionnaire that included seven open ended questions in addition to a battery of quantitative questionnaires. Myers et al. (2009) reported thematic analysis of parents' responses to one of these open-ended questions: "How has your child on the autism spectrum affected your life and your family's life?". They reported a total of 15 negative themes and nine positive themes that they grouped into five main clusters: (1) Stress, (2) Child's behaviour and demands of care and therapy, (3) Impact on parents' personal well being, work lives, and marital relationship, (4) Impact on the family as a whole, including siblings and extended family, and (5) Social isolation. Myers et al. reported several negative as well as positive themes within each of these clusters excepting social isolation. Parents reported positive effects such as understanding others' difficulties, accepting and loving their child's uniqueness, enrichment of their lives, learning to slow down and appreciate little things, compassion,

tolerance and patience. More recently, two other studies (Luthra, Perry, & Minnes 2014; Nurullah, 2013) conducted similar analysis of qualitative responses of parents of children with a DD, and reported themes both about challenges and rewards of raising a child with a DD. These studies reflect the growing interest and effort by researchers in examining positive impact of raising a child with DD.

Positive Impact on Parents

With this significant shift in thinking about the impact of having a child with a disability in the past two decades, researchers have increasingly started exploring the possible positive impacts that raising a child with a disability can have on the parents (Hastings & Taunt, 2002). As an outcome variable, positive impact has been conceptualized in terms of Positive Outcome in parents (e.g., increase in patience, acceptance of differences, and outlook towards life etc.), as well as an overall Family Quality of Life (Brown, Anand, Fung, Isaacs & Baum, 2003; Brown et al., 2006; Isaacs et al., 2007). Positive impact has sometimes been conceptualized differently as a protective factor or coping mechanism, such that a more positive appraisal of their child's challenges helps parents cope with their situation more effectively, thereby leading to lower distress in parents (Lloyd & Hastings, 2008, 2009; Trute, Benzies, Worthington, Reddon & Moore, 2010). In the current study, positive impact was studied as an outcome variable because literature has emphasized positive changes in parents as a result of coping with and managing their child's challenges.

One theoretical framework outlining the coexistence of positive and negative family outcomes is the caregiving model developed in the older adult literature by Lawton, Moss, Kleban, Glicksman, and Ravine (1991). According to this two-factor model of caregiving, there are two partially independent outcomes with different antecedents: (a) negative emotional state

due to the difficult characteristics of the cared-for person such as behaviour problems, and (b) positive emotional state due to perceived positive characteristics of the cared-for person such as adaptive skills, positive affective relationship with the caregiver and so on (Lawton et al., 1991).

Most of the early literature on positive impact was qualitative in nature, in which researchers noted several categories of positive contribution made by children with disabilities (e.g., source of love, source of joy, source of learning life's lessons) in comments or letters written by parents and relatives of people with disabilities (Summers, Behr, & Turnbull, 1989; Turnbull, 1985; Turnbull & Behr, 1986; Turnbull, Guess, & Turnbull, 1988). Closer to the turn of this century, researchers started conducting qualitative research with a direct focus on better understanding parents' positive experiences in raising a child with a disability (Patterson et al., 1993; Stainton & Besser, 1998). Gradually, several measures have been created and used to measure positive outcomes in parents of children with a disability, and they have used a few different names for these outcomes such as positive impact, positive gain, and positive perceptions.

During this period, two measures that were developed and widely used were the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993) and the Family Impact of Childhood Disability (FICD; Trute & Hiebert-Murphy, 2002). Both of these measures have separate and independent negative and positive impact scales and they have been used very frequently to measure outcomes in the field of DD research. In 2007, Trute, Hiebert-Murphy and Levine revised the FICD in 2007 and added more positive impact items in the measure, which might reflect increasing awareness of the importance given to the study of positive outcomes in parents.

Using either qualitative or quantitative methods using the above measures, various researchers (Blacher & McIntyre, 2006; Hornby, 1995; Lloyd & Hastings, 2009; Phelps,

Hodgson, et al., 2009; Phelps, McCammon, et al., 2009), including Perry (2004), have explored parents' perceptions and concluded that, while parents reported significant demands and emotional stress, the majority of them also reported feeling that their lives were enriched and had increased meaning as a result of their experience with their children. In addition, the results of these studies suggest that parents can experience independent positive and negative outcomes, depending upon the resources they have internally and the supports available to them.

However, there is a lack of conceptual clarity as to what is meant by positive impact. Blacher and Baker (2007) discussed three approaches with which researchers can conceptualize and assess the positive impact of the child: (a) the *Low negative* view, which defines a positive impact as the absence of a negative impact (as used in the Double ABCX model) measured in terms of low scores on stress and depression; (b) the *Common benefits* view, which implies that, despite the child's disability, parents experience the same joys of child rearing as parents with typically developing children; and (c) the *Special benefits* view, which suggests that parents experience some unique benefits because of the disability that are not otherwise experienced by parents of children without a disability.

Research that uses the special benefits view typically involves parents of children with a disability only and does not necessarily include a control group of typically developing (TD) children. The Perry (2004) model and studies carried out by other researchers (Blacher & Baker, 2007; Blacher & McIntyre, 2006; Hastings & Taunt, 2002) that have looked at the co-existence of positive and negative impact often use the special benefits view of positive impact. In the current study, I use this conceptualization of positive outcomes.

In a research review, Hastings and Taunt (2002) reported that the parents of children with a disability experience positive feelings or personal and emotional enrichment (besides

experiencing distress). The authors based their conclusions on three main sources of information about the positive impacts of having a child with a disability: (a) anecdotal reports of the experience of mothers and fathers that have emphasized both positive and negative impacts, (b) descriptive studies that have identified a range of 14 key themes/features of raising a child with intellectual disability such as pleasure/satisfaction in providing care for the child, the child as a source of joy and happiness, a sense of accomplishment in having done one's best for the child, strengthening of the family, development of new skills/abilities, increased self-efficacy and confidence, and so on, and (c) a small number of quantitative research studies focussed on parental perceptions of positive experiences with their child with the intellectual disability.

In a mixed methods design study, Phelps and colleagues studied 80 caregivers of 3- to 35-year-old individuals with ASD to explore the parental effect of raising a child with autism. They published their results as separate quantitative (Phelps, McCammon, et al., 2009) and qualitative (Phelps, Hodgson, et al., 2009) papers outlining the presence of both negative (stress) and positive (enrichment) impact on caregivers. In the quantitative study, they reported that parents experienced negative and positive impact independent of each other, such that both could coexist. In addition, the parents in the qualitative study reported that coping with the challenges of the child with autism resulted in growth and enrichment personally, socially, psychologically as well as within family.

It is well established that the level of both positive and negative impact varies across parents, with some parents experiencing high levels of both, low levels of both or their experiences fall somewhere in between. At present, there is significant research into stressors as well as resources and supports that influence negative impact on parents, however, there is little research on positive impact as an outcome and its relationship to various child, caregiver and

family variables. In the following sections I review the current literature for each of the stressor, resource and support variables.

Stressors Contributing to Parent Impact

Stressors are all the stimuli and events in the families' environment that put a strain on their ability to cope in their daily lives. For parents of children with DD, these could include child characteristics as well as other life stressors.

Child Characteristics. A number of child characteristics have been studied as potential stressors for parents of children with DD. These include their child's severity of ID, severity and frequency of maladaptive behaviour, his or her level of independence or dependence in daily life or adaptive skills, specific diagnosis or type of DD, as well as the child's age and gender. While some studies have concluded that child's IQ or severity of ID or adaptive behaviour of the child with DD and/or autism are significant predictors of parent stress (Bishop et al., 2007; Koegel et al., 1992; Plant & Sanders, 2007; Weiss, Sullivan, & Diamond, 2003), others have not supported this conclusion (Hassall, Rose, & McDonald, 2005).

When speaking to parents of children with DD, besides discussing their child's adaptive skills, parents frequently focus on their child's maladaptive behaviours as these are often disruptive and stressful for the child and their family. Baker, Blacher, Crnic, and Edelbrock (2002) reported that, even by age 3, children with DD were three to four times more likely to show clinically significant behaviour difficulties (both internalizing issues such as anxiety and externalizing issues such as aggression) than their typically developing counterparts. Lopez, Clifford, Minnes, and Ouellette-Kuntz (2008) found that mothers of preschoolers with a DD reported significantly more problem behaviours than their typically developing counterparts. Although these behavioural challenges improve over time with treatment, new behaviours may

emerge from time to time as children grow up, and some individuals continue to experience these difficulties well into young adulthood. Blacher and McIntyre (2006) worked with parents of a group of young adults (16-26 years old) with various forms of DD. Based on these parents' reports about their child's behaviour difficulties, the authors found that 41% of these individuals had significant behavioural challenges that required intervention.

Moreover, these challenging behaviours, regardless of the diagnosis, have been generally found to be strong and consistent predictors of high parental distress or lower well being (Abbeduto et al., 2004; Baker et al., 2002; Lloyd & Hastings, 2008, 2009; Minnes, Perry, & Weiss, 2015). Although most parents with a child with DD experience a certain degree of negative impact, diagnoses such as ASD have been related to particularly high rates of negative impact on parents (Bishop et al., 2007; Karst & Van Hecke, 2012). The results of these studies consistently show that parents of children with autism tend to report more distress than do parents of children with other developmental disabilities, including Down syndrome (Blacher & McIntyre, 2006; Eisenhower, Baker & Blacher, 2005; Hartley, Seltzer, Head, & Abbeduto, 2012), cystic fibrosis (Bouma & Schweitzer, 1990), cerebral palsy (Eisenhower et al., 2005), Fragile X syndrome (Abbeduto et al., 2004), intellectual disability without ASD or parents of typically developing children (Donenberg & Baker, 1993; Eisenhower et al., 2005; Kasari & Sigman, 1997; Rao & Beidel, 2009).

Researchers have explored child characteristics such as level of personal/social development and level of problem behaviour such as aggression, self injury, tantrums, and repetitive behaviours in children with ASD as possible factors related to higher negative impact in their samples of parents. A number of studies have shown that the child's social interaction skills significantly predict parenting stress in mothers (Davis & Carter, 2008; Firth & Dryer,

2013; Smith, Oliver, & Innocenti, 2001; Weiss et al., 2003), such that parents of more socially responsive children with autism reported lower levels of parenting stress compared to those whose child is less socially responsive (Kasari & Sigman, 1997).

Moreover, even though maladaptive behaviour has generally been reported to be related to more negative impact in most parents of children with DD, some of these behaviours are more frequent in children with autism or even characteristics of autism. For example, children with autism often have certain restricted and repetitive behaviours that are often difficult to stop or change. Some studies have found maladaptive behaviour and restricted and repetitive behaviours associated with autism to be significant predictors of perceived negative impact or burden in parents (Baker et al., 2002; Baker et al., 2003; Floyd & Phillippe, 1993; Manning, et al., 2011; Paynter et al., 2013; Stuart & McGrew, 2009), even after controlling for the cognitive level of the child (Bishop et al., 2007). Eisenhower et al. (2005) also found that, regardless of diagnosis, change in problem behaviour of their children was a significant predictor of maternal negative impact. Therefore, perhaps parents' negative impact is related to their child's challenging behaviours and delay in skills as opposed to their label/diagnosis itself.

On the other hand, there is a very limited body of literature that actually looks at whether and how diagnosis, maladaptive behaviour, adaptive behaviour, or other child specific characteristics are related to positive outcomes, and even then, the results are mixed. One study by Minnes et al. (2015) looked at 155 mothers of children with a developmental delay or disability and found that their child's behaviour and adaptive skills did not significantly predict positive outcomes in mothers. Eisenhower and colleagues (2005) studied positive impact, using the Family Impact Questionnaire, in the mothers of 215 children with autism, undifferentiated delays, Down syndrome, cerebral palsy, and typically developing children. They found that,

although the autism group ranked the lowest amongst the groups on positive impact, their scores did not differ significantly from those of others. In addition, Donenberg and Baker (1993) reported lower positive impact for parents of children with autism compared to the control group, while Baker et al. (2002) reported no difference between delayed and non-delayed children. In the current study, I attempt to fill this gap by exploring the effect of child's age, diagnosis, level of adaptive skills as well as maladaptive behaviour on both negative and positive impact.

Other Stressful Life Events. In addition to the stressors directly related to raising a child with a disability, families may also experience a "pile-up" of demands, stressors or other life events (McCubbin & Patterson, 1983; Perry, 2004). These include other life changes that could occur in any family such as financial changes (Minnes et al., 2015), loss of employment (Ramisch, 2012), parents' divorce, death in the family, diagnosis of another child in the family, or even events like immigrating to a new country. Parent outcomes need to be studied in such a way as to consider the impact of these life events along with the stressors associated with their child. Higher pile-up of demands has been frequently found to be related to poor outcomes in mothers of children with a disability (Bristol, 1987; Manning et al., 2011; Paynter et al., 2013; Stuart & McGrew, 2009). However, I was unable to locate a study that explored this variable in relation to positive impact. In the current study, I explore financial burden, pile up of other stressful life events and SES as stressors in relation to both negative and positive impact in parents of children with DD.

In addition, the Perry (2004) model, suggests that *parents' personal resources, family system resources, informal social support and formal supports and services* mediate the relationship between these stressors (child variables and other life stressors) and both positive and negative outcomes experienced by parents. Thus, it is essential to look at the relationship

among all of these mediating variables and both positive and negative outcomes separately because there may be different variables that influence positive and negative outcomes.

Parents' Individual Personal Resources

Personal resources within parents that have been studied in the literature include personality characteristics and beliefs, self-efficacy in parenting a child with a disability, their own state of mental well being, and their coping/appraisal styles. In this study, I focus on three important factors that emerge from the literature are: *Self-efficacy* in parenting a child with a disability, mothers' *mental health* and mothers' *coping mechanisms*.

Self-efficacy. Parenting self-efficacy can be conceptualized as the individual parent's perception or confidence in his or her knowledge about child rearing and ability as a parent to successfully carry out child rearing tasks or behaviours (Bandura, 1977; Coleman & Karraker, 1997). This confidence or belief in oneself is usually developed and shaped over time by success and failure expectations, as well as perceived difficulty of tasks. In both quantitative and qualitative studies, parents of children diagnosed with a DD have reported feeling lost, not knowing how to help their child, and struggling with finding and acquiring the most appropriate services for their child (Luthra et al., 2014; Myers et al., 2009; Nurullah, 2013). Navigating their child's challenging behaviours and teaching their child takes greater parental effort throughout their child's lifetime. Parents eventually learn to manage their child's needs, however, the time and effort that this requires varies from time to time as their child goes through different developmental stages. Therefore, their sense of self-efficacy tends to fluctuate over time.

In addition, due to the "pile up" of other life stressors (e.g., unemployment, death in the family) parents may feel that they are unable to manage and, in turn, that they are unable to help their child, leading to increased levels of parenting stress, whereas greater levels of self efficacy

may help in reducing parenting stress (Giallo, Wood, Jellet, & Porter, 2011; Kuhn & Carter, 2006). Moreover, having higher levels of parenting self-efficacy has been shown to mediate the negative effect of children's behaviour or mental health problems on maternal anxiety and depression (Hastings & Brown, 2002). Furthermore, a more general sense of self-efficacy in parents has been found to be related to lower stress and greater family adjustment (Benzies, Trute, & Worthington, 2013).

While there is some research suggesting that parenting self-efficacy might mediate the relationship between stressors related to parenting a child with autism and DD and negative outcomes, there is very limited research that looks at the relationship of parenting self-efficacy with positive parent outcomes. In one study, Minnes et al. (2015) reported that greater self efficacy was related to greater levels of positive gain in 155 mothers of children with a DD. Much more research is needed in order to understand the role of self-efficacy in the relationship between stressors and positive impact. It is quite possible that the direction and strength of relationships may differ between self efficacy and both negative and positive outcomes (Luthra, 2010). Therefore, in this study I attempt to further understand these interrelationships using both quantitative and qualitative methods.

Maternal Mental Health Problems. Another variable that is important to consider as a potential mediating variable between stressors and maternal outcomes is mothers' mental health. This is an area of deficit in the literature and research published to date, because mental health difficulties such as depression are typically viewed as negative outcome variables. Parents of children with a disability such as autism or DD have been found to experience higher levels of psychological distress or more severe levels of depression compared to parents of typically developing children (Baker et al., 2002; Beckman, 1991; Blacher, Lopez, Shapiro, & Fusco,

1997; Hastings, 2003; Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005).

Severity of child behaviour problems is one of the child variables most commonly linked with higher levels of mental health difficulties in parents of children with a disability (Beck, Hastings, Daley, & Stevenson, 2004; Hastings, 2003; Hastings, Kovshoff, Ward, et al., 2005; Weiss, Cappadocia, MacMullin, Viecili & Lunskey, 2012).

The general depression research suggests that mothers who are depressed often find it hard to structure their child's routine and to provide him/her with emotional support and guidance (Downey & Coyne, 1990; Gelfand & Teti, 1990). In addition, Gelfand, Teti and Fox (1992) found that, in mothers of typically developing infants, severity of maternal depression accounted for 38% additional variance in parenting stress, when controlling for infant age, maternal education and family income. Therefore, since raising a child with a DD compared to a typically developing child comes with additional challenges related to parenting, it becomes essential for us to consider the effect of this state of mental health in mothers as a mediator that ultimately influences their report of positive and negative outcomes of raising a child with a disability.

Some research has been done to study the relationship between mental health difficulties and parenting stress. Hastings (2003), Hastings, Kovshoff, Ward, et al. (2005) as well as Davis and Carter (2008) explored the relation between several child and parent factors known to influence parenting stress in both mothers and fathers of children with autism. They found both maternal and paternal anxiety and/or depression to be significantly related to stress in both parents. However, Hastings, Kovshoff, Ward, et al. (2005) did not find a relationship between mental health indicators and positive impact in mothers of children with autism. In a longitudinal analysis over two years, Hastings, Daley, Burns, and Beck (2006) reported that both maternal

depression at time 1 and change in depression over time significantly predicted maternal stress at time 2, over and above the effect of child externalizing behaviours. In a recent study done by Weiss, Perry, and Isaacs (2013), mental health problems was one of the strongest predictors of parent outcome measured in terms of Family Quality of Life, such that lower levels of mental health difficulties predicted better family quality of life. However, the limited literature that looks at maternal mental health as a mediator between stressors and outcomes uses different measures and outcome variables. Although there is some research on mental health as a mediator or predictor of negative outcomes, there is a dearth of this kind of research with positive outcomes in mothers of children with a disability. In the current study I further examine this relationship using psychometrically strong quantitative measures as well as qualitative means.

Coping. It has already been established that raising a child with a DD is stressful for parents and they need to constantly cope with the unique challenges that come with these diagnoses. Coping is "an ongoing cognitive and behavioural effort to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 237). Based on Lazarus and Folkman's (1984) classic conceptualization of styles of coping, two primary approaches are generally used by individuals to cope with difficult situations: (1) Problem-focused coping that involves focusing on the stressors and finding solutions or strategies that will help in altering these sources of stress in the future (e.g., planning, taking direct action), and (2) Emotion-focused coping that involves focusing on the emotions elicited by the stress in the present without actually dealing directly with the stressors or finding solutions (e.g., denial, venting emotions etc.). These two responses are not mutually exclusive and often are elicited either at the same time or depending on the situation. When the person under stress feels that he/she can do something constructive about the

source of stress, he/she often uses problem focused strategies. On the other hand, when he/she feels overwhelmed and feels like he/she has to endure and get through the emotions elicited by the stressors, he/she often uses emotion focused strategies (Folkman & Lazarus, 1985; Lopez et al., 2008; Stuart & McGrew, 2009).

Over the years several measures such as the Ways of Coping (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984), Multidimensional Coping Inventory (Endler & Parker, 1990), and the COPE Inventory (Carver, Scheier & Weintraub, 1989) have been developed and used to measure both problem-focused and emotion-focused coping strategies. The COPE Inventory was 60 items long and a briefer, more conceptually focused measure, the Brief COPE, was proposed by Carver (1997). This measure consists of 14 scales that measure various coping strategies, some of which are adaptive or functional, while others often make coping harder or less functional. This measure has been frequently used in research with families with a child with DD due to the flexibility in format (can be used for a specific incident or for a general coping disposition) and shorter length that makes it easier to include in longer batteries of questionnaires often completed by families.

Although most studies within the DD literature report similar trends with regards to use of problem focused and emotion focused coping strategies, the results have still been inconsistent at times. Perhaps this is due to the inherent individual variability in effectiveness of coping strategies across time. Nevertheless, most studies suggest that parents who use problem-focused/task-oriented coping (or adaptive coping) strategies tend to have lower levels of parenting stress (Abbeduto et al., 2004; Miller, Gordon, Daniele, & Diller, 1992; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Peer & Hillman, 2012; Stuart & McGrew, 2009) and better maternal well being (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), while others

suggest that using these strategies moderates the negative effect of stressors on mothers' psychological well being (Essex, Seltzer, & Krauss, 1999; Woodman & Hauser-Cram, 2013) or various types of stress experienced by parents (Lyons et al., 2010).

In a qualitative study with mothers of children who had recently received the diagnosis of a particular form of DD, Bingham et al. (2012) reported that mothers' use of several problem-focused coping strategies such as seeking information, seeking social, spiritual and professional support, and reframing helped them cope with their child's diagnosis. Interestingly, during the initial phase post diagnosis, these mothers reported that strategies such as denial and wishful thinking helped them in taking time to process their child's diagnosis and what it meant to them and their family. Gray (2003) also reported that both fathers and mothers used problem-focused and emotion-focused coping strategies, however, mothers reported using more coping strategies such as getting practical and emotional support from family and friends. These processes occurred in cycles at various points during which these strategies helped with their adjustment.

Hastings, Kovshoff, Brown, Ward, Espinosa & Remington (2005) conducted a factor analysis of the Brief COPE measure completed by 89 parents of preschool children and 46 parents of school aged children with autism. They reported four factors or coping dimensions including active avoidance coping, problem-focused coping, positive coping and religious/denial coping. However, in this study, problem focused coping (e.g., planning, active coping, seeking social support) was not related to parent outcomes.

According to Hastings, Kovshoff, Brown, et al. (2005), active avoidance coping (e.g., behavioural disengagement, self-blame, venting of emotions, distraction & substance use), that is similar to emotion-focused coping, was related to increased levels of stress in parents of children with autism. Several other studies (Abbeduto et al., 2004; Dunn, Burbine, Bowers, & Tantleff-

Dunn, 2001; Miller et al., 1992; Peer & Hillman, 2012) have similarly reported that more frequent use of emotion focused coping (e.g., escape or avoidance strategies) is related to increased stress/depression indicators in parents or moderates the relationship between child problem behaviour and parent well being (Woodman & Hauser-Cram, 2013).

Lyons et al. (2010) reported that more frequent use of emotion focused coping moderated the relationship between autism severity and parenting stress in the form of pessimism, such that parents of children with more severe autism who used emotion focused coping reported more pessimism stress whereas it did not matter so much when children had less severe autism symptomatology. One variation to this trend was reported by Lloyd and Hastings (2008), who used the Brief COPE and found that active avoidance coping was moderately related to anxiety and depression, but had only a small association with stress.

Positive Coping, which included humor and positive reframing, acceptance, and positive emotional support was related to lower levels of stress, perhaps reflecting adaptive coping when it is difficult to act directly on the stressors to reduce them (Hastings, Kovshoff, Brown, et al., 2005). Folkman and Moskowitz (2000) also suggested that positive appraisal or coping may help to bolster psychological and physical resources in times of crisis and act as a buffer against stress and depression. In addition, the use of positive reappraisal strategies is related to positive parent outcomes, measured in terms of happiness and fulfillment, strength and family closeness, personal growth and maturity (Hastings, Allen, McDermott, & Still, 2002). In fact, positive reappraisal is one of the few factors that has been studied in relation to positive outcomes. Minnes et al. (2015) found that positive reframing as measured by Brief COPE was a significant predictor of positive gain reported by 155 mothers of young children with DD.

Another interesting finding reported by Hastings, Kovshoff, Brown, et al. (2005) was that

the more frequent use of religious/denial coping (mix of adaptive and less adaptive strategies) was mildly related to higher levels of mental health difficulties in parents, but it was not as strongly related to parenting distress. Some studies in the coping literature have however reported that parents affiliated with religious groups often turn to their religious beliefs in an attempt to understand and make sense of their child's disability, why it happened to them and what it means to their family (Gray, 2003; Newton & McIntosh, 2010; Scorgie & Sobsey, 2000). Moreover, in a review of 212 studies that used Brief COPE as a measure of coping strategies used by individuals in a wide range of stressful situation, Krageloh (2011) found that the religious coping items from Brief COPE were included with adaptive and maladaptive coping strategies based on the types of factor analysis conducted and on characteristics of the sample, especially how strongly the participants were affiliated with religious beliefs and practices. Depending on how they interpret it, religious coping may be adaptive in terms of coping, and needs to be further examined. Therefore, it is evident that there is a need to examine various strategies of coping as mediators between stressors and positive as well as negative outcomes.

Family Resources

Taking care of and supporting a child with a DD affects various areas of family functioning. A family functions well when the family members have a strong emotional bond with one another (Olson, Portner, & Lavee, 1985) and when they are able to adapt their ongoing roles based on needs. When faced with challenges, each family accesses its psychological resources, the family characteristics that help in coping with challenging situations such as raising a child with autism or DD and functioning adequately. *Family Hardiness* and *Marital Satisfaction* are two of these resources frequently studied in the literature.

Family hardiness. Despite all the difficulties and stressors families experience in the

process of raising a child with a disability, most families remain resilient and continue to function as a family unit (McCubbin & McCubbin, 1996). Family hardiness is one of the factors that helps families maintain resilience through hardship. It can be defined as a family's overall sense of control over various stressors in life, by being able to consider possible benefits of a challenging situation as well as dealing with the stressors themselves, while having the confidence in their abilities to accomplish this balance (McCubbin, McCubbin, & Thompson, 1987).

More studies in the field of DD have focused on hardiness as related to coping in individual parents of children with DD. Hardiness in mothers of children with intellectual disability and autism has been found to be related to lower levels of depression, and anxiety (Weiss, 2002). In addition, higher levels of hardiness have been associated with lower parenting stress in parents of children with autism (Gill & Harris, 1991; Plumb, 2011) and DD (Ben-Zur, Duvdevany, & Lury, 2005).

Few studies have actually explored family hardiness as a factor in successful adaptation and functioning of a family with a child with DD. Failla and Jones (1991) looked at the relationship between family hardiness and parents' perception of stress, amongst other variables, and found that higher levels of family hardiness were related to more satisfaction with family functioning and appraisal of the stressor in a more positive and adaptive manner. Weiss and Lunsky (2011) studied family crisis in relation to a number of child, family and outcome variables and reported a moderate negative correlation between family hardiness and both parent mental health as well as burden. In addition, Weiss et al. (2013) reported that family hardiness mediates the relationship between stressors and parents' perceptions of family distress.

Although the results from several studies have consistently shown that family hardiness

can help parents deal with stressors and reduce negative impact on mothers, there is almost no literature on whether hardiness as a family would be related to a stronger positive impact. In the current study, I attempt to fill this gap by studying the role of family hardiness in the relationship of stressors to both positive and negative outcomes.

Marital satisfaction. In addition to the overall effect on family hardiness, the demands related to raising a child with autism and DD often put a strain on the marital relationship of the parents (Bekhet, Johnson, & Zauszniewski, 2012; Freedman, Kalb, Zaboltsky, & Stuart, 2012). One way of studying the parental relationship is in terms of "marital quality" or a combination of positive and negative feelings that individual parents extract from their relationship, involving conflict, sharing of activities, confidence and expression of affection (Erel & Burman, 1995; Spanier, 1976). Several studies have compared marital quality/satisfaction in groups of parents of children with a DD with parents of typically developing children. However, research support for the argument about higher rates of divorce or lower marital quality in parents of children with autism and DD compared to parents of typically developing children has been mixed.

Hartley et al. (2010) reported higher divorce rates in their sample of parents of mostly older adolescents and adults with autism compared to parents of typically developing adolescents and adults. On the other hand, results from other studies (Baker, Blacher, & Olsson, 2005; Freedman et al., 2012; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011; Norlin & Broberg, 2013) reported that the level of marital quality or satisfaction was not significantly different between the two groups. The main reason reported for this trend has been that parents become each other's primary source of support in dealing with their child's disability. Moreover, higher levels of marital satisfaction and quality have been related to individual parents reporting higher levels of well being (Norlin & Broberg, 2013) or lower levels of stress (Baker et al., 2005;

Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Sloper, Knussen, Turner, & Cunningham, 1991), daily hassles (Stoneman & Gavidia-Payne, 2006) and parenting burden (Hartley et al., 2011).

Despite some differences in results and sample characteristics of these studies, a constant theme is that marital quality or satisfaction is an important variable to consider when trying to understand how the stressors involved with raising a child with DD impacts mothers (Bekhet et al., 2012). In the current study I attempt to clarify how the quality of or satisfaction with their marriage influences the relationship of stressors with both negative and positive impact.

Informal Social Support

Social support is defined by Dunst, Trivette, and Cross (1986) as a multidimensional construct involving the exchange of physical, instrumental, resource, emotional, and psychological support with family and friends. Social support from family and friends has been repeatedly found to be related to lower stress in mothers (Boyce, Behl, Mortensen, & Akers, 1991; Bristol, 1984; Bromley, Hare, Davison & Emerson, 2004; Kazak and Marvin, 1984). Stuart and McGrew (2009) found that social support was related to lower levels of parent reported individual and family burden. In addition, researchers have also consistently found that social support serves to buffer the effects of stressors on parents (Dunn et al., 2001). In a regression analysis done by Bishop et al. (2007), social support emerged as a significant moderator of perceived negative impact such that mothers with higher levels of self reported social support had significantly lower levels of negative impact than those with limited social support.

Over the years, researchers have attempted to conceptualize and measure social support in a number of different ways such as the number of supports available, perceived helpfulness of

supports available, and a combination of number and helpfulness of social support. It seems to be an elusive concept with most measures showing low to moderate psychometric properties.

Helpfulness of social support has been particularly interesting to study as it has been found that, at times, "supports" such as extended family could, in fact, increase the experience of stress in parents of children with a disability. White and Hastings (2004) looked at informal social support using multiple measures and found that helpfulness of these supports was significantly negatively correlated with parent stress, depression and anxiety (Boyd, 2002).

Although the helpfulness of social support has been associated with both positive and negative outcomes (Ekas, Lickenbrock & Whitman, 2010; Smith, Greenberg & Seltzer, 2012), a greater number of studies have focused on negative outcome. A study done by Hastings et al. (2002) was one of the few that looked at a direct relationship between informal social support and positive outcomes. They found helpfulness and usefulness of informal support from family and friends to be a significant predictor of positive outcomes in parents of children with DD (Hastings et al., 2002). In the current study I further explore how helpfulness of informal social support influences the effect of stressors on both negative and positive impact.

Formal Supports and Services

Another aspect of support is related to the parents' perception of availability of formal supports and services and satisfaction with these services (Bristol, 1984). Support can also be received in the form of formal services from professional organizations that may add value to the family's life and be deemed important by them (Dunst et al., 1986). However, with the ongoing debate over optimal treatment for these disorders, families often have to navigate the complex service system (Karst & Van Hecke, 2012). Families of children with a disability can receive a wide range of services including services for the child (e.g., speech therapy, behavioural

intervention) and those for the family more generally (e.g., service coordination and respite). In a study done by Honig and Winger (1997), longer duration of strong and supportive professional supports and services were related to lower levels of stress reported by mothers.

However, there are mixed results about the buffering effect of formal sources of support (Boyd, 2002; White & Hastings, 2004) on the relationship between stressors and parent outcomes. For example, in an empirical study, White and Hastings (2004) found that, although formal support was negatively related to parental stress, this effect became non-significant once the child's adaptive and maladaptive behaviour were controlled. Similarly, Boyd (2002) conducted a systematic review of research on the effects of social support on parent outcome, and reported that parents were impacted positively or negatively depending on the nature of the formal support. For example, they reported that parents found it helpful to share experiences with other parents in a support group, but also found it more stressful when they talked about the range of difficulties their children experienced.

In addition, most of the above literature has studied effect of formal supports on negative outcomes. There is limited research that examines formal and informal support in relation to positive outcomes. White and Hastings (2004) did not find any significant correlations between measures of helpfulness of formal supports, and caregiver satisfaction around their interactions with their child. Similarly, Weiss, Perry, and Isaacs (2013) also found that formal supports and services were not significant predictors of positive outcome measured in terms of family quality of life. In addition, Perry (2004) reported that only 1% of the variance in outcomes was accounted for by formal supports and services, when other domain factors were considered first or controlled. Therefore, it seems like there is variability in research results based on child characteristics such as severity of maladaptive behaviours, the form of formal supports accessed

and the extent of support parents reported receiving from these services, as well as what other factors were simultaneously examined in the study.

Another important aspect to note is that there is a trend of more mothers participating and responding in the studies reported above. Some of these studies invited only mothers to participate, while others invited parents, but in the end a significant majority of participants were mothers. There is a small, slowly expanding body of literature, that suggests that fathers and mothers respond differently to raising a child with DD (Gray, 2003; Hartley et al., 2012). It has been found that they tend to focus on different aspects of their child's difficulties, have somewhat different coping mechanisms, and report different levels of outcomes. However, in most families, mothers tend to be primary caregivers, and in this study, I focus only on mothers' experiences of raising a child with DD.

The literature discussed above makes it obvious that a number of child, parent and family characteristics are essential to study in order to best understand the variability in parent outcomes. Best practice guidelines suggest that it is essential for service providers to provide individualized service plans that take into consideration the social and cultural values of the family as well as their overall life situation (Harry, 2002; Skinner & Weisner, 2007). When these conditions are not met, unfortunately interacting with professionals may lead to increased parental stress (Bernheimer & Weisner, 2007). This suggests that in order for us to understand maternal outcomes in families coming from diverse cultural backgrounds in Canada, it becomes extremely important to consider these outcomes within the cultural as well as immigration context for these families.

Role of Culture in Parental Outcomes

Based on the above model, perceptions of positive and/or negative impact are also likely to be associated with the broader context of family values and culture. However, there is very limited research intersecting the concepts of culture and maternal outcomes of children with DD, and there is a lack of understanding and definition of the concept of “culture” in the studies that do address it. In this section, I will discuss culture as conceptualized in the social sciences, following which I will discuss the differences in concepts of disability across cultures and focus on studies conducted with parents in South Asian Countries and South Asian immigrant parents in Canada, USA and UK. I will also present small body of literature with South Asian parents that has examined the target variables from the model discussed above. Finally, I will discuss the concept and influence of acculturation on this model.

What is culture?

Researchers from different fields of study have attempted to define *culture* in various ways but it has proven to be an elusive and dynamic concept. There have also been attempts to develop theories and instruments for mapping and comparing national cultures (e.g., Schwartz, 2006). Schwartz approached culture as the rich complex of meanings, beliefs, practices, symbols, norms and values prevalent among people in a society. He emphasized that *cultural values/value orientations* shape and provide a basis for individual and group beliefs, actions and goals, promote coherence among various aspects of the culture and generate tension if aspects of a culture are incompatible with these values (Schwartz, 2006).

Based on three bipolar cultural value dimensions (autonomy vs embeddedness, egalitarianism vs hierarchy, and harmony vs mastery), Schwartz (2006) proposed seven transnational cultural groupings: English Speaking, Eastern European, Western European, Latin

American, South Asian, African & Middle Eastern and Confucian Influenced countries. Canada is one of several western countries in the English Speaking group and India, Pakistan, Bangladesh, Sri Lanka, Nepal and Afghanistan are included in the South Asian group according to Schwartz (2006).

Cultural Differences in Concepts of Disability

Culture influences how members of different cultural groups respond to having a child with a disability, perceive experiences and seek services to manage health and illness (Mandell & Novak, 2005; Narayan, 2002; Skinner & Weisner, 2007; Welterlin & LaRue, 2007). Even the extent to which a disability is considered a stressor or a handicap depends on the family's attitudes, the stigma or acceptance in the society as well as financial resources, legislation and adaptations to support the disability in their environment (John & Montgomery, 2016; Ravindran & Myers, 2012).

Bishop et al. (2007) explored the extent to which demographic characteristics of the family such as ethnicity, maternal education, number of children in the family, and parent marital status are associated with perceived negative impact in parents of children with ASD. They found that, of the family demographic variables, ethnicity was the most robust predictor of perceived negative impact. Even when taking site and maternal education into account, African American mothers reported significantly lower levels of perceived negative impact than did Caucasian mothers. Bishop et al. (2007) suggested that this difference could be a result of a number of factors such as cultural differences in reporting styles, African American mothers not necessarily attributing their negative feelings to rearing a child with ASD, or having effective coping strategies to deal with challenges posed by their child's disability.

In another study, Blacher and McIntyre (2006) found that Latina mothers of children with MR, cerebral palsy, Down syndrome, or autism reported higher positive impact of their children compared to Caucasian mothers. In addition, Blacher and Baker (2007) explored the buffering role of cultural group on the relationship between behaviour problems and positive impact. Although both Latina and Anglo mothers reported almost similar positive impact when the child was not delayed, Latina mothers reported significantly higher positive impact than Anglo mothers when the child was developmentally delayed (Blacher & Baker, 2007).

South Asian countries are a few of the most populous countries of the world, however they fall under the Low and Medium Income Countries (LMIC). Available government resources are spread thin amongst the vast population, and mental health and developmental disorders fall towards the bottom of the resource allocation priorities (Daley, Singhal & Krishnamurthy, 2013; Minhas et al., 2015; Shrestha & Shrestha, 2014). In addition, there is limited awareness, knowledge, acceptance and services for ASD in these countries. In 2012, Elsabbagh et al. (2012) reviewed prevalence studies conducted across the globe and found no prevalence studies for Autistic Disorder. They reported only one prevalence study for PDD (Perera, Wijewardena & Aluthwelage, 2009), in which authors reported a prevalence estimate of 100/10 000 in Sri Lanka. In a recent systematic review of epidemiological studies across eight countries including India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan, Maldives and Afghanistan, Hossain et al. (2017) were left with just six studies (from India, Bangladesh and Sri Lanka, none from the other countries) that met the criteria within their review. Based on these studies, Hossain et al. (2017) estimated prevalence rates of ASD from .09 to 1.07% of the population, suggesting that approximately 1 in 93 children in these countries are likely to have a diagnosis of ASD (Hossain et al., 2017). In spite of the high prevalence (albeit, mostly concentrated around urban centres

with some services for children with ASD), the majority of the current literature on this group is comprised of qualitative, descriptive studies conducted either in South Asian countries or in the USA, Canada and the UK.

Fortunately, a small but slowly growing (even since the beginning of the current study) body of cross-cultural literature on the experiences of families with an individual with a developmental disability living in South Asian countries now exists including *India* (Banga & Ghosh, 2017; Daley, 2002; Daley, 2004; Daley & Sigman, 2002; Daley et al., 2013; Das et al., 2017; Desai, Divan, Wertz & Patel, 2012; Dhar, 2009; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Hossain et al., 2017; John, 2012; John & Montgomery, 2016; John, Bailey & Jones, 2017; Kishore, 2011; Minhas et al., 2015; Siddiqui, 2014; Singh, Ghosh & Nandi, 2017), *Pakistan* (Hossain et al., 2017; Lakhani, Gavino & Yousafzai, 2013; Mirza, Tareen, Davidson & Rahman, 2009; Sabih & Sajid, 2008; Yousafzai, Farrukh & Khan, 2011), *Bangladesh* (Hossain et al., 2017; Maloni et al., 2010; Monawar Hosain & Chatterjee, 1998; Parvin et al., 2015), and *Nepal* (Heys et al., 2016; Shrestha & Shrestha, 2014). These authors discuss the influence of culture on disability perception and the importance of considering culture when providing services to South Asian families in Western countries.

This set of literature (that I will summarize in the following section) gives us insight into the cultural beliefs, attitudes and possibly experiences that South Asian parents bring with them as a part of their psyche when they immigrate to a western country such as Canada. When families immigrate to a new country, they are exposed to a new culture, social service system, society and expectations. It then becomes essential for us to examine if and how their adjustment to this new culture and system influences their overall adaptation to raising their child with DD.

In a multicultural country like Canada, many communities experience a flow of immigrants from many diverse cultures. According to the 2011 Immigration and Ethnocultural Report of Statistics Canada, Ontario, the Greater Toronto Area (GTA) is one of the main hubs for immigrant settlements. Based on the 2016 Census report on the city of Toronto website, about 51% of the population of Toronto consists of immigrants. There has also been an increase in immigrant families being referred for autism services. In a recent study done by Luthra et al. (2009) to examine parent outcomes in Schwartz's seven cultural groups, a sample of parents of children with autism who were receiving IBI in Ontario included families from over 20 different countries (Luthra et al., 2009).

Despite a large number of South Asian immigrant families with a child with DD being served within the public and private service organizations in Canada, especially Ontario, I was able to locate only one study (Daudji et al., 2011) that specifically examined the perceptions of disability amongst this immigrant group. Similar to Canada, the USA and UK are also quite multicultural and have a steady flow of immigrants from South Asia. Currently, there are a few studies conducted in the *USA* (Gabel, 2004; Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010; John, Bower & McCullough, 2016; Mandell & Novak, 2005; Masood, Turner & Baxter, 2007; Ravindran & Myers, 2012; Tway, Connolly & Novak, 2007; Zechella & Raval, 2016) and the *United Kingdom* (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Dura-Vila & Hodes, 2012; Gilligan, 2013; Hatton & Emerson, 2009; Heer, Rose & Larkin, 2012; Hussain, 2005; Hussain, Atkin & Waqar, 2002) that discuss the influence of culture on disability perception and the importance of considering culture when providing services to South Asian families. I will review these in the following section.

Based on these studies conducted in South Asian countries as well as those with South Asian immigrant parents in western countries, along with other cross-cultural research, cultures may vary in their responses to disability in the following ways:

Timetable of development and what is considered "delayed". Westernized cultures have adopted beliefs about an earlier timetable of development in infancy than the more traditional cultures in the other parts of the world (Daley, 2002, 2004; Harry, 2002). The behaviours that may be viewed as "delayed" in the west, may not be viewed in the same light in other cultures and may reflect an acceptable child-rearing practice, for example, feeding a 3-year-old child, letting him/her sleep with parents, or belief that its common for boys to talk late (Daley, 2004; Minhas et al., 2015; Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). Therefore parents may wait to see if speech delays resolve with time before seeking advice from a doctor. Even doctors in South Asian countries wait till a child is 34-36 months on average, before raising concerns about speech delay or referring for services (Daley & Sigman, 2002; John & Montgomery, 2016). Research conducted in South Asian countries also suggests that the wait time from initial recognition of difference in their child to obtaining a diagnosis usually ranges from about two to four years (Kandasamy et al., 2017; Mirza et al., 2009), and in some places, even up to 13 years (Shrestha & Shrestha, 2014).

Most qualitative studies with immigrant parents in Canada, the USA and the UK reported results similar to those discussed above in mothers in South Asian countries. Like their South Asian counterparts in their native countries, these immigrant parents in the west still waited longer before approaching a professional for help, hoping that their child would improve with time, especially when grandparents (who were more strongly entrenched in traditional beliefs) were living with these families (Jegatheesan, Fowler & Miller, 2010; Ravindran & Myers, 2012).

Symptomatology Noticed and Explanation Models of Disability. In the west, language and behaviour may be noted as the first symptoms parents are concerned about whereas, in South Asian countries such as India, social difficulties may be the first to be noticed and considered problematic, followed by speech delays (Daley, 2004; Mehrotra & Vaidya, 2008). This may be due to a difference in the importance given to social relatedness from an early age in the eastern countries.

All parents whose child is diagnosed with a disability go through the process of trying to understand their child, the child's diagnosis, and its causes, if known (Altier & Von Kluge, 2009; Desai et al., 2012; John, Bailey & Jones, 2017). Even though the earliest understanding of a diagnosis of autism in the west included the “refrigerator mother” theory (Kanner, 1944), it has long been taken over by a scientific focus. Today, with a surge in research and understanding of disorders, in most western countries like the USA and Canada a medical/biological model has been adopted for defining what is typical and atypical (Harry, 2002; Welterlin & LaRue, 2007). However, most Caucasian parents in the west, who follow more traditional religious practices, also have strong faith in the will of God, do turn towards their congregations and religious leaders for support, and tend to use more adaptive coping strategies if they believed that their child’s challenges are in their control (Newton & McIntosh, 2010).

Even though there is variability in the awareness and understanding of DD in parents in Canada and other western countries, South Asian Parents of typically developing children as well as others in the South Asian community may have even less knowledge about these diagnoses, and children with DD are often given negative labels such as “mad”, “slow minded”, “dumb”, “abnormal” etc. (Daley, 2004; Heys et al., 2016; Mirza et al., 2009). Parents may have specific views of what is defined as disability, which may be based on their unique social and cultural

background, as well as their economic and political history. Understandably, there is much variability in the model used to understand disability in different cultures, ranging from a completely religious/traditional explanation (e.g., God's will, penance for past sins) to more medical explanation (e.g., differences in brain and development).

It is interesting to note that the understanding of disability in South Asian mothers (both in their country and here in the western countries like Canada) has been usually found to be a mix of a medical model as well as traditional/religious and environmental beliefs about the cause and explanation of a disability (Bywaters et al., 2003; Daley, 2004; Daudji et al., 2011; Heer et al., 2012; Heys et al., 2016; Jegatheesan, Miller & Fowler, 2010; John, Bailey & Jones, 2017; John & Montgomery, 2016; Mandell & Novak, 2005; Mehrotra & Vaidya, 2008; Mirza et al., 2009; Ravindran & Myers, 2013; Zechella & Raval, 2016). It was also common for South Asian immigrant parents in these studies to default to traditional explanations at first, especially when consulting with elders, and move towards a mixed model as they research and learn to understand their child's disability (Ravindran & Myers, 2013; Zechella & Raval, 2016).

Daudji et al. (2011) conducted semi-structured interviews with five South Asian immigrant mothers of children with a congenital spinal cord injury in Toronto. Their children suffered from physical impairments along with an overall delay in development. In spite of being in a country where there are significantly more services for children with disabilities, these South Asian immigrant mothers reported a mix of more traditional and medical beliefs regarding their child's diagnosis and rehabilitation (Daudji et al., 2011), and tried to focus on their child's strengths.

On the other hand, Masood et al. (2007) explored the attributions about their child's diagnosis in parents in Pakistan and the USA. They reported that parents in Pakistan tended to

attribute their child's diagnosis to God's will or personal failure, while parents in USA tended to attribute it more to genetic and medical factors. Even amongst parents who subscribe to religious explanations, both adaptive/positive and maladaptive/negative beliefs exist in South Asian families. On the positive end, mothers may accept their child's disability as God's will/plan, view their child as a blessing, that God will give them the strength and means to support their child (John, Bailey & Jones, 2017; John & Montgomery, 2016; Kharti et al., 2011; Mirza et al., 2009) and usually reject negative religious explanations. On the other end, negative religious explanations include the belief that family members are responsible for the child's disabilities, it is thought of as a form of God's wrath or punishment for past family sins, and that their child's disability is a sign of possession by ghosts or spirits (Daley, 2004; John & Montgomery, 2016; Maloni et al., 2010; Mirza et al., 2009; Welterlin & LaRue, 2007). Depending on their belief, they may or may not actually consider their child to be disabled. They may consider it as a temporary condition due to reincarnation, and that it will get better (Maloni et al., 2010). The results from some of these studies are quite similar to those done in East Asian countries such as China, Taiwan (Chang & Hsu, 2007; Chang & McConkey, 2008) and with East Asian immigrants in the USA (Luong, Yoder & Canham, 2009) and Canada (Su, Khanlou & Mustafa, 2018).

Implications of Having a Child with DD. As a result of some of the negative traditional/religious beliefs, some families may be reluctant to interpret their child's behaviour as a disability, since it would imply that they had committed sins in the past. In fact, qualitative studies done with South Asian parents (both in South Asian and western countries) reflect lack of understanding and acceptance of children with disabilities, and indicate that having a child with disability results in social stigma, shame, isolation and parent blaming (e.g., poor parenting,

unacceptable maternal behaviour during pregnancy, maternal diet etc.) such that social barriers are created for the whole family (Bywaters et al., 2003; Croot, Grant, Mathers & Cooper, 2012; Daley, 2004; Gabel, 2004; Gupta, Mehrotra & Mehrotra, 2012; Heer et al., 2012; Heys et al., 2016; Hussain, 2005; Hussain et al., 2002; Jegatheesan, Fowler & Miller, 2010; John & Montgomery, 2016; Maloni et al., 2010; Mehrotra & Vaidya, 2008; Mirza et al., 2009; Monawar Hosain & Chatterjee, 1998; Shrestha & Shrestha, 2008; Yousafzai et al., 2011; Zechella & Raval, 2016). Parents may choose not to share their child's diagnosis initially with their family, and pass it off as just delayed speech. In addition, the stigma attached to having a child with a developmental disability may be further exacerbated by the genetic underpinnings of some disorders and the importance given to genetics while arranging for marriages and other social unions, especially for female siblings of the child with a diagnosis (Daley et al., 2013; Divan et al., 2012). However, some immigrant parents expressed their relief regarding greater acceptance and lower stigma post immigration to Canada (Daudji et al., 2011).

Knowledge and Training in Professionals in South Asia. There might also be an underlying lack of understanding of health care and special education systems and procedures and the risks and benefits in South Asian countries (Heys et al., 2016; Parvin et al., 2015). Often physicians or pediatricians are the primary sources of health care, when parents do decide to seek help. Doctors are considered “next to God” and parents follow exactly what doctors suggest. Unfortunately, research conducted with professionals (physicians, pediatricians, nurses, health workers, school teachers etc.) in South Asian countries indicates a lack of knowledge, training, exposure and experience with developmental disabilities, especially ASD (Daley & Sigman, 2002; Dalwai et al., 2017; Divan et al., 2012; Heys et al., 2016; Imran et al., 2011; Kharti, Onta, Tiwari, & Choulagai, 2011; Rahbar, Ibrahim & Assassi, 2011; Rohanachandra, Dahanayake,

Rohanachandra & Wijetunge, 2017). Younger doctors and interns tended to report better knowledge and experience with ASD, which might suggest an increased awareness and training in the current medical system. Trained psychologists and psychiatrists had better expertise in DD and ASD, however even then services may vary quite a bit since psychology is not a regulated health profession in South Asian countries such as India (Barua, Kaushik & Gulati, 2017; Daley & Sigman, 2002).

Even though there are legal initiatives for right to an education for all in some countries like India (Barua et al., 2017), fewer than 4% of children with a disability have access to any type of education according to the 2005 National Council of Educational Research and Training in India. This number has certainly improved in the past decade. In 2010, Singhal reported that about 48% children with ASD in India are not going to school, due to a lack of acceptance as well as lack of trained teachers and therapists, and at times, having a diagnosis might lead to the removal of a child from school. However, there has been significant development in recognition of specific diagnoses such as Autism as a disability, in training of professionals in assessment and intervention, provision of services and a general increased awareness in the past few years (Dalwai et al., 2017; Barua et al., 2017).

Choice of Treatment Approaches. John and Montgomery (2016) reported that parents' causal beliefs may influence the treatment approach and focus they choose to pursue. Parents who have a more positive religious explanation may choose to focus on rehabilitation and strength based approaches, while still getting spiritual support in adapting to and accepting their child's disability. When parents adapt more positive religious explanations, parents express that they have been chosen by God to support their child's development and accepting/loving him or her comes naturally to these parents. They may not feel the shame that some other families might

feel in society (John & Montgomery, 2016). Those who have a shame focused negative explanation for their child's disability might focus their energy on deeply traditional faith healing, astrology etc., instead of rehabilitation and services. On the other hand, parents who have a primarily medical explanation for their child's disability may completely reject religious explanations and focus primarily on medical treatment, social support and advocacy for improvement of services (Daley, 2002; John & Montgomery, 2016).

Parents' beliefs about the etiology of autism or DD may also influence the treatment methods adopted or accepted by these families. Initially, they may believe in superstitious, culturally rooted explanations and thus rely on family members, elders, spiritual and folk healers, and traditional medicine for information and treatment, rather than western trained professionals (Chang & McConkey, 2008; Daley, 2004; El-Islam, 2008; Gabel, 2004; Jegatheesan, Miller & Fowler; 2010; John et al., 2017; Parvin et al., 2015; Ravindran & Myers, 2013; Shrestha & Shrestha, 2014; Welterlin & LaRue, 2007; Yousafzai et al., 2011). However, as they research more about treatment options and explore more evidence based options, South Asian parents in urban areas in South Asian countries as well as immigrant parents in the west have been reported to choose multiple systems of treatment including religious healers, Ayurveda, Homeopathy, Accupressure and medication along with Speech therapy, behavioural and educational treatments (Daley, 2002; Divan et al., 2012; Gabel, 2004; Jegatheesan, Fowler & Miller, 2010; John et al., 2017; Maloni et al., 2010; Parvin et al., 2015; Ravindran & Myers, 2012; Yousafzai et al., 2011).

Treatment Goals and Concept of Progress. Even if families of different cultures accept a western diagnosis of autism or DD, there might be major differences in what they consider “normal” functioning, compared to what is considered normal in a western medical model framework, on which treatment decisions are based. For example, the western mainstream goal

for treatment revolves around the idea of “quality of life” involving independence, self-reliance, and personal choices, which may not be shared by a number of immigrant groups such as Asians, African-Americans, and so on, who believe in family interdependence. Even though their ultimate goal may be to make their child independent, the path to this independence or the way in which it is conceptualized, may be different in different cultural groups (Harry, 2002; John et al., 2017; Minhas et al., 2015; Mirza et al., 2009; Welterlin & LaRue, 2007). Based on their beliefs, parents may have different expectations of treatment and the meaning of their child’s “progress” (as defined by the North American treatment providers).

In addition, on one hand, traditional beliefs such as Hindu belief in reincarnation and Muslim parents’ belief in themselves as protectors of Allah’s “special child” may help parents to accept their child in a positive manner, to do everything to keep their child healthy and cared for, and include them in normal social and religious activities at home and in the community. On the other hand, these beliefs may mean that they trust that their child will gradually progress, may underestimate their abilities, have minimal expectations from them and hence may not necessarily be overly concerned about their child achieving developmental milestones (Bywaters et al., 2003; Gabel, 2004; Gupta & Singhal, 2004; Hussain, 2005; Hussain et al., 2002; Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010; Kaul, Mukherjee, Ghosh, Chattopadhyay & Sil, 2003). However, research also suggests that beliefs could be modified, changed or strengthened in families who immigrate based on diagnosis in the host country, availability of resources and families’ ability to use these resources (Mandell & Novak, 2005; Ravindran & Myers, 2012). In fact, some parents have reported greater acceptance of their child’s disability and presence of better and more appropriate services for their child as primary reasons for them to immigrate to the west. They also were reported to be grateful for the

services, in spite of the challenges they experienced (Daudji et al., 2011; Zechella & Raval, 2016).

Cultural and Language Barriers to Service Utilization in Immigrants. Once parents have immigrated with these hopes and in spite of the presence of evidence based intervention for various challenges related to DD, immigrant mothers have been reported to have lower rates of service utilization due to a number of barriers such as language, knowledge of services and rights, availability of services in low income areas of urban centres, transportation challenges for new immigrant families, communication, interpersonal styles (some South Asian mothers may not be comfortable speaking in front of male strangers) and expectations from professionals, and cultural differences in treatment goals between parents and professionals (Bywaters et al., 2003; Daudji et al., 2011; Gilligan, 2013; Heer et al., 2012; Khanlou et al., 2017; Jegatheesan, Fowler & Miller, 2010; Jegatheesan, Miller & Fowler, 2010; Zechella & Raval, 2016).

Immigrant mothers might not be able to fully understand information conveyed to them and may have difficulty expressing their needs and issues with professionals, because of limited English skills (Jennings, Khanlou & Su, 2014; Khanlou et al., 2017) but also different communication styles in terms of formal relationships, direct and non-direct interactions and non-verbal mannerisms, such as eye contact. South Asian Muslim mothers in USA reported initially seeking help from South Asian doctors who were more warm, empathetic and genuinely interested in their experience and understanding of their child's disability, even though they were not experts in developmental disabilities. When the same parents subsequently went to Caucasian experts in DD, they reported these doctors to be more direct, impersonal, time conscious and expressed no interest in their personal experience and background (Jegatheesan, Fowler & Miller, 2010). These may lead to mothers having a lack of information and inaccurate

messages being transmitted between parents and professionals (Bywaters et al., 2003; Harry, 2002; Welterlin & LaRue, 2007).

In addition, South Asian immigrant families are immensely diverse such that even within their countries, they often belong to multiple subgroups based on religion, caste, language, dialects, rural/urban settlement, educational background as well as migration histories (Bywaters et al., 2003; Gilligan, 2013; Harry, 2002; Heer et al., 2012; Ravindran & Myers, 2013). They often speak more than two languages at home, especially when grandparents, who mostly speak their native language, are living with the families. Their child's ability to interact with their grandparents and other extended family and community members (central and important to the collectivistic South Asian culture) might hinge on their ability to speak in multiple languages. However, Caucasian professionals may not be aware of this and might push the family to choose to interact with their child exclusively in English so as to make it easier for them to cope with their language delays. The families may perceive this as disrespect of their culture and a lack of understanding on the part of the professionals, and may lead to failure in achieving treatment goals (Bywaters et al., 2003; Gilligan, 2013; Heer et al., 2012; Jegatheesan, Fowler & Miller, 2010). Moreover, it might be important to some immigrant families to teach their child specific religious practices, which may seem not so central to treatment plans developed by western professionals who may not have awareness about these issues (Gilligan, 2013; Hussain, 2005; Hussain et al., 2002).

Moreover, financial instability experienced by immigrants who moved to North America in search of economic stability, and who are now employed in low paid jobs with minimal benefits, further impedes their health care use. They may not be able to afford private services and may have a lack of access to transportation, child care and so on, thus limiting their access to

services even when low cost treatments are available (Harry, 2002; Khanlou et al., 2017; Welterlin & LaRue, 2007). However, socio-economic status did not seem to influence how severity of child problem affected parents' overall stress in the study by Hatton and Emerson, 2009).

Domains of Perry Model within the South Asian Literature.

Raising a child with a DD very often comes with its challenges, however, only recently have studies actually looked more specifically and somewhat quantitatively at the variables that affect parent outcomes and at the overall effect of raising a child with disability in South Asian mothers. Researchers in South Asian countries have reported significant levels of parenting stress (Das et al., 2017; Gupta et al., 2012; John, 2012; Kishore, 2011; Mirza et al., 2009; Sethi, Bhargava & Dhiman, 2007), subjective burden (John, 2012; Kandolkar & Kenchappanavar, 2014; Sabih & Sajid, 2008; Singh et al., 2017) and mental health problems (Singh et al., 2017).

Similarly, South Asian immigrant mothers report significant negative impact in the form of stress due to the initial social exclusion related to their child's disability, learning about and accepting their child's disability, promoting acceptance in their own family and community here in the west as well as back home, accessing and navigating services for their child as well as lack of the presence of family close to them in times of emergencies, and long term planning for their child's future (Jegatheesan, Fowler & Miller, 2010; John, Bower & McCullough, 2016; Ravindran & Myers, 2013; Zechella & Raval, 2016). John (2012) measured parenting stress in Indian mothers of children with DD and compared it to parenting stress scores in Caucasian mothers in other studies done in Canada, USA and UK, and reported significantly higher mean parenting stress score in Indian mothers. However, there is variability in the questionnaires used to measure outcome in South Asian parents. They range from measures developed and validated

in the west such as Parenting Stress Scale (PSS; Berry & Jones, 1995), but frequently used cross culturally, to measures developed in South Asia such as the National Institute for the Mentally Handicapped – Disability Impact Scale (NIMH-DIS; Peshawaria, et al., 2000).

However, only a handful of qualitative studies in South Asia (Gupta & Singhal, 2004; Lakhani et al., 2013; Minhas et al., 2015; Rajan & John, 2017) and western countries (Zechella & Raval, 2016) also examine positive impact in South Asian mothers. These studies report about positive perceptions that South Asian parents have about their child with a disability, and positive changes they have seen in themselves such as learning from special problems, feeling happy and fulfilled, change in perspective and purpose, personal growth and maturity, being stronger as a person, parent and family, appreciating small gains, and developing a personal sense of control. Some mothers in South Asian countries feel empowered by taking charge of their child's success, advocating for supports and services for him or her, attending parent groups, exchanging resources with other mothers and in the process having the freedom to go out and away from home (Lakhani et al., 2013; Yousafzai et al., 2011).

In addition, some immigrant mothers report that they have learned to balance multiple roles in their child's life, to focus on one day at a time, promote independence in their child, along with instilling their cultural practices in their daily lives (Zechella & Raval, 2016). Interestingly, in the only quantitative study examining both negative and positive impact in Indian mothers, Kishore (2011) reported a non-significant relationship between negative and positive impact suggesting that they may be independent of each other such that parents can experience highs and lows in both at the same time.

A limited number of quantitative studies have examined the effect of some stressors and mediating variables on parent outcomes. Similar to other stressors discussed in previous sections,

some Indian mothers of children with ID (Sethi et al., 2007) reported greater stress when their child had more severe levels of ID. However, Siddiqui (2014) conducted semi structured interviews with 100 families of children with ID in India, using the Family Interview for Stress and Coping in Mental Retardation (FISC-MR; Girimaji, Srinath, Seshadri & Krishna, 1999), which was developed and validated in India to measure stress and coping mechanisms in parents of children with MR. This is an observer rated measure, such that the interviewer rates the parents' level of stress in four areas (Daily care stress, Family emotional stress, Social stress & Financial stress) using 11 subscales and their coping strategies in five areas (Awareness, Attitudes and expectation, Rearing practices, Social support & Global) using 9 subscales during the interview. Siddiqui (2014) reported that none of the child's age, gender, severity of diagnosis or the family's SES, were significantly related to parenting stress in a sample in India. Only mother's education level was significantly related, interestingly such that higher education was related with higher levels of stress (Siddiqui, 2014). In another study (Sabih & Sajid, 2008), amongst 60 Pakistani parents (30 mothers & 30 fathers) of children with autism, all parents reported significant levels of stress, more so when their child with autism was a girl. Some mothers of children with ASD in South Asia reported that giving up their careers to care for their child (Das et al., 2017; Divan et al., 2012) as well as worry about their child's future contributed significantly to their stress (Das et al., 2017; Divan et al., 2012; Mirza et al., 2009; Yousafzai et al., 2011).

In addition, due to the complexity of social interactions of families in South Asian countries with a child with DD, parents have reported initially withdrawing from society as they dealt with the new diagnosis and trying to understand what it meant for their child and family, and subsequently reintroduced themselves back within their community once they had a better

understanding (Desai et al., 2012; Divan et al., 2012; Yousafzai et al., 2011). Generally, similar to reports from studies in North America, within South Asian families, there have been mixed reports on the usefulness of social support, usually received from spouse, grandparents, siblings and extended family. John et al. (2016) reported positive support from spouse, support groups and close family and friends as the top three sources of support. These people in the social network have been reported to be both sources of support and/or stress depending on their understanding and acceptance (Daley, 2004; Desai et al., 2012; Divan et al., 2012), and at times social support has been reported to erode over time (Divan et al., 2012). When present, social support was found to moderate the relationship between subjective burden and depression in a sample of 70 mothers of children with ASD in India (Singh et al., 2017) when mothers had lower levels of burden. However, at higher reported levels of subjective burden, social support did not appear to make a difference.

The differences between Canadian and South Asian immigrant parents may also be evident in the coping mechanisms used by them to deal with these stressors, thereby resulting in different levels of negative and positive impact. Kishore (2011) reported that mothers in India used both problem focused and emotion focused coping mechanisms and found stronger non-materialistic positive impact in parents who used more problem focused coping mechanisms. Mothers in South Asian countries relied on religious activities and spiritual connections as one of the ways of coping with their stress (Daley, 2004; Das et al., 2017; Divan et al., 2012; Minhas et al., 2015; Maloni et al., 2010; Mirza et al., 2009). In addition, they turned to their spouse and parents to share their concerns and worries with them when they were overwhelmed (Divan et al., 2012).

Recently a study explored both positive and negative impact on parents of children with intellectual disability in India in an attempt to examine how to promote resilience in parents. Rajan and John (2017) reported that parents reported significant negative as well as positive impact, and that the extent of each was related to the parents' perceptions about their child's disability. If they had more positive views about their child's disability, they were more likely to report more positive impact on themselves, while negative perceptions were related to high negative impact.

In a study with 55 parents (mix of Caucasian and Asian American) of children with ASD in the USA, Tway et al. (2007) found that most parents depended on close family and friends for help with coping and used reframing strategies to accept their child's disability. Overall, 47% of these parents reported having faith in God, but did not always seek support from religious or spiritual leaders/practices as means of coping. Interestingly, Caucasian parents in this sample reported using more passive appraisal strategies, whereas Asian American parents reported greater use of reframing as a strategy. In addition, parents who spoke English as a Second Language (comprised mostly of Asian American parents) reported using significantly more spiritual support than English speaking parents (Tway et al., 2007).

Besides these more obvious challenges, they may also be influenced by the differences that may exist between the culture and beliefs in Canada in relation to their own culture through the process called acculturation (Berry, 1980, 1997; Daley, 2002; Mandell & Novak, 2005).

Acculturation and Disability Experiences.

As defined by Berry (1980, 1997, 2005), *acculturation* is a bi-dimensional process of change in self-identity, attitudes, behaviours and values as people move from one culture to another in order to adapt to the new host culture, such that both a "heritage identity" and a

"mainstream identity" are formed to different levels. An individual's heritage and mainstream identities are not considered to be mutually exclusive such that he/she could have varying levels of both at the same time. This bidimensional process of acculturation has been empirically confirmed by several researchers over the years (Flannery, Reise & Yu, 2001; Ryder, Alden & Paulhus, 2000). Following Berry's (1997) bidimensional conceptualization of the acculturation process, Ryder et al. (2000) developed a measure called the Vancouver Acculturation Index (VIA). They adapted some items from Berry's (1997) measure of acculturation and simplified the statements such that the responder rates 20 statements (10 for "Heritage" culture and 10 for the "Mainstream" culture) on a 10-point scale. Higher scores on the two dimensions indicated stronger identities related to that culture. Although not as well known as Berry's measure (1997, 2001, 2005, 2011, 2013), Ryder and his colleagues' (2000) research as well as the VIA have been frequently used in acculturation research with South Asian and East Asian populations in Canada (e.g., Brown et al., 2013; Jurcik, Ahmed, Yakobov, Solopieieva-Jurcikova & Ryder, 2013).

Berry (1980, 1997, 2005) proposed that a combination of these independent bidimensional processes can result in four main acculturation outcomes: (1) *Integration*, a strong heritage identity and a strong mainstream identity, (2) *Assimilation*, a weak heritage identity and a strong mainstream identity, (3) *Separation*, a strong heritage identity and a weak mainstream identity, and (4) *Marginalization*, weak heritage and mainstream identities (Berry, 1997).

Research has also indicated that Integration is the best acculturation outcome whereas Marginalization is the worst one, while Assimilation and Separation fall somewhere in between (Berry, 2001; 2005).

One of the approaches to the assessment of acculturation outcomes that has been suggested by Berry and Sabatier (2011) and used by several researchers (Playford & Safdar,

2007; Snauwaert et al., 2003) has been to measure individuals' scores on the two dimensions. Following this, the scores on the two dimensions can either be split at the median value of each dimension in the sample or at the mid point of the scale in order to determine high and low heritage and mainstream identities. Based on the above classification (Berry, 1980; 1997), each person in the sample then is classified in one of the four acculturation outcome categories. In the current study, I use the VIA to measure the heritage and cultural identity and the mid-point of each scale to classify each participant into one of the four categories.

Over the years Berry's (1980, 1997, 2005) conceptualization has been used numerous times in order to study the process of immigration and settlement, as well as in relation to other outcome variables such as health and psychological well being (e.g., Jurcik et al., 2013; Ryder et al., 2000; Salant & Lauderdale, 2003). However, it has not been studied empirically in relation to parents of children with a disability. Using an online questionnaire, Ravindran and Myers (2012) explored the concept of acculturation informally in their study with 24 Indian immigrant parents of children with a disability, 22 of whom were in the USA, one was in Canada and one in Kuwait. The time since immigration for these participants ranged from 10 to 20 years. They asked participants to report on their beliefs about causes of and treatments for autism, use of and preference for Indian medicine and practices, their thoughts about the services and treatments their child received and about what country they considered to be their "real home". According to Ravindran and Myers (2012), about 67% of the parents reported that they considered India to be their real home, 17 % considered their current country of residence to be their real home and 38% parents reported that although they did not consider their host country to be their real home, they were well settled and comfortable in the life there. These results were based on open ended questions and did not include any formal quantitative measure for acculturation.

Based on their adaptation and exposure to a new set of beliefs and models, acculturation can play an important role in modifying or further strengthening parents' current perceptions of health and illness, their beliefs about causes, treatments and expectations for their child (Heer, Rose & Larkin, 2012; Mandel & Novak, 2005). However, most medical center staff are trained from a western perspective and may not be aware of this phenomenon or have sufficient training in working with families and individuals of diverse backgrounds (Welterlin & LaRue, 2007). But before we can train professionals in being sensitive to and aware of these differences, it is essential for us to better understand if and how acculturation plays a role in the adaptation of immigrant mothers raising a child with a DD in Canada.

A large number of researchers have studied acculturation as a process and factors related to it in the general population and in youth. However, there is a distinct lack of research examining acculturation in mothers of children with a DD. In the current study, I hope to contribute to this area of research and take a step forward to fill this gap. As reported earlier, about 51% of the population of Toronto is made up of immigrants. However, as reported by Statistics Canada, as of 2011, South Asian immigrants account for about 25% of the immigrant groups in Canada, thereby making them one of the largest immigrant populations. Even within this group, there is immense diversity in terms of religious background (Sikh, Hindu, Muslims, Christians, Jains etc.), language, and possibly sub-cultures. It is beyond the scope of this study to examine all immigrant groups or to compare subgroups within the South Asian immigrant population, therefore in this study I focus on South Asian immigrants as a whole group, regardless of their country of origin, religion, etc..

Current Study

To summarize, in the mainstream western literature, less severe child maladaptive behaviour, low pile-up of stressors, high parent self-efficacy, problem-focused coping and positive reframing, better maternal mental health, better family hardiness, better marital satisfaction, helpful formal and informal social supports have been shown to be related to lower negative parent impact. A few of these variables including problem-focused coping and positive reframing, better family hardiness and helpfulness of informal social support have also been related to positive parent outcomes. In addition, there is a lot of variability in the measurement of these constructs, their conceptualization as stressor, mediator or outcome variables, and the research methodology used to study these. The majority of research done on negative outcomes has been quantitative in nature, with some qualitative studies. On the other hand, the positive outcome literature has come primarily from qualitative studies involving semi-structured or open ended parent interviews, and only recently have quantitative methods been used. Most of the predictor variables described in the above literature review have also been studied primarily with a quantitative focus.

Being from a different culture such as the South Asian culture, which is distinctly different from the majority culture, can affect families in a number of ways. The research discussed here provides a rationale for investigating differences in the level of stress experienced by mothers (negative impact) and, on the other hand, in the positive impact they may experience as a result of raising their child with disabilities. In addition, other intervening factors may also operate differently in South Asian families as compared to Canadian families. It is important to note that of the studies with South Asian parents reviewed here, close to two-thirds of the studies were qualitative in nature and were conducted in South Asian countries with local samples.

These studies used mostly semi-structured interviews and two of them used ethnographic qualitative methods. There are some quantitative studies done in native countries, mostly with service professionals in their health care system in order to assess their understanding of DD such as autism and ID. Three of these studies (Daley, 2004; Gupta et al., 2012; Mirza et al., 2009) also used mixed-methods designs, although they did not use the term "mixed method" to describe their methodology. These studies were mostly surveys that included specific demographic questions, items about the diagnostic process and some openended questions.

In spite of an emerging literature on the influence of culture on these variables in immigrant families raising a child with a disability in the USA, UK and South Asia, there have been only a handful of mostly qualitative studies examining immigrant mothers' experiences with obtaining services and supports while raising their child with DD in Canada (e.g., Su et al., 2018; Jennings et al., 2014; Khanlou et al., 2017). Surprisingly, only two studies (both qualitative) have been conducted by researchers in Ontario, Canada, with South Asian mothers of children with disabilities. Of these two, one was conducted in rural Bangladesh (Maloni et al., 2010), while the other was conducted in Toronto with South Asian immigrant mothers from various countries, speaking different languages and belonging to different religions (Daudji et al., 2011).

Moreover, there were only a limited number of studies conducted in South Asian countries or in the USA and UK that use quantitative means of measuring parent outcomes or factors affecting parent outcomes in South Asian parents of children with DD (Das et al., 2017; Gupta et al., 2012; Hatton & Emerson, 2009; John, 2012; John et al., 2016; Kandolkar & Kenchappanavar, 2014; Lakhani et al., 2013; Mirza et al., 2009; Rajan & John, 2016; Sabih & Sajid, 2008; Siddiqui, 2014; Singh et al., 2017; Twoy et al., 2007). Even then, the measures used

by these studies is a mix of measures developed in the west, but not necessarily validated in South Asia, and measures developed in South Asia to examine stress and coping in parents of children with DD. Some researchers also reported using observer rated measures which may involve subjective interpretation of the parents' responses. To my knowledge, the literature contains no direct quantitative comparison of these variables between South Asian immigrant mothers and a primarily Caucasian group in any of the western or English-Speaking Countries, especially Canada.

Needless to say, there is a general dearth of cultural literature on the experiences of South Asian immigrant mothers raising a child with a DD in Canada. My focus in this study is to explore differences between immigrant families from South Asian countries (India, Pakistan, Bangladesh, Sri Lanka, Nepal & Afghanistan) and Canadian families. This group is particularly interesting to study, not only because of their cultural background, but also because: South Asians form one of the biggest immigrant groups in Canada (especially Ontario); a large proportion of mothers are highly educated and qualified, often moving to Canada for better opportunities for their children; and they have a strong ethnic identity, along with a sense of adapting to the new culture.

The current study aims to begin to fill this gap in the literature, by examining negative and positive maternal outcomes in the process of raising a child with a disability as well as factors predicting these outcomes in South Asian immigrant and mainstream Canadian mothers, using both quantitative and qualitative means. I use a correlational embedded mixed method design (Creswell, Plano Clark, Gutmann & Hanson, 2003), in which qualitative data was embedded within a larger quantitative design. (Figure 2). The primary purpose of this study is to use a number of quantitative parent questionnaires (QUAN) for parent impact, stressors, supports

and resources to test the Perry (2004) model of stress, with a cross-cultural comparison. A secondary purpose is to gather qualitative semi-structured interview data (qual process) about mothers' perceptions of the influence of stressors on their positive and negative outcomes, the role of supports and services in changing these outcomes and mothers' overall experience of raising a child with a disability. The purpose of the secondary qualitative data is to further explain and interpret the quantitative results and to gain a richer understanding of mothers' experiences by tapping into issues that we either did not know ask about or did not have suitable quantitative measure for.

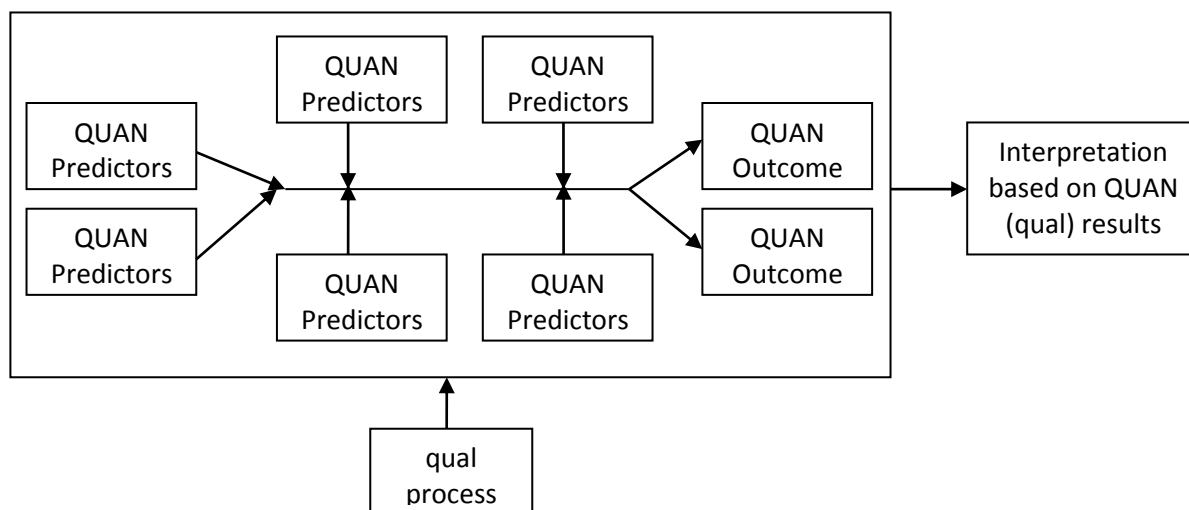


Figure 2. Correlational embedded design for the current study

Therefore, using the above research design, the purpose of this study was to address the following research questions.

Research Questions

1. Is there a significant difference between a group of South Asian immigrant mothers and Canadian mothers of children with a disability on any of the stressor, outcome, resource or support variables?
2. Based on the Perry (2004) model of parental outcomes, are the magnitude and patterns of stressors and mediating variables that predict maternal outcomes different in the South Asian and Canadian groups? Does acculturation account for additional variance in maternal outcomes in the South Asian group?
3. How do South Asian mothers articulate their understanding of disability, their journey of raising a child with a disability, and their perception of the influence of their cultural background on the eight components measured above?

Methodology

Operationalization of Theoretical Model in the Current Study

In order to address the research questions for this study, I operationalized the eight components of the Perry (2004) model of parent outcomes in this study as shown in Figure 3.

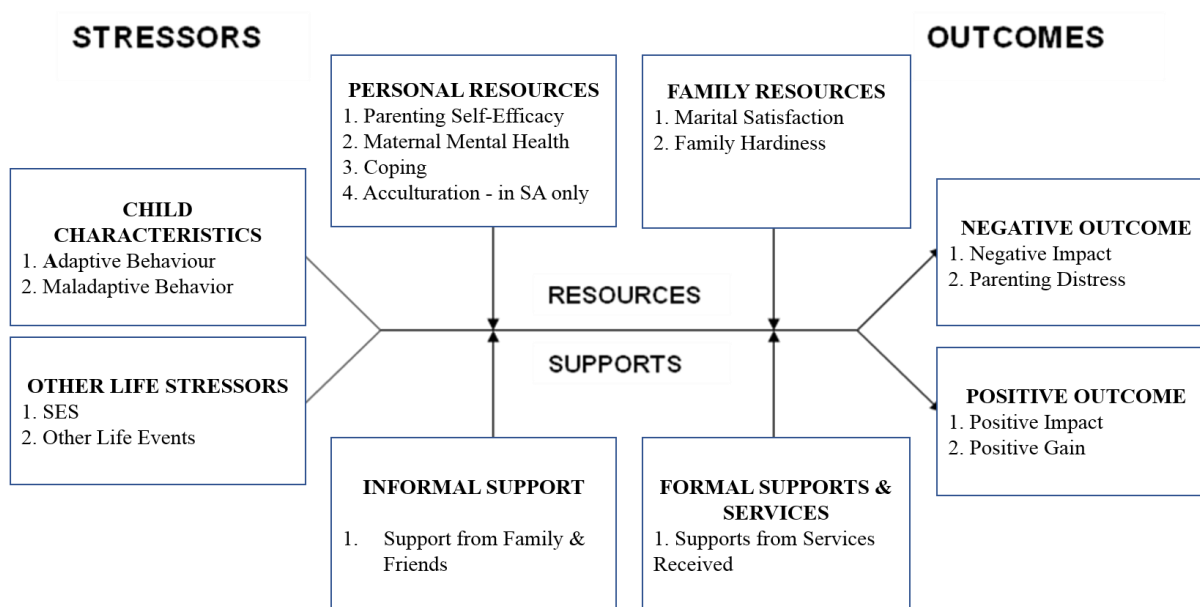


Figure 3. Variables included in this study for each component of Perry (2004) model of parent outcomes

I collected both quantitative and qualitative data concurrently from both Canadian and South Asian Immigrant groups, using questionnaires for each component, followed by a more detailed exploration using semi-structured interviews. In the following sections, I will describe participant demographics of my final sample, followed by the measures I used as part of my quantitative questionnaire as well as the semi structured interview guide. Finally, I will describe the procedures I followed to recruit these participants and collect both quantitative and qualitative data.

Participant Demographics

I recruited participants from various organizations across the Greater Toronto Area that serve children with Autism Spectrum Disorder, Developmental Disorder in general along with a genetic syndrome (e.g., Down Syndrome) or physical disability. I used pre-approved inclusion

criteria for the two groups. Participants in the *South Asian* group were (1) mothers of children with a DD (autism, PDD-NOS, ID, Down syndrome etc.), whose child was diagnosed at least 2 years ago, (2) mothers who immigrated from India, Pakistan, Bangladesh, Sri-Lanka, Afghanistan or Nepal, or identify as South Asian immigrant, (3) immigrated to Canada when they were at least 18 years of age, and (4) immigrated in the past 2 to 20 years. Participants in the *Canadian* group were (1) mothers of children with autism, DD, or physical disability, whose child was diagnosed at least 2 years ago, (2) mothers were born and raised in Canada, who identify themselves as Canadian, and are at least second generation immigrants i.e., their parents could have been immigrants. South Asian mothers were also recruited through several organizations serving South Asian families who have a child with such a disability.

Since I wanted to explore a number of variables in relation to maternal impact, and there was a limitation of time and resources, I needed to collect a large enough sample that would still provide me with a moderate power in my analyses. I conducted a preliminary power analysis in order to determine the number of participants to aim for in each group. I looked up the mean difference between two diagnostic groups and/or between two cultural groups in studies that used measures of family impact such as The Family Impact of Childhood Disability (FICD) and Questionnaire of Resources and Supports – Short Form (QRS-F) as well as coping measures such as the Brief COPE. These studies generally report significant differences between diagnostic groups and/or cultural groups with small to medium effect sizes. Using a mean difference on the QRS-F as the outcome, I conducted a power analysis, with a Cohen's d of .3 (small to medium), for a two tailed t test with α of .05, aiming for a power of .80. This suggested that a sample size of approximately 60 would provide sufficient power to do the analyses proposed. However, in order to balance power requirements for the analysis and pragmatic

considerations, the sample size for each group was aimed at a minimum of 50, making a total minimum of 100 participants for the quantitative portion of the study.

My final sample consisted of a total of 107 participants, of whom 56 mothers were in the Canadian group while 51 were in the South Asian group. As part of the questionnaire, basic child, parent and family demographics (Table 1) were collected for all participants.

Table 1

Child, Parent and Family Demographics for the Canadian and South Asian Groups.

	Canadian (<i>n</i> = 56)		South Asian (<i>n</i> = 51)	
	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>n</i> (%)	<i>M</i> (<i>SD</i>)
<i>Child Demographics</i>				
Child's Gender				
Male	41 (74.5)		41 (80.4)	
Female	14 (25.5)		10 (19.6)	
Child's Diagnosis				
DD and ASD	45 (80.4)		44 (86.3)	
DD Only	11 (19.6)		7 (13.7)	
Child's Age		12.7 (4.6)		11.4 (4.7)
<i>Parent Demographics</i>				
Mother's Age**		44.6 (7.0)**		40.9 (7.3)**
Marital Status: Married	44 (78.6)		46 (90.2)	
Mother – Biological Parent	51 (92.7)		51 (100)	
Father - Biological Parent**	35 (76.1)		46 (100)	
Mother's highest level of education**				
High School or less	10 (17.9)		19 (37.1)	
College/University	41 (73.2)		22 (43.2)	
Graduate Degree	5 (8.9)		10 (19.6)	
Father's highest level of education**				
High School or less	12 (26.6)		17 (36.9)	
College/University	29 (64.5)		13 (28.3)	
Graduate Degree	4 (8.9)		16 (34.8)	
Mother's current work status**				
Not working currently	23 (41.1)		37 (72.5)	
Part time	15 (26.8)		7 (13.7)	
Full time	18 (32.1)		7 (13.7)	

	Canadian (<i>n</i> = 56)		South Asian (<i>n</i> = 51)	
	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>n</i> (%)	<i>M</i> (<i>SD</i>)
Decrease in mother's work hours	28 (50.0)		27 (52.9)	
Increase in mother's work hours	17 (30.4)		10 (19.6)	
Father's current work status				
Not working currently	6 (13.3) ^a		4 (8.7) ^b	
Part time	7 (15.6)		7 (15.2)	
Full time	32 (71.1)		35 (76.1)	
Decrease in father's work hours	13 (28.3) ^b		11 (23.9) ^b	
Increase in father's work hours	21 (45.7) ^b		24 (52.2)	
<i>Family Demographics</i>				
Size of community where they live**				
Remote area of Canada	0 (0.0) ^c		1 (2.0) ^d	
Rural area of Canada	7 (12.7)		1 (2.0)	
Suburban area of Canada	23 (41.8)		13 (26.0)	
Urban are of Canada	25 (45.5)		35 (70.0)	
Number of adults living at home				
1	9 (16.1)		3 (6.0) ^d	
2	32 (57.1)		30 (60.0)	
3	10 (17.9)		11 (22.0)	
4 or more	5 (8.9)		6 (12.0)	
Number of adults with a disability				
0	38 (77.6) ^e		40 (85.1) ^f	
1	8 (16.3)		6 (12.8)	
2	3 (6.1)		1 (2.1)	
Number of children living at home				
1	18 (32.1)		10 (20.4) ^e	
2	20 (35.7)		24 (49.0)	
3	13 (23.2)		7 (14.3)	
4 or more	5 (9.0)		8 (16.3)	
Number of other children with disability				
0	37 (66.1)		39 (81.3) ^g	
1	13 (23.2)		8 (16.7)	
2	2 (10.7)		1 (2.0)	
Birth order of child				
Oldest or only child	28 (50.0)		27 (52.9)	
2 nd oldest	16 (28.6)		19 (37.3)	
3 rd oldest	9 (16.1)		3 (5.9)	
Youngest	3 (5.4)		2 (3.9)	

Note. ^a*n*=45. ^b*n*=46. ^c*n*=55. ^d*n*=50. ^e*n*=49. ^f*n*=47. ^g*n*=48. ***p*<.05.

Based on mothers' report about their children, the mean age, gender ratio as well as diagnosis category were similar in both groups (Table 1). On average, children in the Canadian group were about 12 years 6 months old, while they were about 11 years 6 months old in the South Asian group. The majority (over 80%) of children were diagnosed with an ASD along with a Developmental Disability (e.g., Intellectual Disability, Down Syndrome, Fetal Alcohol Spectrum Disorder) and/or medical complications. A large portion of the Canadian mothers (about 93%) were a biological parent to their child(ren) with some adoptive parents and grandparents, while all South Asian mothers (100%) reported being a biological parent. A similar trend was also noted for father/mother's partners' relationship to the child.

Canadian mothers were significantly older on average than South Asian mothers. Although there was no significant difference between the groups on mother's marital status and the majority of mothers in both groups were married, more South Asian mothers (close to 90%) were married compared to Canadian mothers (about 79%). Over 60% of all mothers and fathers had completed some form of post secondary education. However significantly greater proportions of Canadian mothers and fathers were college or university graduates compared to South Asians, while a larger portion of South Asian mothers and fathers had completed a graduate degree compared to Canadian mothers. In addition, compared to their Canadian counterparts, South Asian mothers were significantly less likely to be employed in spite of being highly educated, whereas fathers in both groups were more likely to be employed.

Mothers also reported on their family's structure and characteristics on the questionnaire. Although a clear majority of families lived in suburban or urban areas of Canada, almost 1.5 times more South Asian families resided in Urban areas (70%) compared to Canadian families (46%). This trend might be present due to urban areas being more accessible and diverse, and

relatively easier to acculturate to for new immigrants compared to rural areas. Although there was some variability in family structure, both Canadian and South Asian families had similar structures such that the majority of families had two typically developing adults living at home, with one to two children. In most cases they had one child with a disability, while some families had multiple children with a disability, often with a DD alone or in a combination with ASD or other medical diagnosis.

In addition to these general demographic questions, South Asian mothers were also asked to report on some specific information about their immigration (Table 2). They were asked an open-ended question about their country of birth, their age when they moved to Canada, number of years since they moved here and their reasons for moving to Canada.

Table 2

Immigration Related Demographics for the South Asian Group.

	n (%)	M (SD)
Mother's country of birth		
India	10 (19.6)	
Pakistan	8 (15.7)	
Bangladesh	9 (17.6)	
Sri Lanka	22 (43.1)	
Afghanistan	2 (3.9)	
Mother's first language		
Tamil	19 (37.3)	
Bengali	10 (19.6)	
Urdu	7 (13.7)	
Hindi	3 (5.9)	

Singhala	2 (3.9)	
Gujarati	2 (3.9)	
Punjabi	2 (3.9)	
English	2 (3.9)	
Pashto	1 (2.0)	
Farsi	1 (2.0)	
Konkani	1 (2.0)	
Malayalam	1 (2.0)	
Age of mother at immigration to Canada		27.4 (6.0)
Years since immigration to Canada		13.7 (5.9)
Mother's reason for immigration ^a		
Husband in Canada	18 (36.0)	
Work/Better life	14 (28.0)	
Escape from civil war/safety	9 (18.0)	
Parents moved to Canada	5 (10.0)	
Better education/treatment for child	4 (8.0)	

^a*n*=50.

The demographics reported above reflect the immense diversity present within the South Asian group. Even within families from the same country (e.g., India), there were several different languages spoken (e.g., Hindi, Gujarati, Punjabi, Urdu, Konkani & Malayalam) based on the part of the country they came from. In addition to this, their educational background and regional experiences and beliefs most likely influence how they view disability, how they deal with the challenges associated with their child's disability and possibly reasons why they moved to Canada. Moreover, after moving to Canada, some families chose to live in parts of city that are largely populated by others of their own community while others chose to live in more diverse parts of the city.

In addition, demographic characteristics of all mothers who participated in the interview process are reported in Table 3. As is evident from this table, these mothers were quite diverse in terms of their child's age and gender as well as their own education and work status.

Table 3.

Demographics for Mothers who Interviewed From Both Groups.

	Canadian (<i>n</i> = 6)	South Asian (<i>n</i> = 10)
Child's age		
4-12 years	3	7
13 years and over	3	3
Child's Gender		
Male	3	8
Female	3	2
Child's Diagnosis		
ASD	4	10
DD & specific diagnosis	2	0
Family's Residence		
Urban Area	2	9
Suburban Area	3	1
Rural Area	1	0
Mother's Education		
High School	0	5
College/University	6	3
Graduate Degree	0	2
Mother's Work Status		
Full Time	1	0
Part Time / Work at Home	2	4
Stay at Home/Retired/Disability Leave	3	6
Mother's Country of Birth		
India		4
Bangladesh		2
Sri Lanka		4

	Canadian ($n = 6$)	South Asian ($n = 10$)
Mother's First Language		
Hindi		1
Punjabi		2
Urdu		1
Bengali		2
Tamil		2
Singhalese		2
Mother's Religion		
Hinduism		2
Sikhism		2
Christianity		3
Islam		3

The South Asian mothers were from diverse backgrounds in terms of their country of birth, language primarily spoken as well as their religious background. They had been in Canada from two to 21 years, and thus represented diversity in terms of their possible adaptation to the new country and culture as well as in other ways. Therefore, even though I treat South Asian as one group because of basic set of common values and beliefs, I remain cautious in making generalized inferences of the results.

Measures

Quantitative Measures

The quantitative questionnaire consists of measures used to assess each of the eight components of the Perry (2004) model (Figure 4). Two slightly different versions of these questionnaires were used for the Canadian and South Asian groups, in order to get some data on immigration and acculturation in the South Asian group. All the basic demographic information collected as well as the measures used were the same on both versions except that the South Asian version of the questionnaire included the acculturation measure, additional demographic

questions regarding immigration and two open ended questions about the influence of culture on mother's experiences.

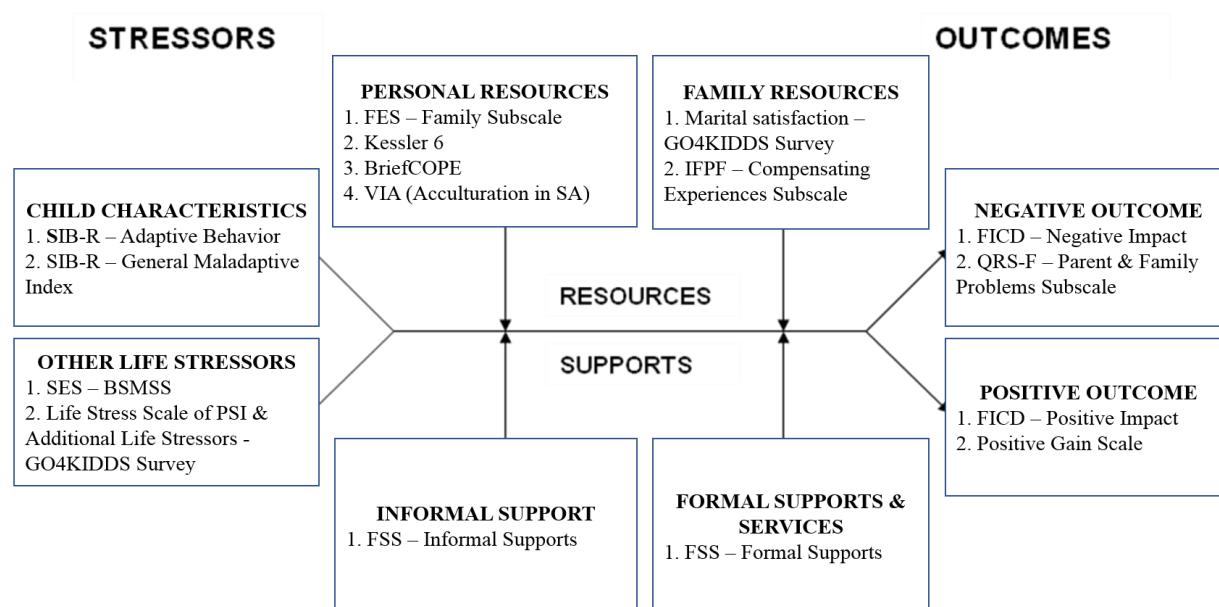


Figure 4. Measures used for each variable in the Perry (2004) model of parent outcomes

Before beginning recruitment and data collection, the quantitative questionnaires were pilot tested with seven MA/PhD level clinical psychology students and one mother of a child with DD known to this author, in order to determine the time required to complete the survey and ease of completion. Four of the seven students were immigrants themselves, and attempted to complete the South Asian version of the questionnaire. They completed the questionnaire in 25 to 35 minutes. They were fluent in English and were familiar with some of the measures used. They reported that although the questionnaire was easy to read, it was lengthy, and predicted that some of the South Asian mothers might take longer to complete it and may require help with some parts of the questionnaire. The remaining three students as well as the pilot mother

completed the Canadian version of the questionnaire in 25-35 minutes, and reported similar observations about the questionnaire. Based on these observations, I expected more face to face involvement with South Asian mothers, as compared to Canadian mothers.

As each participant actually completed the questionnaire, I entered her responses into an SPSS database. I used raw scores in the individual sections to derive composite or summary scores. I will describe these scoring procedures and will report internal consistency scores for each measure in this section.

1. Dependent Variables: Negative & Positive Outcome

I used two measures of both negative and positive outcomes to examine the experiences of mothers raising a child with a DD.

Negative Impact & Positive Impact. I used The Family Impact of Childhood Disability (FICD; Trute & Hiebert-Murphy, 2002; Trute, Hiebert-Murphy & Levine, 2007) as an additional measure of both negative and positive outcomes. FICD is a 20-item measure of parental appraisal of positive and negative impact of childhood disability on the family. It has an equal number of negative and positive impact items and requires the parents to assess the influence of their child. Mothers were asked to respond to positive items on the FICD Positive Impact subscale (e.g., "Raising a disabled child has made life more meaningful for family members") and FICD Negative Impact subscale (e.g., "There has been an unwelcome disruption to normal family routines") on a 4-point Likert scale from *Not at all* (1) to *A substantial degree* (4). I calculated scores for the FICD Positive and Negative Impact subscales by summing the items on each scale.

High internal consistency for both Positive ($\alpha = .81$) and Negative ($\alpha = .89$) impact have been reported by Trute, Hiebert-Murphy and Levine (2007). In a more recent analysis done by

Benzies et al. (2011), an alpha level of .85 was reported for the FICD Positive impact subscale and .86 for FICD Negative impact subscale, in addition to strong test-retest reliability of .77 for Positive and .86 for Negative impact in a 4-week retest. Similarly, I obtained high internal consistency of the FICD Positive impact subscale in the Canadian ($\alpha = .85$) and South Asian ($\alpha = .81$) groups in the current study. Moreover, I found that the reliability score for the FICD Negative impact subscale was strong for both the South Asian ($\alpha = .91$) and Canadian ($\alpha = .87$) groups.

Parent Distress. I measured Parenting stress using the Friedrich short form of the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg & Crinc, 1983), which is a measure used to study stress experienced by families of children with disabilities. The QRS-F consists of 52 items that assess four different aspects of parenting stress (Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacity). For this study, I included only the 20 items in the Parent and Family Problems subscale since these measure the child's impact on parents and family.

Mothers were required to answer whether each statement was True or False for their situation. These items included both negatively worded items (e.g., "I get almost too tired to enjoy myself") and positively worded items (e.g., "I can go visit with friends whenever I want") I scored negatively worded items as 1 and I reverse scored positively worded items that were initially scored as 0 to 1. A higher total score, obtained by adding individual item scores, indicates higher levels of stress reported by mothers. This measure has been used with parents of children with a disability including autism, and has shown good internal consistency reliability of .93 for the full scale (Friedrich et al., 1983) and ranging from .77 to .85 for the subscales (Osborne, McHugh, Saunders & Reed, 2008). In the current study, I obtained strong internal

consistency reliability of the Parent and Family subscale of QRS-F for both the Canadian (Cronbach's $\alpha = .87$) and South Asian (Cronbach's $\alpha = .88$) groups.

Positive gain. In this study, I measured Positive impact in terms of positive gain using the Positive Gain Scale (PGS; Pit-ten Cate, 2003). PGS is a 7-item parent report measure of the degree to which they experience positive outcomes in the process of raising a child with a disability (e.g., "Raising this child helps put life into perspective"). The seven items were answered on a 5-point Likert scale ranging from 1=*Strongly Agree* to 5=*Strongly Disagree*, with higher total scores indicating greater positive gain. Parents with higher scores experience greater positive impact. Several studies done with parents of children with a disability have reported high internal consistency of items on this measure, with an alpha of .80 (MacDonald, Hastings, & Fitzsimons, 2010) and .87 (MacMullin, Tint, & Weiss, 2011). The internal consistency of items I obtained in the current study on this measure were somewhat lower, but still acceptable for both the Canadian ($\alpha = .76$) and South Asian ($\alpha = .78$) groups.

Independent Variables

2. Stressors: Child Characteristics

Maladaptive and Adaptive Behaviours. I measured mothers' report of their child's maladaptive and adaptive behaviours using the short form of the Scales of Independent Behavior - Revised (SIB-R; Bruininks, Woodcock, Weatherman & Hill, 1996). The SIB-R is one of the most commonly used measures of adaptive and maladaptive behaviours within the DD population. In the adaptive behaviour section, adaptive skills including Motor skills, Social Interaction and Communication skills, Personal Living skills and Community Living skills are measured, using 40 items such as "Stands alone and walks for at least 6 feet", "Asks simple questions" etc. Mothers were asked to respond to these items on a 4-point Likert scale from

Never or rarely (0) to *Does very well* (3), based on how well the individual does or could do each task completely without any help or supervision. Weiss and Perry (2013) reported good internal consistency for the adaptive section of the measure with a Cronbach's alpha of .93. The internal consistency of adaptive skills items on this measure was excellent for the Canadian ($\alpha = .95$) and South Asian ($\alpha = .93$) groups in the current study.

In the maladaptive section of the SIB-R, parents were asked to indicate if their child exhibits any of the eight categories of maladaptive behaviours (hurtful to self, hurtful to others, destructive to property, disruptive behaviour, unusual or repetitive habits, socially offensive behaviour, withdrawal or inattentive behaviour, and uncooperative behaviour). If a behaviour is present, parents were asked to rate the *frequency* of this behaviour on a 6-point Likert scale from *Never* (0) to *One or more times an hour* (5), and the *severity* of this behaviour on a 5-point Likert scale from *Not serious; not a problem* (0) to *Extremely serious; a critical problem* (4). Total scores on a General Maladaptive Index (GMI) range from +10 (good) to -74 (extremely serious), with an average of 0 and standard deviation of 10. Lower or more negative scores indicate more serious levels of maladaptive behaviours. The SIB-R administration manual (Bruininks et al., 1996) reports good test retest reliability ($r = .86$) and Cronbach alpha of .80. In addition, Weiss and Perry (2013) reported good internal consistency with a Cronbach's alpha of .92.

Other Life Stressors

Family SES. The *Barratt Simplified Measure of Social Status* (BSMSS; Barratt, 2006, 2012) has been used to measure social status in older individuals. For the current study, I used an adapted version of the Barratt Simplified Measure of Social Status (Barratt, 2012) to measure the social status of the child and their family. It consists of six divisions of level of education completed and nine categories of occupation, each of which gives a score, ranging from three

(less than seventh grade) to 21 (graduate degree) for level of education and five (day labourer, janitor, house cleaner, etc.) to 45 (physician, attorney, professor, CEO, etc.) for occupation. I assigned a score for each participant mother and her husband (or partner) for education and one for occupation, based on the mothers' report of their highest level of education and their occupation. For single mothers, I then added their scores on level of education and occupation to get a continuous score for social status that can range from 8 to 66 (Barratt, 2012). In two-parent families, I calculated the mean of both parents' education scores and that of their occupation scores, and then added them to get their overall score between 8 and 66.

Since some mothers had given up work to care for their child, and in immigrant families, there was often a noticeable difference between an expected occupation based on their education and their actual current occupation, I included *Financial Hardship* as another indicator of SES. Mothers were given a list of seven things/conveniences (ranging from fresh fruit and vegetables at least once a day, shoes or clothing, to new furniture and small amount of money to spend on themselves) that they had to go without in order to meet their child's needs in the past year. They were asked to indicate all items that applied to their situation. I summed the number of these items reported as an indicator of financial hardship on the family, that may influence their positive or negative outcomes.

Other Stressful Life Events. I measured the influence of other life events outside of a direct parent child relationship using a combination of items from the Parenting Stress Index – Life Stress or LS scale (PSI, Abidin, 1995) and the GO4KIDDS survey (Perry & Weiss, 2009) developed as part of the GO4KIDDS project described earlier. The Life Stress scale of the PSI includes 19 items that provide an assessment of global situational stressors that may influence parenting stress. Parents are asked to indicate life stresses on the list that they have experienced

during the last 12 months (e.g., “Loss of employment”, “Death of a close relative”). In addition, I also included 10 items from the GO4KIDDS survey (Perry & Weiss, 2009). As part of the GO4KIDDS project, an extensive survey (Perry & Weiss, 2009) was used to assess several areas of parents’ experiences. One of the aspects assessed was the effect of additional life stressors in the life of parents raising a child with DD. The 10 items of this list include life changes that might be specific to the life of a child with DD. This list includes events such as “Experienced another difficult transition”, “Lost a good educational assistant or teacher”, “diagnosis of another child/family member with a disability” etc. Mothers were asked to indicate any or all of the listed life events experienced by their family or their child in the last 12 months. I used the total number of additional life events indicated by the mother as a measure of additional stressors that the family may have experienced, that may ultimately influence her positive or negative outcomes.

Resource variables

3. Mother's Personal Resources

Parenting Self-efficacy. I used the 12-item Family subscale of the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) to measure parenting self-efficacy. This subscale measures the parents' feelings about their own sense of control and efficacy in parenting their child with a disability, in terms of their personal attitudes as a parent, knowledge of their child's disability and empowering behaviours. Mothers responded to the 12 items on a 5-point Likert scale from *Not true at all* (1) to *Very true* (5), with higher scores indicating greater empowerment and parenting self-efficacy. Koren et al. (1992) reported high internal consistency ($\alpha = .88$) and test-retest reliability ($r = .83$). Other recent studies that used this measure reported alpha coefficients of .87 (Weiss & Lunskey, 2011) and .89 (Weiss et al., 2013). This measure has

been used quite frequently with parents of children with DD and has consistently shown good reliability and validity with this population. In the current study as well, this measure showed excellent internal consistency with a Cronbach's $\alpha = .89$ for the Canadian group and .91 for the South Asian group.

Maternal Mental Health Problems. I measured maternal mental health problems using the Kessler 6-item Psychological Distress Scale (K6; Kessler, et al., 2003). Mothers were required to report the frequency of symptoms such as nervousness and hopelessness in the past four weeks on a 5-point Likert scale ranging from *None of the time* (0) to *All of the time* (4). It has been reported to have high internal consistency ($\alpha = .89$) and construct validity compared to other mental health screening tools (Furukawa, Kessler, Slade & Andrews, 2003; Kessler, et al., 2002). Both the Canadian ($\alpha = .83$) and South Asian ($\alpha = .88$) groups in the current study indicated strong internal consistency of this measure.

Coping. I used Carver's (1997) brief situational format of the COPE inventory (Carver, Sheier & Weintraub, 1989) or the Brief COPE to measure strategies used by mothers to cope with stressors associated with raising their child with a disability. The Brief COPE (Carver, 1997) consists of 28 items presented in the form of coping statements, with two items contributing to each of 14 subscales. Mothers were asked to rate the extent to which they use each of these ways of coping to deal with stressors associated with raising their child with a disability, on a 4-point Likert scale from *I haven't been doing this at all* (1) to *I've been doing this a lot* (4). Carver (1997) reported internal consistency scores ranging from .64 to .90 in 11 of the 14 subscales.

Based on a factor analysis of Brief COPE responses of 135 parents of preschool and school aged children with autism, Hastings, Kovshoff, Brown, et al. (2005) further grouped these

items into Active avoidance coping ($\alpha = .78$), Problem-focused coping ($\alpha = .82$), Positive coping ($\alpha = .68$) and Religious/Denial coping ($\alpha = .73$). In the current study, I initially summed items within these four factors to obtain four subscale scores and tested their internal consistency reliability for both Canadian (Active avoidance $\alpha = .79$; Problem focused $\alpha = .84$; Positive $\alpha = .73$; Religious/Denial $\alpha = .60$) and South Asian (Active avoidance $\alpha = .63$; Problem focused $\alpha = .63$; Positive $\alpha = .60$; Religious/Denial $\alpha = .45$) groups. The reliability of these subscales in the Canadian group was quite similar to those reported by Hastings, Kovshoff, Brown, et al. (2005). However, in the South Asian group, these items demonstrated lower reliabilities, especially in the Religious/Denial subscale. This could perhaps be due to the cultural interpretation or importance of these specific items.

To obtain a subscale structure that represents both groups better, I conducted a Principal Component Analysis (PCA) with all mothers across the two groups, resulting in a total sample of 107 participants. Principal Component Analysis with Varimax rotations were conducted with two, three and four component structures for the full sample. I included items within a component if they met two basic criteria: (1) item loading on that component was $> .350$ and was $< .350$ on all other components, and (2) item loading on this component was positive.

Overall, the two component structure emerged as the most parsimonious model, while still structuring the measure with two conceptually sound components. However, four items, that were not strongly related to either of the two factors discussed substance abuse and making fun of the situation as coping strategies. Once these items (4, 11, 18 and 28) were removed, Component 1 (Positive Coping) accounted for 21% and Component 2 (Negative Coping) accounted for 14%, with the complete model now accounting for 35% of the variance in Brief COPE scores. I summed the item scores within these two components for each participant, and

obtained reliability for both the Canadian and South Asian groups. Although the internal consistency for both components was stronger for the Canadian (Positive Coping $\alpha = .87$; Negative Coping $\alpha = .79$) group as compared to the South Asian (Positive Coping $\alpha = .74$; Negative Coping $\alpha = .67$) group, they were all within the acceptable range.

Acculturation. I used the Vancouver Index of Acculturation (VIA; Ryder, Alden, & Paulhus, 2000) to measure the level of acculturation in the South Asian mothers in terms of two dimensions: Heritage identity and mainstream or Canadian identity. The VIA is a 20-item measure with 10 items each for the two dimensions e.g., "I behave in ways typical of my *heritage culture*", "I often behave in ways that are 'typically North American' ". Mothers were required to score these items on a 9-point Likert scale ranging from *Strongly Disagree* (1) to *Strongly Agree* (9), with higher scores indicating stronger identity. I calculated a total Canadian Identity and South Asian Identity score by summing ratings on the 10 items in each scale. Cronbach alpha for the Heritage dimension has been reported to range from .91 to .92, and that for the Mainstream dimension from .85 to .89 in East Asian and Chinese samples (Ryder et al., 2000). In the current South Asian sample, internal consistency reliability for both the Mainstream ($\alpha = .79$) and Heritage ($\alpha = .79$) dimensions was slightly lower than those found previously for East Asian and Chinese samples but still acceptable. As indicated earlier, the South Asian sample is quite diverse in terms of languages, religion and sub cultures present, as well as in the amount of time mothers have been in Canada and their reasons for immigrating. For each participant, I categorized their South Asian and Canadian identity scores as high if the score was greater than 5 and low if it was lower than 5. Based on the high and low combination of heritage and mainstream identity, I classified these scores into Berry's (1980, 1997, 2005) four

acculturation outcomes – Marginalization (low SA, low CA), Assimilation (low SA, high CA), Separation (high SA, low CA), and Integration (high SA, high CA) acculturation outcomes.

4. Family System Resources

Marital satisfaction. In order to assess mothers' satisfaction with their marriage, I used two questions from the GO4KIDDS survey (Perry & Weiss, 2009), which assess mother's marital satisfaction. The first question asked the parent to rate "How happy is your marriage/relationship?" on a 5-point Likert scale from *Very unhappy* (1) to *Very happy* (5). Then they were asked to rate "How much support do you feel you receive from your spouse/partner related to caring for your child with a developmental disability?" on a 5-point Likert scale from *Makes it more difficult* (1) to *Extremely helpful, I depend on them* (5). The internal consistency of these two items was moderate at .71 for the Canadian group and .77 for the South Asian group in the current study, but acceptable for a 2-item measure.

Family hardiness. I used the 4-item Compensating Experiences subscale of the Inventory for Family Protective Factors (Gardner, Huber, Stelner, Vazquez & Savage, 2008) to measure family hardiness. For these four items, mothers were asked to rate their perception of how their family experienced mastery within the context of raising their child with a disability on a 5-point Likert scale from *Not at all like my family* (1) to *Almost always like my family* (5). Higher scores on this scale reflects greater family hardiness. Weiss and Lunsky (2011) reported high internal consistency of this scale, with a Cronbach's alpha of .84. The internal consistency in the current study was also strong with a Cronbach's alpha of .86 for the Canadian group and .89 for the South Asian group.

Support Variables

5. Formal Services and 6. Informal Social Support.

I used the 18-item Family Support Scale (FSS; Dunst, Jenkins & Trivette, 1984) to measure the availability and helpfulness of various kinds of informal and formal sources of support. Mothers were asked to rate the helpfulness of these sources of support (e.g., parents, relatives, friends, professionals and services etc.) on a 5-point Likert scale from *Not at all helpful* (1) to *Extremely helpful* (5), or *Not available* (0). I used the mean score of helpfulness of informal and formal sources of support in addition to the total number of supports available. White and Hastings (2004) reported good internal consistency for helpfulness of informal support ($\alpha = .74$), but moderate internal consistency for formal supports ($\alpha = .57$). In the current study, the internal consistency for helpfulness of informal supports was higher in South Asian ($\alpha = .86$) compared to Canadian ($\alpha = .79$) group. On the other hand, Cronbach's alpha for helpfulness of formal supports, was somewhat higher in the Canadian ($\alpha = .82$) than the South Asian ($\alpha = .77$) group. All were acceptable.

Interview Guide

A semi structured interview guide was prepared for both Canadian and South Asian (Appendix A) groups. This was based on interview guides in studies developed by Khanlou et al. (2017), Desai et al. (2012), and Daudji et al. (2011). All three of these studies used qualitative analysis of parent interviews to study parental experiences of raising a child with disability, with Desai et al. (2012) and Daudji et al. (2011) focussing on South Asian parents. This interview guide contains enquiry into the eight components of the Perry (2004) model, as well as a possible influence of culture on these components. The guide was identical for the two groups except two extra questions that were added for the South Asian group to learn more about the influence of

culture on their experience of raising a child with a DD. I also pilot tested the qualitative interview with two mothers of children with DD. Minor changes were made to the way some questions were worded in the interview guide, based on the feedback from the pilot testing.

Recruitment & Data Collection Procedure

I contacted the person in charge of research and recruitment within 15 organizations and groups serving children with DD and their families in the GTA. Three of these organizations did not respond, while five of them responded initially but were not able to provide help with recruitment. Seven of these organizations were able to provide some form of recruitment for this study. The extent of access to their clients as well as the ethics review by these agencies varied widely. Some organizations permitted more indirect methods of recruitment. They posted printed flyers about the study on parent bulletin boards or printed as part of their newsletter, while others posted flyers on their website and other social media outlets. Mothers who were interested in the study then contacted me directly to complete the paper pencil questionnaire or went to the link provided in the flyer to complete the online questionnaire. In either format, each participant was provided with an information letter (Appendix B), outlining the purpose and voluntary nature of the study, confidentiality etc., and an informed consent form (Appendix C) that the participant signed before completing the questionnaire.

Other organizations provided more direct access to their clients, however the recruitment process still varied across organizations. At some of these organizations, I conducted brief information sessions before a parent workshop or group, provided flyers to the prospective participants in case they wanted to think about it, and had questionnaire packages available in case they wanted to complete it or take it with them. In other organizations I underwent a thorough research ethics review by their Research Ethics Board (REB) or their executive board,

following which I directly contacted clients shortlisted by their staff using my inclusion criteria. I described the study to these prospective participants in detail, answered any questions they had, and if they agreed to participate, I arranged for them complete the questionnaire in either of the two formats available.

In addition, I also contacted various clinicians working in the community with this clinical population as well as some personal contacts who passed the information on to prospective participants. Moreover, a flyer about this study was circulated on multiple listservs and a newsletter within York University. The final two sources of recruitment were existing clinical research databases from previous research projects conducted by the author's supervisor, Dr. Adrienne Perry at York University. One of these projects was the Great Outcomes for Kids Impacted by Severe Developmental Disabilities or GO4KIDDS project. This was a Canada wide project with multiple sub projects that looked at the health, well being and social inclusion of children with severe developmental disabilities, as well as their family's quality of life. In the past, these participants had provided written consent to be contacted for future research projects in the lab. The executive committee of this research project reviewed my application to access these participants and provided me with a list of prospective participants that met the inclusion criteria for the current study. I then contacted these participants directly by phone and/or email and followed the same protocol described above.

Once a participant provided consent for this study, I collected both quantitative and qualitative data concurrently. The process of data collection is described in the following sections.

Quantitative Data Collection

As predicted, the actual data collection process turned out to be quite different for the two groups. The first wave of participants included several mothers whom I contacted from existing clinical research databases as well as those that responded to flyers posted in various organizations, bulletin boards, listservs, newsletters, and social media outlets. Participants could either complete the questionnaire online, or in a printed paper and pencil format that was mailed to them along with a postage paid return envelope.

Data for the Canadian group was collected swiftly and mostly through either indirect recruitment via flyers, newsletters, listservs etc., or in response to a phone call and/or email I sent to prospective participants in the two clinical databases at York University. All Canadian mothers completed the questionnaire independently. Over only a span of four months, I was able to obtain a total sample of 56 participants in the Canadian group. Approximately 95% of the participants completed the questionnaire online and only 5% completed a printed format.

On the other hand, data collection for the South Asian group was more involved and lengthy, even though it was started at the same time as Canadian. Over a span of nine months, only nine participants completed the questionnaire online in response to posted flyers and calls/emails to mothers in the two clinical databases at York University. In addition to the methods described above for the Canadian group, prospective South Asian participants also had to be recruited more directly from several agencies during this time. I conducted information sessions at these agencies, and/or contacted prospective South Asian mothers from lists provided by the organizations. Due to possible barriers related to English being a second language for South Asian immigrant mothers, I offered to support them in completing the questionnaires in person. I could converse in Hindi, Punjabi, Urdu and my research assistant could speak Tamil.

A total of 94 mothers were contacted from these organizations, of which 36 participated in the study. Amongst those contacted almost half of the mothers completed the printed questionnaire on their own (or with the help of a family member), while I visited and completed the questionnaire with the rest of them in person. I often needed to translate and/or read out the questionnaire to these participants for them to be able to complete it. This often took about 60-90 minutes to complete since the participants related stories of their experiences and emotions about their child(ren) and/or services they received. Overall, from a total sample of 51 participants in the South Asian group, only about 22% of the participants completed the questionnaire online, while 78% completed a printed format.

Once the entire questionnaire was completed by a mother, I assigned a participant number for the respective group and de-identified the data. If the questionnaire was completed online, I downloaded and printed the entire response. Only the consent page had identifying information on it. I separated this page and wrote the participant number on top of the first page of the actual questionnaire and on the consent page. I stored these consent pages for participants in a confidential, sealed envelope, and separate from all the questionnaires. I mailed a cheque for \$35 to the participant in a sealed confidential envelope.

Qualitative Data Collection

For each group, a sub sample of participants was selected from those who consented to participate in an interview using purposive sampling based on child's diagnosis and age in both groups and on mother's country of origin/religion within the South Asian group to be able to access diversity within the sample. A semi-structured interview was conducted with these participants to better understand the relationship between the predictor and outcome variables, as well as to understand the overall experience of raising a child with a disability in the two cultural

groups. The length of these interviews ranged from about 25 to 90 mins. Each interview was audiotaped, and following the interview, was transcribed by the research assistant who had undergone confidentiality training with me.

I used a qualitative descriptive approach (Sandelowski, 2000, 2010) to analyse the interview data for my study. I grounded my coding into participant narrative and stories, instead of conducting deeper interpretations. I coded the transcripts in several steps in a systematic manner. First, once each interview was transcribed, I read the transcript line by line, identified and noted (on the transcript) the different concepts discussed within each participant's narrative (sub-codes) of her experience in raising a child with a DD. My primary supervisor (Dr. Perry), one other committee member (Dr. Khanlou) and I independently reviewed the transcripts and then met in person to discuss these sub-codes. The three of us were mostly in agreement and discussed some of the different perspectives we had. We grouped some of these sub-codes into broader themes or categories (codes).

Following this, I conducted additional interviews with mothers in both groups, while simultaneously making notes about emergent themes in my field notes. As each interview was transcribed, I continued reviewing printed transcripts to note down sub-codes or sub-themes or concepts on them. I continued this process for both groups until similar concepts kept emerging and no significant new concepts were being discussed by mothers in their interviews. This saturation was reached much faster for the Canadian group compared to the South Asian group. A total of six interviews were completed with Canadian mothers and 10 with South Asian mothers.

Once I had sub-coded all transcripts, I further analysed these sub-codes into larger emergent themes or codes, constructed a table of these codes and noted them in upper case letters

on each transcript during a second review of these transcripts. As a third step, I completed the table by cross analyzing between interviews within and between the two groups, further organizing sub-themes within larger themes, and copied the relevant sets of quotes from the transcripts into this table. I reviewed this table with my supervisor (Dr. Perry) to ensure that the coding system seemed appropriate. I then printed this table out and found that most of these themes and sub themes could be conceptually organized within the framework of the Perry (2004) model of parent outcomes. As a final step, I re-organized them within this framework when finally writing my results down in the following sections.

Results

Based on the embedded correlational mixed methods design used in this study, the quantitative results obtained from questionnaire data formed the primary source of information, while the qualitative themes obtained from the interviews provided a secondary source of information to supplement the quantitative data. In this section, I will present the preliminary analysis conducted with all the quantitative variables, followed by the results pertaining to the two quantitative research questions and the final qualitative question that will integrate the qualitative findings with the quantitative results.

Preliminary Analysis

Before conducting the main statistical analysis, I completed a thorough preliminary analysis with the goal of cleaning and screening the database for any unexpected, extreme or missing data. Even though I entered all the data for this study together with my research assistant to reduce data entry errors, I checked the accuracy of data by cross examining the data for random participants with their original questionnaire. The demographic section had some missing information, and the sample size for demographic descriptives was reported above in the

participant section. Fewer than 5% of the items for the main variables of the model were randomly missing. I used the mean of the remaining items within a measure for that participant to impute for this missing data. I dropped one participant from the final sample due to entire missing sections from their questionnaire.

After careful examination of the descriptive statistics including the mean (*M*), standard deviation (*SD*), minimum and maximum values of all variables (Table 4), I concluded that all values were within the expected range of scores for each measure.

Table 4.

Descriptive Statistics for all Variables in the Canadian (CA) and South Asian (SA) Group

	<i>M (SD)</i>		<i>Minimum-Maximum</i>		<i>Skewness / Kurtosis</i>	
	CA	SA	CA	SA	CA	SA
<i>Parent Outcome Variables</i>						
FICD Negative Impact	26.33 (7.0)	27.3 (7.8)	11 – 39	10 – 40	-0.065 / -0.742	-0.209 / -0.660
FICD Positive Impact	28.7* (6.1)	31.5** (5.6)	16 – 40	13 – 40	-0.368 / -0.691	-1.017 / 1.650
Parenting Stress – QRS-F – Parent and Family Problems Scale	9.9 (5.0)	12.3* (4.9)	0 – 19	0 – 19	-0.305 / -0.775	-0.796 / 0.000
Positive Gain – Positive Gain Scale	30.6** (3.7)	29.3* (4.2)	21 – 35	16 – 35	-0.504 / -0.549	-0.803 / 1.092
<i>Stressor Variables – Child Characteristics</i>						
Child’s age	12.7 (4.6)	11.4 (4.7)	4.5 – 21.5	4.5 – 22.4	0.307 / -0.892	0.587 / -0.643
Adaptive Behaviour – SIB-R Age Equivalent (months)	70.1* (43.5)	43.5** (29.2)	4 – 169	8 – 129	0.518 / -0.297	0.956 / 0.168
Maladaptive Behaviour – SIB-R GMI	-12.8* (11.1)	-15.5* (16.3)	-45 – 3	-54 – 4	-0.610 / -0.095	-0.848 / -0.279

	<i>M (SD)</i>		<i>Minimum-Maximum</i>		<i>Skewness/Kurtosis</i>	
	CA	SA	CA	SA	CA	SA
<i>Other Life Stressor Variables</i>						
Barratt – Mother’s Education	16.8** (2.9)	15.8** (4.4)	9 – 21	3 – 21	-1.072 / 0.579	-0.690 / -0.322
Barratt - Overall SES	43.6** (11.8)	38.9 (15.3)	6 – 61	9 – 66	-1.097 / 1.404	-0.338 / -0.968
Financial Hardship	2.7** (2.1)	2.5** (1.9)	0 – 7	0 – 7	0.381 / -0.791	0.476 / -0.551
Grand Total Other Life Events	3.4** (2.5)	3.4** (2.7)	0 – 10	0 – 10	1.090 / 0.784	0.851 / -0.076
<i>Parent’s Personal Resource Variables</i>						
Self Efficacy – FES – Family Subscale	47.2 (6.8)	46.9** (8.3)	31 – 59	22 – 60	-0.329 / 0.168	-0.934 / 1.045
Mental Health Problems – Kessler 6	6.7 (4.5)	9.5 (5.9)	0 – 18	0 – 24	0.563 / -0.208	0.422 / -0.336
Coping – BriefCOPE						
- Positive	38.6 (8.5)	44.4 (6.3)	22 – 55	30 – 59	-0.007 / -0.679	-0.120 / 0.210
- Negative	17.0** (5.0)	19.2 (4.5)	10 – 30	10 – 27	0.815 / -0.025	-0.103 / -0.827
Acculturation – VIA						
- Canadian Identity		57.7 (11.1)		27 – 82		-0.258 / 0.298
- South Asian Identity		71.9 (10.8)		49 – 90		-0.153 / -0.846
<i>Family Resource Variables</i>						
Marital Satisfaction	7.2** (2.0)	8.0** (1.8)	2 – 10	4 – 10	-0.589 / -0.004	-0.473 / -0.686
Family Hardiness – IFPF – Compensating Experiences Scale	14.6* (3.3)	14.1 (3.8)	6 – 20	4 – 20	-0.427 / -0.104	-0.564 / 0.500
<i>Support Variables</i>						
Social Support – FSS mean helpfulness - Overall	2.7 (0.7)	3.1* (0.9)	1 – 4	1 – 5	-0.037 / -0.015	0.088 / -1.167
- Informal	2.4 (0.8)	2.9 (1.0)	1 – 4	1.2 – 5	0.171 / 0.575	0.150 / -1.005
- Formal	3.1 (1.1)	3.3 (1.0)	1 – 5	1.4 – 5	-0.264 / -0.551	-0.138 / -0.770

Note. * $p < .05$ on either Kolmogorov-Smirnov OR Shapiro-Wilk tests for normality. ** $p < .05$ on both Kolmogorov-Smirnov AND Shapiro-Wilk tests for normality.

About 75% of South Asian immigrant mothers fell in the Integration category or domain (strong Canadian and South Asian identities) which is the best acculturation outcome according to Berry (1980, 1997, 2005). Another 24 % were on the other end, in the Marginalization domain (weak Canadian and South Asian identities). However, there was only 1 mother that fell into a medium domain (i.e., Segregation). Moreover, the actual total scores of Canadian and South Asian identity would be more appropriate for further analysis since they have a continuous distribution of scores. Therefore, I used the total Canadian and South Asian identity score for further analysis.

I studied the distribution of scores on each variable by examining their skewness and kurtosis statistics as well as by conducting the Kolmogorov-Smirnov and Shapiro-Wilk tests for normality with a null hypothesis of normality. The closer values are to zero, the more likely it becomes that the distribution of scores is closer to a normal distribution. As a general rule, distributions with skewness and kurtosis values within ± 1 are considered to be acceptable and do not require a transformation (Hair, Black, Babin, Anderson & Tathan, 2006). As can be seen from Table 4, the skewness and kurtosis values for most variables are within this limit.

I also examined individual histograms with a normal curve overlay of these distributions to visually inspect the spread of scores on these variables. The Kolmogorov-Smirnov and/or Shapiro-Wilk tests for normality were significant for some variables (indicated in Table 4). I dropped the two Barratt scores (Mother's Education and Overall SES) from further analysis since the distributions were highly skewed, and the scoring was challenging and subjective due to the nature of employment of various immigrant parents working in low paying jobs in spite of being highly educated. In most other cases, the greater frequency of scores in the higher or lower end of the distribution made theoretical sense, and transforming scores would make it less

clinically interpretable. Therefore, taking into account all of the above statistics and visual inspection of distribution of scores, I took an informed decision and did not transform any variables before further analysis. Next, I examined differences between the two groups on all variables in order to answer the first research question.

Research Question 1. Differences Between the Groups

I used an Independent Sample t test for all stressor, resource, support and outcome variables to answer the first research question: Is there a significant difference between the South Asian immigrant mothers and Canadian mothers of children with a disability on any of the stressor, outcome and mediating variables? The results of this analysis are presented in Table 5

Table 5.

Comparison of Canadian and South Asian Groups.

	<i>Mean</i> CA	<i>Mean</i> SA	<i>Mean</i> CA – SA	<i>t</i>	<i>Df</i>	<i>p</i> (2-tailed)	<i>Cohen's</i> <i>d</i>
<i>Parent Outcome Variables</i>							
FICD Negative Impact	26.3	27.3	-1.0	-.675	104	.501	
FICD Positive Impact	28.7	< 31.5	-2.8	-2.427	104	.017**	-.478
Parenting Stress	9.9	12.3	-2.4	-2.516	105	.013**	-.486
Positive Gain	30.6	< 29.3	1.3	1.758	105	.082	
<i>Stressor Variables – Child Characteristics</i>							
Child's age	12.7	11.4	1.3	1.371	104	.173	
Adaptive Behaviour	70.1	> 43.5	26.7	3.750	96.795	.000**	.718
Maladaptive Behaviour	-12.8	-15.5	2.7	.994	87.444	.323	
<i>Other Life Stressor Variables</i>							
Financial Hardship	2.7	2.5	0.2	.616	105	.539	
Grand Total Other Life Events	3.4	3.4	0.0	.008	105	.993	
<i>Parent's Personal Resource Variables</i>							
Self Efficacy	47.2	46.9	0.3	.228	105	.820	
Mental Health Problems	6.7	< 9.5	-2.8	-2.709	92.473	.008**	-.533
Coping – Positive	38.6	< 44.4	-5.7	-3.965	101.09	.000**	-.775
- Negative	17.0	< 19.2	-2.2	-2.304	105	.023**	-.463
<i>Family Resource Variables</i>							
Marital Satisfaction	7.2	< 8.0	0.8	-2.049	87	.043**	-.420
Family Hardiness	14.6	14.1	0.5	.776	105	.439	
<i>Support Variables</i>							
Social Support-Overall	2.7	< 3.1	-0.4	-2.275	91.09	.025**	-.496
- Informal	2.4	< 2.9	-0.5	-2.797	91.36	.006**	-.543
- Formal	3.1	3.3	-0.2	-1.357	105	.178	

As noted earlier, there were two positive and two negative outcomes measures. South Asian mothers, compared to Canadian mothers, reported significantly greater level of parenting stress on the QRS-F, with a moderate effect size, but reported similar negative impact on the FICD. These two questionnaires possibly measure somewhat different aspects of negative impact, as the QRS-F focuses more on the individual responding while FICD focuses on the effect on the family. A similar trend was noted with positive outcome as well. The FICD Positive Impact score was significantly higher in the South Asian group while the other positive measure, the Positive Gain Scale scores did not differ.

Amongst child characteristics, Canadian mothers reported significantly higher levels of child's adaptive behaviour skills than South Asian mothers, with a strong effect size. This suggests that the child's skills are significantly different in the two groups, and need to be covaried for. However, adaptive skills will be entered in the first step of regression models for research question 2, and will therefore be controlled for prior to consideration of other variables. The other child characteristics, age and maladaptive behaviour, were similar in both groups on average. In addition, neither of the Other Life Stressors were significantly different between the groups.

Looking at the Resources and Supports domains, there was a tendency for South Asian mothers to report higher scores on a number of variables. They reported significantly higher levels of Mental Health problems, but also more frequent use of Positive and Negative coping mechanisms to deal with the stressors discussed above. In addition, South Asian mothers reported significantly higher levels of Marital Satisfaction than Canadian mothers.

Finally, amongst support variables, South Asian mothers reported greater overall helpfulness of all available social supports than Canadian mothers. Interestingly, when separated

into Informal and Formal sources of support, South Asian mothers continued to report better social support from informal sources such as husband, family, relatives and community. However, both groups reported similar levels of support from Formal services. The following section will combine these findings with additional correlational analysis to determine the variables to be used in the regression analysis.

Research Question 2. Predictors of Maternal Impact

In the second research question, I examined whether the magnitude and pattern of stressors and mediating variables that predict maternal outcomes differ in the South Asian and Canadian groups. In order to answer this question, I conducted a set of four hierarchical regression analyses with child variables, other life stressors, mothers' personal resources, family system resources, and social support as predictors of negative and positive impact in the Canadian and South Asian groups separately.

However, there is a limited amount of power predicted for these analyses based on the power analysis I conducted in the methods section above. Thus, only a limited number of variables could be included in the regression to have a low to medium power for these analyses. Before conducting the regression analysis, I narrowed these variables down by examining the correlations among all the dependent variables and the multiple positive and negative outcomes (Table 6), intercorrelations within each block of the model (Appendix D) along with the results of the preliminary analysis and *t* tests.

Table 6.

Pearson Correlations among all Outcome Variables and Stressors, Parent & Family Resources, and Supports in Canadian (CA) and South Asian (SA) groups

	<i>QRS-F</i>		<i>Positive Gain Scale</i>		<i>FICD – Negative</i>		<i>FICD – Positive</i>	
	CA	SA	CA	SA	CA	SA	CA	SA
<i>Stressor Variables – Child Related</i>								
Child's age	.06	.01	-.33*	-.15	-.11	.10	-.43**	-.22
Adaptive Behaviour	-.23	-.39**	-.02	.08	-.32*	-.31*	-.27*	-.17
Maladaptive Behaviour	-.47**	-.51**	.12	.39**	-.41**	-.56**	.03	.19
<i>Other Life Stressor Variables</i>								
Financial hardship	.31*	.38**	-.02	-.34	.41**	.38**	.11	-.15
Other life events	.15	.44**	-.06	-.39**	.28*	.31*	-.03	-.15
<i>Parent's Personal Resource Variables</i>								
Self Efficacy	-.50**	-.54**	.50**	.59**	-.20	-.37**	.32*	.49**
Mental Health Problems	.61**	.66**	-.10	-.40**	.62**	.42**	.14	-.42**
Coping								
- Positive	.05	-.28*	.47**	.46**	.25	-.19	.60**	.51**
- Negative	.32*	.49**	.06	-.38**	.33*	.39**	.20	-.54**
Acculturation								
- CA Identity		-.15		.22		.03		.06
- SA Identity		-.15		.34**		-.17		.19
<i>Family Resource Variables</i>								
Family Hardiness	-.52**	-.37**	.49**	.56**	-.31*	-.28*	.42**	.45**
Marital Satisfaction	-.21	-.33*	.36*	.51**	-.26	-.28	.18	.44**
<i>Support Variables</i>								
Social Support – Overall Mean Helpfulness	-.40**	-.45**	.39**	.57**	-.28	-.41**	.35**	.43**

Note. *. Correlation is significant at $p < .05$. **. Correlation significant at $p < .01$.

The first step in determining variables for the regression analysis was to reduce the dependent variables from four to two (one positive and one negative) to decrease the Type I error. I did so by examining the correlations (Appendix D) between the two negative and two positive outcome variables, as well as the distributions of scores and reliability of these scores in order to decide which one negative and one positive impact variable would be most appropriate to use. The FICD Negative Impact had better internal consistency reliability score (Canadian $\alpha = .87$; South Asian $\alpha = .91$) compared to QRS-F (Canadian $\alpha = .87$; South Asian $\alpha = .88$), and had a more normal distribution of scores. Moreover, there was a strong significant correlation between FICD Negative Impact and Parenting Stress on QRS-F in both Canadian ($r = .73$) and South Asian ($r = .70$) groups. In addition, the QRS-F score had moderate significant correlations with both positive impact scores, while FICD Negative Impact score did not. Therefore, FICD Negative Impact was selected as one of the two dependent variables.

A similar examination was completed to compare the FICD Positive Impact and the Positive Gain score. Even though FICD Positive Impact had a somewhat negatively skewed distribution, it had a much stronger internal consistency reliability in both groups (Canadian $\alpha = .85$; South Asian $\alpha = .81$), while Positive Gain had the lowest internal consistency score (Canadian $\alpha = .76$; South Asian $\alpha = .78$) and was also somewhat skewed in both groups. These two scores had a significant strong correlation in the Canadian group ($r = .74$) and a moderate one in the South Asian group ($r = .45$). In addition, while Positive Gain was moderately correlated with both QRS-F (Canadian $r = -.31$; South Asian $r = -.38$) and FICD Negative Impact (Canadian $r = -.09$; South Asian $r = -.40$), FICD Positive Impact was only correlated with QRS-F in the South Asian group ($r = -.40$). Moreover, the FICD Positive and Negative Impact scores belong to the same measure with the same response format (5-point scale), and thus might

provide a more coherent picture of coexisting positive and negative impact in mothers raising a child with DD. Furthermore, the FICD measure has more family oriented (versus individual) items on it. Therefore, I decided to use the two scores of the FICD as the dependent variables in my regression analyses.

Once the dependent variables were decided, I included independent and mediating variables that met the following criteria: (1) Good internal consistency as determined in the methods section above. (2) Intercorrelations of 0.40 or less amongst variables within a block (to minimize redundancy and conserve power), and (3) A moderate to strong correlation with the outcome variables. If a variable had one or more intercorrelations of more than 0.40 within a block (Appendix D), then the variable that was significantly different between the Canadian and South Asian groups and had a stronger correlation with the outcomes was chosen to be included in the regression analysis.

Based on these criteria, I entered Child's age, SIB-R Adaptive Behaviour AE, SIB-R GMI in the first step of the hierarchical regression model. In the second step, I entered Financial Hardship (number of things the family had to do without), and Total number of Other Life Events. In the third step, I included Self Efficacy, Mental Health Problems, Positive Coping, and Family Hardiness. I added the Mean helpfulness of all available sources of social support in the fourth step. This model was used to predict FICD Positive and Negative impact in the Canadian and South Asian groups separately, thereby resulting in four hierarchical regression models. In the South Asian regression models, the two acculturation variables, South Asian and Canadian Identity scores were added in a fifth step.

Predictors of Positive Impact in Canadian Mothers. The results of the regression analysis predicting Positive Impact based on child's age, adaptive behaviour, and maladaptive behaviour in Canadian mothers (Table 7, Appendix E) suggest that about 21% of the variance in the FICD Positive Impact scores can be explained by this model. More specifically, Child's age accounted for a significant amount of unique variance in Positive Impact when all other variables were held constant, with a moderate partial regression coefficient ($\beta = -.39$), suggesting that Canadian mothers of younger children tended to report more positive impact. On the other hand, level of adaptive or maladaptive behaviour in children did not significantly contribute to variance in Positive Impact. Adding financial hardship and other life stressors in model 2, did not significantly explain any additional variance in Positive Impact.

However, when the resource variables self efficacy, mental health problems, positive coping, and family hardiness were included in the model, an additional 36% of the variance in Positive Impact was explained by this model. Positive coping ($\beta = .46$) and family hardiness ($\beta = .44$) explained significant amounts of variance in Positive Impact, and child's age was no longer a significant predictor ($p = .098$). Mean helpfulness of social supports was included as the final variable in the model, but the model did not explain much additional variance in Positive Impact. The final model (Appendix E) explained 58.7% of variance, $F(10, 43) = 6.107, p < .001$, in Positive Impact in Canadian mothers of children with a developmental disability.

Table 7.

Hierarchical Regression of Positive Impact in the Canadian Group.

<i>Model: Positive Impact in CA</i>	<i>B</i>	<i>SE(B)</i>	<i>β</i>	<i>R²</i>	<i>R²Δ</i>	<i>FΔ</i>	<i>p value</i>
Model 1				.208	.208*	4.377	.008
Child's age	-.508	.174	-.385*				.005
SIB-R Adaptive AE	-.021	.019	-.153				.252
SIB-R Maladaptive GMI	.008	.070	.015				.907
Model 2				.212	.004	.113	.893
Child's age	-.534	.186	-.405*				.006
SIB-R Adaptive AE	-.024	.020	-.170				.231
SIB-R Maladaptive GMI	.003	.073	.005				.968
Financial Hardship	-.207	.439	-.071				.640
Total Other Life Events	.079	.347	.032				.821
Model 3				.571	.359*	9.203	.000
Child's age	-.256	.152	-.194				.098
SIB-R Adaptive AE	-.012	.016	-.087				.450
SIB-R Maladaptive GMI	-.038	.058	-.069				.515
Financial Hardship	-.053	.349	-.018				.879
Total Other Life Events	-.467	.286	-.189				.110
Self Efficacy	-.051	.139	-.057				.712
Mental Health Problems	.200	.171	.147				.248
Positive Coping	.328	.085	.457*				.000
Family Hardiness	.812	.255	.441*				.003
Model 4				.587	.016	1.665	.204
Child's age	-.236	.151	-.179				.127
SIB-R Adaptive AE	-.011	.016	-.081				.478
SIB-R Maladaptive GMI	-.046	.058	-.084				.430
Financial Hardship	.000	.348	.000				.999
Total Other Life Events	-.356	.296	-.145				.236
Self Efficacy	-.079	.139	-.087				.573
Mental Health Problems	.239	.172	.176				.173
Positive Coping	.303	.087	.421*				.001
Family Hardiness	.802	.253	.435*				.003
Social Support	1.393	1.079	.155				.204

Predictors of Positive Impact in South Asian Mothers. When the same models were computed for the South Asian group (Table 8, Appendix F), mostly similar results were obtained with a few exceptions. Unlike the Canadian group, the first model where Positive Impact was predicted based on child's age, adaptive behaviour, and maladaptive behaviour in South Asian mothers, the model only contributed about 8% of the variance in the FICD Positive Impact scores. In addition, child's age was not a significant predictor of Positive Impact for this group. Like the Canadian group, adding financial hardship and other life stressors in model 2 did not significantly explain any additional variance in Positive Impact in South Asian mothers.

When the resource variables, self efficacy, mental health problems, positive coping, and family hardiness were included in model 3, a significant 37.4% of the variance in Positive Impact was explained by this model. In South Asian mothers, positive coping ($\beta = .27$) and mental health problems ($\beta = -.40$) significantly contributed to variance in Positive Impact. Unlike Canadian mothers, family hardiness was not a significant predictor of positive impact in South Asian mothers. Including Mean helpfulness of social supports in model 4 and South Asian as well as Canadian identity in model 5 did not explain much additional variance in Positive Impact. The final model (Appendix F), $R^2 = .540$, $F(12, 38) = 3.716$, $p = .001$, explained about 54% of variance in Positive Impact in South Asian mothers of children with a developmental disability.

Table 8.

Hierarchical Regression of Positive Impact in the South Asian Group.

<i>Model: Positive Impact in SA</i>	<i>B</i>	<i>SE(B)</i>	<i>β</i>	<i>R²</i>	<i>R²Δ</i>	<i>FΔ</i>	<i>p value</i>
Model 1				.080	.080	1.368	.264
Child's age	-.164	.185	.597				.380
SIB-R Adaptive AE	-.023	.028	.203				.425
SIB-R Maladaptive GMI	.052	.051	.018				.313
Model 2				.103	.022	.556	.577
Child's age	-.162	.187	-.137				.392
SIB-R Adaptive AE	-.032	.030	-.166				.296
SIB-R Maladaptive GMI	.025	.060	.073				.677
Financial Hardship	-.361	.462	-.128				.439
Total Other Life Events	-.148	.362	-.073				.684
Model 3				.476	.374*	7.313	.000
Child's age	.001	.155	.001				.994
SIB-R Adaptive AE	-.044	.025	-.232				.088
SIB-R Maladaptive GMI	-.045	.055	-.131				.418
Financial Hardship	-.221	.386	-.078				.569
Total Other Life Events	.304	.349	.149				.389
Self Efficacy	.181	.125	.268				.154
Mental Health Problems	-.374	.150	-.403*				.017
Positive Coping	.241	.122	.274*				.054
Family Hardiness	.110	.231	.074				.638
Model 4				.481	.005	.395	.533
Child's age	-.001	.156	-.001				.992
SIB-R Adaptive AE	-.044	.025	-.230				.093
SIB-R Maladaptive GMI	-.049	.055	-.142				.384
Financial Hardship	-.243	.391	-.086				.537
Total Other Life Events	.304	.351	.150				.391
Self Efficacy	.182	.126	.270				.154
Mental Health Problems	-.342	.160	-.367*				.039
Positive Coping	.220	.127	.250				.091
Family Hardiness	.085	.237	.057				.723
Social Support	.551	.877	.092				.533

	<i>B</i>	<i>SE(B)</i>	β	<i>R</i> ²	<i>R</i> ² Δ	<i>F</i> Δ	<i>p</i> value
Model 5				.540	.059	2.418	.103
Child's age	-.078	.155	-.066				.619
SIB-R Adaptive AE	-.048	.025	-.251				.060
SIB-R Maladaptive GMI	-.079	.055	-.230				.162
Financial Hardship	-.214	.385	-.076				.581
Total Other Life Events	.175	.356	.086				.626
Self Efficacy	.230	.123	.340				.070
Mental Health Problems	-.320	.156	-.344*				.048
Positive Coping	.290	.133	.330*				.035
Family Hardiness	.072	.229	.049				.754
Social Support	1.181	.897	.197				.196
South Asian Identity	-.147	.076	-.286				.060
Canadian Identity	-.038	.061	-.076				.535

Predictors of Negative Impact in Canadian Mothers. FICD Negative Impact was predicted based on the same variables in the same hierarchical fashion (Table 9) as Positive Impact above. Model 1 significantly explained about 26% of the variance in the Negative Impact on Canadian mothers. However, unlike Positive Impact, both adaptive ($\beta = -.29$) and maladaptive ($\beta = -.40$) behaviour significantly contributed to unique variance in Negative Impact. Model 2 accounted for an additional 10.5% of variance in Negative Impact and both adaptive and maladaptive behaviour uniquely predicted Negative Impact (Table 9, Appendix G).

Table 9.

Hierarchical Regression of Negative Impact in the Canadian Group.

<i>Model: Negative Impact in CA</i>	<i>B</i>	<i>SE(B)</i>	β	R^2	$R^2\Delta$	$F\Delta$	<i>p value</i>
Model 1				.262	.262*	5.910	.002
Child's age	-.063	.192	-.042				.746
SIB-R Adaptive AE	-.047	.020	-.293*				.026
SIB-R Maladaptive GMI	-.251	.077	-.399*				.002
Model 2				.367	.105*	3.981	.025
Child's age	.033	.190	.022				.863
SIB-R Adaptive AE	-.046	.020	-.289*				.026
SIB-R Maladaptive GMI	-.200	.075	-.318*				.010
Financial Hardship	.712	.449	.215				.119
Total Other Life Events	.577	.355	.205				.111
Model 3				.619	.253*	7.299	.000
Child's age	.094	.163	.062				.567
SIB-R Adaptive AE	-.022	.017	-.139				.203
SIB-R Maladaptive GMI	-.158	.062	-.251*				.015
Financial Hardship	.671	.375	.202				.080
Total Other Life Events	.328	.307	.116				.292
Self Efficacy	.192	.149	.186				.204
Mental Health Problems	.845	.184	.545*				.000
Positive Coping	.017	.092	.021				.850
Family Hardiness	-.365	.274	-.174				.190
Model 4				.620	.001	.116	.736
Child's age	.088	.166	.059				.597
SIB-R Adaptive AE	-.023	.017	-.140				.203
SIB-R Maladaptive GMI	-.156	.063	-.248*				.018
Financial Hardship	.656	.381	.198				.093
Total Other Life Events	.296	.324	.105				.367
Self Efficacy	.200	.152	.194				.196
Mental Health Problems	.834	.189	.538*				.000
Positive Coping	.025	.095	.030				.795
Family Hardiness	-.362	.277	-.172				.198
Social Support	-.402	1.181	-.039				.736

When resources were added in Model 3, an additional 25% of variance in Negative Impact was accounted for. Adaptive behaviour was no longer a significant predictor of Negative Impact, while maladaptive behaviour continued to have a unique contribution ($\beta = -.25$) to Negative Impact. In addition, maternal mental health problems ($\beta = .55$) emerged as a significant contributor to variance in Impact. Adding social support in the final model did not account for much additional variance. The final model (Appendix G), $R^2 = .62$, $F(10, 43) = 7.027$, $p = .000$, accounted for an overall 62% variance in Negative Impact on Canadian mothers.

Predictors of Negative Impact in South Asian Mothers. Somewhat different results were obtained when the same hierarchical regression model was computed for Negative Impact in South Asian mothers (Table 10, Appendix H). Model 1 accounted for 41% of the variance in Negative Impact in South Asian mothers, with adaptive ($\beta = -.32$) and maladaptive behaviour ($\beta = -.55$) contributing significant amounts of unique variance. Models 2, 3, 4 and 5 contributed very small additional variance in impact. None of the resource, support or acculturation variables were significant predictors of negative impact. Only adaptive and maladaptive behaviours continued to contribute significantly to variance in Negative Impact. Overall, the final model (Appendix H), $R^2 = .512$, $F(12, 38) = 3.323$, $p = .002$. accounted for about 51% of the variance in Negative Impact on South Asian Immigrant mothers.

Table 10.

Hierarchical Regression of Negative Impact in the South Asian Group.

<i>Model: Negative Impact in SA</i>	<i>B</i>	<i>SE(B)</i>	β	R^2	$R^2\Delta$	$F\Delta$	<i>p value</i>
Model 1				.410	.410*	10.865	.000
Child's age	.070	.207	.042				.738
SIB-R Adaptive AE	-.086	.032	-.324*				.010
SIB-R Maladaptive GMI	-.262	.056	-.549*				.000
Model 2				.436	.027	1.066	.353
Child's age	.056	.207	.034				.789
SIB-R Adaptive AE	-.078	.033	-.295*				.022
SIB-R Maladaptive GMI	-.263	.066	-.550*				.000
Financial Hardship	.725	.510	.184				.162
Total Other Life Events	-.315	.400	-.111				.435
Model 3				.472	.036	.701	.596
Child's age	-.001	.217	-.001				.995
SIB-R Adaptive AE	-.074	.035	-.279*				.043
SIB-R Maladaptive GMI	-.247	.077	-.517*				.002
Financial Hardship	.612	.540	.156				.264
Total Other Life Events	-.544	.488	-.192				.271
Self Efficacy	.007	.174	.007				.969
Mental Health Problems	.184	.210	.142				.385
Positive Coping	-.053	.170	-.043				.759
Family Hardiness	-.251	.324	-.121				.443
Model 4				.498	.026	2.072	.158
Child's age	.007	.214	.004				.973
SIB-R Adaptive AE	-.075	.035	-.282*				.038
SIB-R Maladaptive GMI	-.234	.076	-.491*				.004
Financial Hardship	.681	.536	.173				.211
Total Other Life Events	-.546	.482	-.193				.263
Self Efficacy	.002	.172	.002				.990
Mental Health Problems	.081	.219	.062				.714
Positive Coping	.014	.174	.011				.937
Family Hardiness	-.172	.324	-.083				.600
Social Support	-1.731	1.203	-.207				.158

<i>Model: Negative Impact in SA</i>	<i>B</i>	<i>SE(B)</i>	<i>β</i>	<i>R²</i>	<i>R²Δ</i>	<i>FΔ</i>	<i>p value</i>
Model 5				.512	.014	.536	.589
Child's age	-.003	.223	-.002				.988
SIB-R Adaptive AE	-.075	.035	-.284*				.040
SIB-R Maladaptive GMI	-.242	.079	-.507*				.004
Financial Hardship	.786	.552	.200				.163
Total Other Life Events	-.703	.511	-.248				.177
Self Efficacy	.009	.177	.009				.961
Mental Health Problems	.116	.224	.089				.608
Positive Coping	.087	.191	.071				.652
Family Hardiness	-.171	.328	-.082				.606
Social Support	-1.628	1.287	-.195				.214
South Asian Identity	-.091	.109	-.127				.408
Canadian Identity	.067	.087	.096				.447

Evidently, there is still a large amount of unexplained variance in maternal outcomes in both groups, more so in the South Asian group. In the next section, I attempted to explain some of these differences and similarities between the groups by presenting the qualitative themes from interviews with sub groups of mothers from both groups.

Research Question 3 – Qualitative Themes to Support Model

In order to answer my third research question, I used qualitative descriptive methodology (Sandelowski, 2000, 2010) to code, summarize and describe themes that emerged from the semi-structured interviews with selected participants from both groups, as described above in the methodology section. Since the goal of this secondary qualitative analysis was to supplement results of the primary quantitative analysis, I did not make in-depth interpretations of these interviews in a vacuum. Rather, I coherently organized and summarized the final codes or themes for both Canadian and South Asian mothers' experiences within the framework of the

Perry (2004) model of stress. In this section I will highlight the similarities in the experiences described by both groups of mothers, and describe any additional culturally related differences that emerged. Before delving into the Perry model, I will describe an overarching theme that emerged across the two groups, that seems to occur early on after the diagnosis, and then becomes intertwined within the model as a dynamic process that changes as well as reoccurs at various times throughout the life of these families.

Dynamic Grieving Process

Almost all Canadian and South Asian mothers described their experience in different ways as being a journey, a process of grieving for what their child could be, and ultimately readjusting their expectations for their child. One Canadian mother (C1) reported: *“there was a lot of, uh really serious grief process um that I think, you know, I don't know, I think it's like any kind of grief, you don't ever complete that, every so often there is some kind of new grieving that happens, you know. When we found out that that's what it was, I mean I, you know, I just did a lot of crying. I kept going downstairs to the laundry and it was, I mean, it was really, cause you have to let go.”*

Initial Disbelief, Sadness & Anger, “Why me?”.

Most mothers described their initial reactions to their child's diagnosis as very challenging. They found it hard to believe that this could happen to their child, especially when they observed their friends and family with typically developing children. Most mothers described feeling sad, depressed, and angry at first. One Canadian mother (C5) said: *“It was very hard. All my life I wanted to have children. I wanted to have lots of kids, like three, four kids...So when my child was born, I found out he was special needs, I was like, I was devastated and um because all around me my friends were all having kids and they're all normal, they're all healthy and normal. And that's what I miss. I miss that relationship I can have with my child...At first I was devastated. He wasn't*

walking, he wasn't talking. He can't tell me: "Mommy, this, that." I went through a lot, you know, nights crying. "Why me, why me?" A South Asian mother (S3) described her reaction: "at that time, we couldn't believe, I have read about it but I never thought it would happen to me, right? I used to go to church and I would just cry. Only cry, nothing else, because I am so sad. I am, like, I am, like, my sisters, they have children. They're all, like, normal children and my husband, they're, his sister has children. Normal children. And every, all my friends in school, they have normal children... You always question that. It's so sad. And when, those days, when I, when I see other children, I used to get so mad in my heart. I used to say: "How come he's talking and he's like smaller than my son?" Like at four or five, my sons were not talking. And then at two years they're talking and they're laughing and they're social. They can do everything else. My son only can like, like say, um, sit on the bicycle, they're riding the bicycle, and uh, like, it's so, like you tend to compare and you say: "Oh the age is so vast and my son hasn't improved yet." And you feel, like, mad, like why?"

Research About Diagnosis: Search for a Cause.

Mother's knowledge and expectations about their child's diagnosis varied within and between groups. Some Canadian mothers reported that they did not know about their child's diagnosis, while a few Canadian mothers reported noticing symptoms in their child(ren) and researching/seeking help from professionals in order to confirm the diagnosis and obtain services for him or her. A Canadian mother (C3) described: "her caregiver actually thought there was a hearing problem when she was um, when she was a year and a half so... well we didn't actually think it was hearing problem, she thought it was a hearing problem and um then we thought it might be autism and then I took her to a paediatrician and they, they wouldn't diagnose her. They wouldn't send her for a diagnosis till we checked her hearing... And then we took her and found out her hearing was fine so we took her to have her assessed... it was not easy but I wanted, I'm not one of those parents that sort of

blindly decides to go it alone, I wanted the diagnosis. I wanted her to have a label so she could get the help she needed. And so she had the diagnosis from before she was three years old. So that helped.”

Some South Asian mothers discussed having previously heard or read about Autism, but were not aware of the exact symptoms of this diagnosis. Some reported using culturally influenced explanations for their child’s challenges initially. In most cases, mothers researched and read about their child’s diagnosis and slowly concluded that their child did match the description of their diagnosis. A South Asian mother (S6) described her thought process around the time her son received the diagnosis: *“So then uh one day, like, um, no, not, I think when he was about to be uh put to school in Senior Kindergarten and then they told me, the teacher told me one day the first week that: “You know, I think your son has problem.” I said: “What do you mean by problem?” I, you know boys, like my mom always says: “Boy are a little bit naughty than the girls, right?” ... And we took him to our doctor. Everything was perfect, like his um personal growth. Everything was perfect. Then she said: “You know what? Just to be on a safer side...” She told us to go and meet a psychologist... The day we got the news that he was diagnosed, autism... I didn’t knew what is autism because coming from [South Asian Country], we never knew what was autism. It was something new to me...And then she said: “You know, what? Your son has autism.” And then I was almost into tears. I didn’t knew what was that. I had to be explained by the doctor as well as my husband, because I was almost crying.”*

Another South Asian mother (S8) who initially thought her daughter had a speech delay, described her search for a true diagnosis: *“So that time, I uh just uh thought that um I should go for something to... what’s going on? Is she okay, or not? And that time um before the diagnosis, I saw she used to do things line up, this another symptom of being autistic. But uh I didn’t have any idea that uh exactly what is the range of symptoms to being autistic child. So I thought, oh my God, my daughter was so perfection, so she’s playing very nicely and neatly. Oh uh but uh when she was diagnosed and I started*

to know about uh the symptoms and uh then I saw. Then I realized, no it was not perfect. And uh first um diagnosis, when the doctor diagnosed, uh it is, he took uh thirty-five minutes first visiting and second visiting also thirty-five minutes, something like that. So I, I thought uh within very short time, no um uh no any type of other test. Usually, we have a concept that there must be some test uh result, like this... It is usual, my usual concept. Just observing the uh child, doctor saying the child is autistic. I did not have that idea, really. So I was um thinking that he might be wrong. And the other thing um for her, um she was diagnosis pervasive developmental disorder, not otherwise specified. The term "not otherwise specified" made also, confused me. I thought, uh, she's not falling in the autistic, I thought maybe doctor is thinking uh the um that she, she has the autism. That also confused me. The "not otherwise specified". So for doctor did some test for her. So I thought um I was not really interested uh to do all other blood test, this and that because I was not sure that, how um within watching uh observing her uh less than one hour, he's giving this uh type of diagnosis? So, I was just uh I didn't believe him that he did the right thing. But um just um, then slowly I started to search in the Web and I got lot of information. It's uh similar with my daughter behaviour and other symptoms. Then I realized, no, I'm wrong. I am wrong...".

Two of the South Asian mothers were educated in child development/early childhood and reported noticing early delays and immediately seeking help from a doctor and/or a psychologist while in their country of origin. Even these mothers experienced some of the struggle experienced by others around their child's diagnosis. Both these mothers subsequently decided to move to Canada in hopes of getting appropriate help from professionals here. South Asian mother (S1) stated: *"so her milestones were delayed from the very beginning and I could, uh, I could see that each milestone was delayed, delayed, delayed. But when the language was too delayed, like when she was eighteen months old and she was still not responding to, um, since she was not talking anything, um, and I could see some of the symptoms. Um, I got a hearing thing done, the first thing, because I was like maybe it's my, it's just that she cannot hear it properly, so she's not responding to some pitches and she's*

responding to some. She's responding to music, she's watching TV, but she's, we're calling her by her name and she's not even looking at us. But they were all okay, so I, I gave her the label, like I told my speech pathologist when she was about 2 years old, that I think my child is autistic and it was in [South Asian Country] at that time...So by the time she was three, they did some social um psychological testing on her and they gave her the label of autism."

In addition, some mothers in both groups described blaming themselves (or their family/husband blaming them) for their child's diagnosis in the process of searching for a cause of their disability. A Canadian mother (C4) described: *"when we got him diagnosed, I thought, what did I do or what didn't I do? And I thought that for years and years. I thought, what could I have done that could have prevented this? Right? Even some, even to this day I'm thinking, well maybe I could have waited to get pregnant with him. You know?.. I mean, for the longest time, I blamed myself."* Similarly, a South Asian mother (S1) described her family's search for a cause: *"there are times when my husband has told me, um, "it's because of you or your family"... So sometimes when he is in real frustration, he, he has said it a few times that it's because of me and my family that this has come in his family. But I know he does not mean it that. But it's just he says it sometimes. Or because of my, my medicine"*.

The New "Normal"

Eventually, all mothers interviewed reached a stage (after their own individual journeys) where they accepted their child's diagnosis, started focusing more on their child's strengths and formulated more realistic expectations for his or her future. One of the Canadian mothers (C1) expressed: *"as a parent, it's a lot easier to make me happy ... (laughs) Like you don't have to go to Harvard, like you know what I mean? I, I, so like my expectations are really honestly, like I think most parents say I want my kids to be happy and I think there may be an underpinning there, like I want them*

to be happy AND be making, you know to make money and do all that, but you know I just want my children to be happy. You know? That's all what I want."

One of the South Asian mothers (S3) described this process of acceptance: *"hearing that they have autism and it's a lifetime disability, it was a real strain on you. Like we don't know, like, you are expecting to have children and you expect for them to do well in life and to get married, to have kids and have a normal thing with like everybody else...But um, after a little while, little by little, you get to know. That's okay and you know, our children, even they have this disability, they're so innocent, they're so pure. They have no wickedness in their heart...We love them for what they are...they say time will heal. Definitely, it helps...It happens gradually, little by little. But you will come to a point..accepted. And then you uh you look for good things in it rather than the bad things."*

The above described grieving and readjustment process occurs at different points in the lives of these mothers when new behavioural challenges develop or when their child(ren) do not develop skills at the same rate expected by parents. The various resource and support variables within the Perry (2004) model influence this dynamic process of adaptation through the recurring challenges that mothers experience over time. I will now present the themes that emerged within each domain of this model, and refer back to quantitative results when needed.

1. Maternal Outcome

In congruence with the quantitative results discussed above, mothers from both groups described experiencing a challenging and stressful life, but at the same time, they also highlighted several ways in which this journey of raising a child with DD has impacted them in positive ways. Some mothers described these challenging and positive aspects simultaneously, while others reported being able to focus on the positives as they slowly adapted to their child's challenges. I will now discuss these negative as well as positive aspects as reported by mothers.

1a. Negative Impact and Stress

Mothers in both groups described several ways in which their child's diagnosis and resulting changes impacted them negatively.

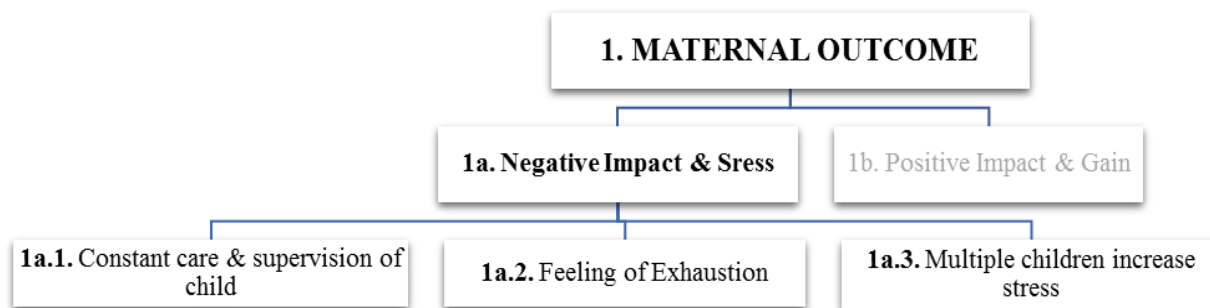


Figure 5. Coding diagram for Negative Impact & Stress.

1a.1. Constant Care & Supervision of Child. Both Canadian and South Asian mothers described their lives as being stressful since they need to constantly care for and supervise their child(ren). A Canadian mother (C3) described: *"That's really impacted, she can't be by herself. She simply can't. So that's the issue, I mean I guess you'd think when the child, when someone's 19, you're free and clear, as we were with my older daughter but um no. That's how it impacts us the most...It's hard because your child – you have to be there for her all the time."* A South Asian mother (S5) stated: *"I'm all the time, I have to be with him. If I away from him, then I have a stress... When I send him to school, I'm always keep my both phone. If they phone, I'm like shivering and you know? I'm worried, what happened to him, whether he fell down or you know? He was very hyper. So I'm always with him. Sometimes I call my parents I'm having, like, very stressful life. But I'm all, I don't want to go away from this problem. I want to keep with him. If it is away from him, this is very stressful for me."*

1a.2. Feeling of Exhaustion. As a result of constantly caring for their child(ren), most mothers described feeling exhausted, and at times frustrated and angry since they are primarily taking care of their child's needs on a daily basis. A Canadian mother (C4) described her feelings: *"Cause a lot of people don't understand, when you're with these kids, basically, it sucks the life*

*out of me. It takes, it takes all my energy... just to spend an hour with him, it takes a lot of energy...I feel like I'm being stretched like an elastic and stretched and stretched. And one time, I feel like I'm gonna snap. Because, you know, I can only be stretched so far. You know, I can't, I can't do everything for everybody". A South Asian single mother (S4) of two children with a diagnosis described feeling very tired but having no time to sleep since both of her children had high needs: "Sometime I'm not held in, sometime my, two, three years my son very trouble. He's cry, he's breaking TV, he's breaking furniture. He's still damage thing. Sometime I'm so tired I'm sleeping. Like I'm, my close eyes, he says: "Bring the water." And his shower is starting, you know? But children and something very difficult. I don't cooking because right away he come in and push me, you know? That's why I'm very difficult to time for me, very tight for me. Day time I'm sleeping, day time I clean, wash clothes for *Children, uh, very hard for challenge life for me. Yeah."*

1a.3. Multiple Children with Diagnosis Increases Stress. Two of the South Asian mothers had two children with a diagnosis. In one case one of the siblings was higher functioning than the other, while in the other family both children had very high needs. Both mothers reported feeling more stressed since they had to manage the needs of both their children. One of these mothers (S4) stated: *"he's not talking. I don't understand what he, she wants. What he like it, I don't understand. Why he like food, doesn't know me. Only he pull my hand and say: "Come, come." And only one word my son say: Doodoo. And I don't understand she (daughter) want food, she want some food, I don't know. Very difficult to me...And because I have challenge, because I have two children. Both of them is one year difference and very difficult to me. My daughter also no speaking too. That's why very difficult. Two children I can't handle. Very difficult to me. And no help, my husband too".* The other mother of twins (S3) reported difficulties with taking both of them out since they would start crying: *"It was hard. Um, mostly because you couldn't uh you couldn't take them anywhere. And also, like, you're always scared what would happen, if they start crying now, like, how am I going to stop it? And what should I*

do? Or you're scared to take them, uh, out. And um, so it was like, always, you know, you're in panic, you're in fear. You don't know what's going to happen." None of the outcome measures in the questionnaire address this important issue.

1b. Positive Impact & Gain

Despite the negative impact that their child's diagnosis has had on their lives, most mothers from both groups expressed their love and pride in their child and reported several positive changes in themselves and their outlook towards life. A Canadian mother (C1) expressed: "I mean its uh parenting I think is uh I mean its um, like it's been challenging but it's rewarding, obviously. It's, you know, I wouldn't trade my children, for sure."

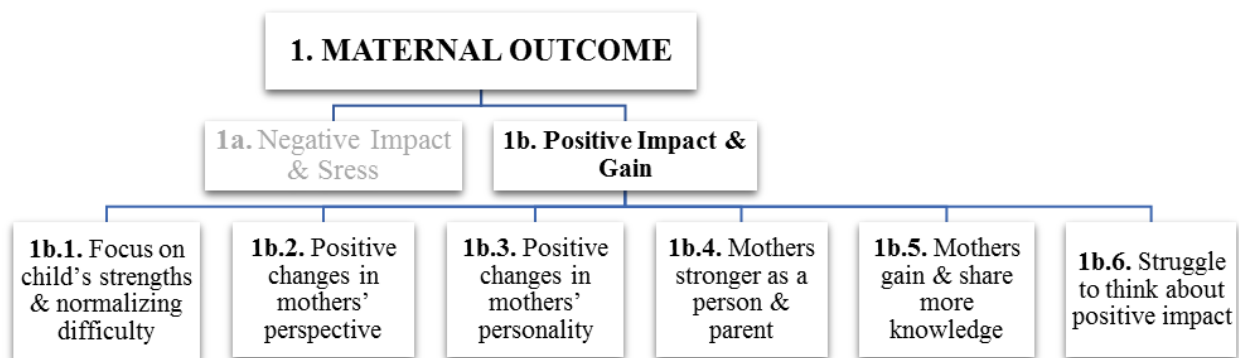


Figure 6. Coding Diagram for Positive Impact & Gain.

1b.1. Focus on Child's Strengths and Normalizing Difficulties. Even though mothers described their child's challenging behaviours and skill deficits, almost all mothers in both groups also focused and highlighted on their child's strengths, his or her intelligence and ability to learn. A Canadian mother (C4) reported: "Everyone said that, everyone that's come across him has said that he's so well-mannered and so polite. Always, please, thank you, um, like if he cuts in front of you and I, if we were talking, I'd go: "Um, excuse me, what do you say?" "Excuse me." He kinda, sometimes

needs little reminders. But I mean, like, he would never interrupt us while we were talking unless he needed something. Right? So whenever he's sitting, I say: "If you need help, you have to ask for help." So he'll stand there and I'll go: "What do you want? Help?" "Help." But he tries to do things on his own, like, he'll try and, he knows where the batteries are so he'll get a screwdriver and he gets the batteries and he'll try and change the batteries for himself. And it's like, no one has showed him this, so he's actually picking up on things. You know? That, now he's doing word finds, which he never used to do before."

Similarly, a South Asian mother (S8) described her daughter's skills: *"her visual communication is very strong...and she's very creative. So she likes to work with different artwork. She likes artwork. When she observe and the outside something, she try to draw those, those things and try to explain with the drawing pictures. And that's why I always try to buy something, whatever related with the art thingy. And she, she always enjoy that things so. I think using the artwork, she shows her creativity that uh that's the way she's thinking. I think it's really, uh, good strength. And another thing is motor skill is growing, was strong for her."*

Mothers described their child(ren) as loving, affectionate and friendly. A Canadian mother (C6) expressed: *"she's always been a very affectionate child... loves to hug and kiss. And we were under the misconception, we had to be educated ourselves a bit, that we were under the, that's why autism didn't really ring a bell because you know, you always had that misconception of autistic people not being able to display affection. Wrong. Completely wrong and boy do I know that now, right? Because I live with the most affectionate child. Oh my god."* Several South Asian mothers expressed similar love for their child(ren), along with more of a sense of pride. One of these mothers (S6) described her son's graduation: *"We never knew, in fact my husband was saying: "You know what, it's not point of going there (his graduation ceremony), like, I don't think he'll be there, standing there for quite a long time." Because he cannot sit in one place for a longer time, right? He needs break, he needs*

*breaks, like, quite often. So I said: "Let's give a try. Might see us, you know, when he sees us, he might be happy or something like that." So even the teacher said: "If he's, if he's okay, we'll take him up on the stage, if not, let him be in the classroom." "We'll give a try, she said," she's a very positive person too, the teacher. Yeah, and then, it was there and then I just saw him on the stage. He was there for more than three and a half without any break... even the teacher that I was almost into tears, like you know. And then teacher came running to me, I was so much, she said: "Don't worry, don't worry, I know it's big thing. It's a big thing for us too. We never expected *Child to, you know, stay there for the three and a half hours." Yeah. That was the biggest I can say in my life, like you know, yeah."*

Finally, more than half of Canadian and South Asian mothers described their child as being honest, pure and guileless. A Canadian mother (C1) described: *"I mean my children are amazing - they're just these amazing people, you know? And they have, I mean I've learned a lot about looking at life from their point of view because they have such a, like when I say child-like, I don't mean childish, I think it's more like naive, you know? Just, like, as if, like they just have a very pure way of looking at the world, and it's very without guile and they, you can get so much from that. So much love and personal enrichment from being around that. Yeah its really great."* Similarly a South Asian mother (S3) expressed: *"How much you scold them, how much you say like how much you say: "Oh you did this wrong", they don't keep a grudge at you. They just love you, love you so much. Like they have this innocence in them and like nobody, no, like, nobody can change them. So that's so beautiful of them and we love them for what they are. Even though they are, they have not all those qualities that other children have, but they are so beautiful. So they love, they love us and we love them back."*

1b.2. Positive Changes in Mothers' Perspective. Besides focusing on their child's strength most mothers were able to describe a positive impact in the way they thought and felt about themselves and others. Both Canadian and South Asian mothers described a general change in perspective about what is important in life and what to focus on. A Canadian mother

(C2) described: *“No regrets. Even though I’m on my own, there are no regrets. Life is what life is. You know what? And you can’t change it right now, I can’t turn back the clock thirty years or whatever. Um, you play the hand you’re dealt and sometimes you pick up cards, right? And, and, whether it completes the hand or not, doesn’t matter – you’re playing it and I enjoy the playing the game of life.”* A South Asian mother (S6) described a change in herself: *“So I know that my, you know, like being positive, since I’ve been so positive, there’s I feel that, like you know, my son can come out of that autism. Like you know, so, that’s the thing. I don’t think about those negatives, like you know, always think about positive.”*

Most of them have reported focusing on small changes in their child and feeling happy about any progress that their child made over time. One Canadian mother (C5) described her experience: *“positively I’ve changed... Hm... I’m trying to think. Um, I don’t know if this answers the question but I love when I see my, when I’m a part of when my son learns something new. Um, I love that. I feel so good about myself, if I taught him something.”* A South Asian mother (S1) elaborated a bit more on this: *“Because of *Child. Uh, I’m, I have, my whole perspective towards life has changed because of *Child, because I don’t uh for me, how much money the other person is earning or how big the house? other one is living in, or how my relatives or my cousins or my family have grown in like, in their lives, it doesn’t matter at all. For me, very small, small things give me, uh, like I don’t look for big milestones for *Child. Very small things she does like uh a new vocabulary word which she uses which a typical teenager use, it gives me a lot of uh happiness. She uses words and she uses it appropriately. How did she know that this is the, the way... and she gives me good, like immense pleasure. Like uh, I really, I look for small, small moments.”*

Some mothers have tried to think positively about their child by focusing on their strengths and recognizing that there are children and families who have many more challenges than they have. One Canadian mother (C3) described this: *“normally I do my own thing and that’s it*

but when you have a child with autism, you're more looking out for other people. So I always look at that, I always, you know, you can't feel sorry for yourself because someone's always in a worse place than you are". Describing similar changes, a South Asian mother (S7) expressed her thoughts: *"I didn't expect. And then maybe, I satisfied or something. I compare, I don't want to tell compare, but it's other, so many kids have so many kind of problems. But maybe he has mild or something."*

Ib.3. Positive Changes in Mothers' Personality: Various mothers described a positive change in their personalities in the process of raising their child with DD. They reported becoming more accepting, patient, tolerant and empathetic towards people in general, and especially towards individuals with special needs. A Canadian mother (C1) stated: *"I have a very patient, I'm very patient with them, I'm very accepting, you know? I, like yeah, I would say, I mean, you know, I mean the positives things."* A South Asian mother (S3) described: *"You tend to develop a skill that um like you, you never had. Like uh like things that you never, you thought never thought you could do. And you get lot of patience. You learn to patient and to um to tolerate and to be um independent and you know, all those skills you, you developed."* Another South Asian mother (S9) aptly described these changes in herself: *"So, being a mother of the, I, I am, I feel I am very much more than sympathized or empathized to other parents too. The other disabled people too."*

Ib.4. Mothers Stronger as a Person and Parent: In addition to the above, South Asian mothers overwhelmingly reported becoming stronger as a person and as a parent in the process of supporting their child with DD. One of the South Asian mothers (S5) reported: *"I think uh because after uh he diagnosed, like, we faced lot of problems and all. So now we are very strong. From the beginning, I cry a lot. When somebody ask, I don't know, I cry. Then my husband cry a lot. Now we are very strong and we know, like, however he's in any, like, level, we are the one have to help him. No? That is what, I think we are very strong parents, like, better than the beginning. For any problem."* One of the South Asian mothers (S3) described becoming stronger while sharing her child's

difficulties with others: *“So that um and to be come strong, like to be honest with people and to share, to talk to people. Sometimes you just hide and you just wait, but now um, I’m open, whenever people talk about, see my kids or talk with me and I’m able share it more than just hiding or just trying to escape from the scene or something like that. So you become stronger.”*

1b.5. Mothers Gain and Share More Knowledge: Besides these changes in personality and perspective, mothers also described becoming more educated about their child’s disability and how to help him or her over time. They also reported wanting to and feeling good about sharing their knowledge with and guiding other mothers. A Canadian mother (C2) reported: *“I happen to know, not everything, but quite a bit, cause I ask a lot of questions as you can figure out...Because I want to learn. I want to know, um and then, I have passed information on about the school board to one of the parents. So that helped them out, so they’ve got, you know, something to think about. Put a plan into place for the fall for their child. It may not work but at least, you’ve got information and that gives you power over the situation. You’re not floundering. Now you’ve got power.”*

South Asian mothers also described a similar sense of learning and supporting other mothers. One South Asian mother (S3) reported: *“when I meet a new mother who have children with autism, they’re not talking, I say: “Speech is the best thing you can give your child.” Like, even if you, they can do everything else, if they cannot tell you what they need, it’s like, um, not worth anything, so. Even though they wouldn’t see any improvement, still keep on giving speech because you don’t know how they will be.”* Another mother (S9) described her desire to spread knowledge and support back in her country of origin as well: *“And my determination is, still my determination is like that. If I can do anything for any autistic child in [South Asian Country]. If I can do anything, anyhow I can contribute for them, I will be happy. And even I, I was over there, I would engage with other different organizations. Those who are engaged with the autistic child.”*

1b.6. Struggle to Think about Positive Impact: Two of the six Canadian mothers of younger (5- and 6-years-old) children with autism struggled to report on any positive impact on themselves or their lives, even though they were able to report on their child's strengths. One of these Canadian mothers (C5) reported: *"The only positive thing I looked at is because he has a more, he is healthier as much as I can hope right now, but more positive, it's hard. For me to be more positive."* The other mother (C6) with a young child expressed a similar emotion: *"Oh my God...I can't even tell you. I, I gotta tell you, maybe that's bad too. Maybe that's gonna make me cry too. I don't know. I wish I could. I wish I could think of something. I don't know, I don't know. I don't think, I, you know. Maybe other people can answer that."*

2. Stressors

2a. Child Characteristics

Families start dealing with their children's delay in development of adaptive skills as well as several challenging or maladaptive behaviours even before their child receives a diagnosis. These levels and/or severity of these skills and behaviours change over their lifetime and have been found to greatly influence parents' outcomes. On the questionnaires, their child's adaptive skills and maladaptive behaviours were the strongest predictors of negative impact in both Canadian and South Asian mothers. In the interviews as well, both groups of mothers highlighted several of these skills and reported a range of behavioural challenges as well. Amongst the mothers interviewed, South Asian mothers were generally more focused on the specific skills or challenging behaviours that their child has demonstrated and how stressful it was to deal with these behaviours. For South Asian mothers, these skill deficits and presence of maladaptive behaviours were the only quantitative predictors of negative impact, with none of the other variables contributing significantly to it. On the other hand, Canadian mothers spoke briefly

about these skills and behaviours and focused more on the challenges they experienced with services (discussed in a later section). When speaking of challenging situations, mothers reported on their experiences with a few different categories of skills and behaviours.

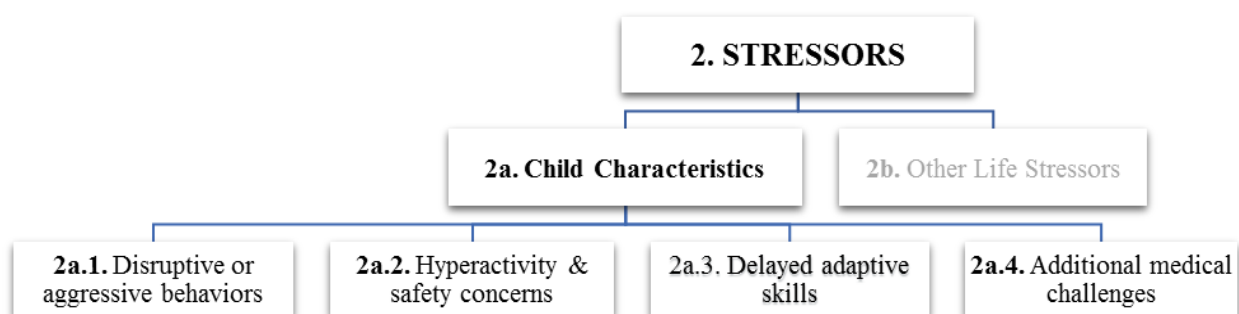


Figure 7. Coding diagram for Child Characteristics as Stressors.

2a.1. Disruptive or Aggressive Behaviours. Several mothers reported that their child used to (or still does) hit, grab or bite him(her)self or others around them. This was stressful for them to deal with. A Canadian mother (C3) reported: “*Well she’s had a lot of behavioural difficulties. Um, when she was in day care, she would bite. And usually when she didn’t get her way. Um, and she’d, usually when she doesn’t get her way or she, her anxiety level was higher. And uh, yeah, so if there was a change in her routine, someone did something that she didn’t like, she would bite that person. Or, she wouldn’t even bite the person that did it, she’d bite whoever was close. It was, it was an issue*” A South Asian mother (S10) stated: “*his behaviour was very bad. He used to grab my hair and uh bite me, nail me and um when we go out, he used to lie down on the floor. It was really hard. Once, in the middle of the road, he lied down and uh it was really hard. But uh time to time, he’s okay. And also, I’m getting services and I know how to deal with him.*”

2a.2. Hyperactivity and Safety Concerns. In addition to aggressive behaviours, mothers also described their experience with and concern about their child’s hyperactivity and impulsive

behaviours that would often put him or her in danger of getting hurt. In the subsequent section they spoke about the need to constantly supervise their child's safety as adding to their stress. A South Asian mother (S5) expressed her concern: *“Running away, jumping, climbing. Very difficult to look after him. Now, little bit reduced. Sometime, get hyper. He's a very hyperactive child. Uh, but he's not aggressive. He's very hyperactive child. Some behaviour little bit low, some behaviour little bit, like, up. Like, I can't say it's uh totally getting low.”* Another South Asian mother (S7) reported: *“Usually the kids um crawling bottom, here to up (while pointing down the staircase in the house), right? He, sometimes, try upside down. I put the gate and, but he knows how to move and then try move, everywhere. And then jumping, he climbing everywhere. And even now, he try to open the windows and the nets, pushing. And then the net falling down.”*

2a.3. Delayed Adaptive Skills. Besides these behaviour excesses, almost all mothers discussed the delay in development of adaptive skills including delayed communication skills, difficulties in social interactions, eating and sleeping difficulties as well as specific routines and rituals. These delays often meant that mothers had to do things for their child, even when they were teenagers and, at times, bigger than them in size. This added to their stress as it took great amount of additional energy to complete simple tasks or identify what their child needed. A Canadian mother (C4) described her experience: *“You know, like if he's sad, I'll ask: “How are you today?” “Sad.” “Why are you sad?” But he won't tell me. So I have to kind of guess, which takes a lot of mental because I have to guess most of the time. Like when he's sick, like when he does get sick, okay, I have to guess. You know, that sort of thing. So I'll ask him just basic questions. “Does your tummy hurt?” “Tummy hurt.” “show me where.” So he'll show me. “Does your head hurt?” “Head hurt.” “Throat hurt.” Like I don't know if he's just repeat, like it's a lot of, it takes a lot out of you because you have to kind of, you're coaxing him to get an answer, right?”* Some mothers discussed specific issues around sleeping and eating that required special attention with their child.

These challenges were not isolated and multiple difficulties were present in some families. A South Asian mother (S9) summarized her child's challenges: *“Actually, she doesn't have any life skill. Kind of, she doesn't like to brush her teeth, brush her hair and she got long hair and she loves to keep. Now it's short, she loves to, she doesn't love to cut. So uh take care of her hair and wearing clothes and changing clothes and toileting. Everything, all the time, I had to make um fight with her. “No.” First and very foremost, only the word “no”. Everything, nothing is positive. “No, no, no.” Each and every time. Only the thing, fooding, there is nothing no and even pick, she was very picky, everything, she will not have. Some of the selected thing she will have but she has no problem with fooding. But other things, no, no, no, no. Everything is no... Yeah, non-stop talking. So she, and just um, she doesn't um she likes kids. But sometimes, all of a sudden, without any reason, I don't know, she slaps them, she push them. Even though she sometimes the adult, she do it. Um, when we are using the staircase, we should say, hi, hello to meeting people. She just push them, she just slap them like this. And sometimes, she just um, coughing or... That behaviour I getting crazy. Oh my God. What can I do? I have to be inside the room with her.”*

2a.4. Additional Medical Challenges. A few of the children have comorbid physical and/or medical issues that further contribute to the challenges and stress. A South Asian mother (S3) whose child had seizures described her experience: *“they have both uh, both had seizures with fever when they were born. I think lot of children with autism have that and uh they, they would like, the first incident we didn't know what's happening. We called 911. Because he suddenly go, eyes were all rolled up and it was uh, um, like, uh, like, uh, all like he's like, I would've have normally thought he'd be dead or something. It's so scary. So we didn't know, like, they had so much of seizures with fevers. So that was really like a nightmare for us.”*

2b. Other Life Stressors

Besides child related stressors described above, mothers also reported other stressors that influenced their overall experience of raising a child with DD.

2b.1. Financial Burden. Both Canadian and South Asian mothers described different ways in which their family's financial situation was affected as a result of the changes that happened after their child was diagnosed with a disability. This often caused tension or stress to them and their family.

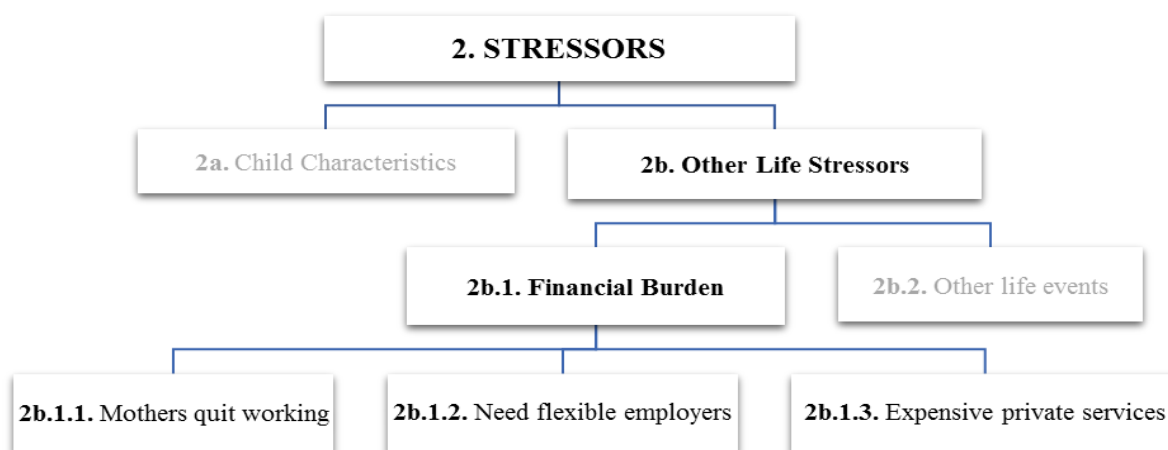


Figure 8. Coding diagram for Financial Burden as Other Life Stressors.

2b.1.1. Mothers Quit Working. A number of Canadian and South Asian mothers reported that they had to quit their jobs in order to take care of their child's needs. A Canadian mother (C4) described: *“Doesn't matter if they're mild, severe, moderate, that sort of thing. You know? You have to be able to put in 100%. That's why I gave up working. Because I wanted him to have some sort of normal life. You know? Because I didn't wanna, like if I wasn't here, God forbid, I didn't want to put him an institution.”* A South Asian mother (S1) expressed similar sentiments: *“when I moved here into this country, it was difficult to survive with single salary but we decided because we cannot, if I go work, I*

will not be able to spend time with her. I would not be able to um cope up with her schedule so we decided not to start working. Like, I will not work till the time she's in full-time school. So my, from till the time she was four, from four till the time she turned seven, first three years, I did not go to work. My whole routine was around her life."

This often led to a decrease in their family's income and many times resulted in an increased financial burden which increased their stress. A Canadian mother (C4) expressed: *"I'm lucky to have a family that helps me. Supports me financially as well because I'm not working, only my husband is working so it's hard financially to make ends meet and to provide help for him."*

2b.1.2. Need for Flexible Employers. Some mothers continued to work to support their family's financial needs, in addition to supporting their child. However they stressed the fact that they were able to manage this because they had flexible and understanding employers. One of the Canadian mothers (C3) reported: *"I'm lucky I work at *workplace because they're pretty flexible. But yeah you can't do things. I mean, she's 19 years old. She can't. She finishes school at 2:30 in the afternoon. Or she's home at 2:30. So I start at 7:00 am, I leave at 3:00 p.m. She has an afterschool, so you're still paying for after school care."* A South Asian mother (S1) described: *"So I started working only part-time. Four hours when she, like, I was going to work only after I am dropping her in the school bus and I am coming back right before the school bus reaches home. And um, once, um, we established that pattern and I was able to find a job, which is giving me all that flexibility, eventually, in the same company I was able to create niche for myself and I was able to tell them that if you need more hours from me, I also need more money. So, give me home access. So still I am working around here... And they were, they were able to understand my situation. And from that day onwards I am working half-time home, half-time office. Sometimes if she's having tantrum I stay home the whole time."*

2b.1.3. Expensive Private Services. Besides the basic change in the family income, a number of mothers also expressed their frustration about private services being really expensive

and adding to their difficult financial situation and stress around it. Mothers often described having to prioritize their child's needs over everything else when managing their finances. A Canadian mother (C1) described her dilemma as: *"I know that if we had more money we could have more service, for sure. Yeah, either privately, there are few things that I would like to be doing right now that we're just not doing because we don't have the funds for"*. South Asian mothers also expressed similar concerns. One South Asian mother (S8) described prioritizing her child's needs: *"So that thing um that, it covers five months uh the funding. Three days, two hours each session. So I saw these five months, *Child changed. *Child changed. So I decided uh when the funding finished, fund finished, I decided to continue. So I squeeze my expenses, whatever I wanted to do. Um I stopped, I wanted to visit my country to see my mother, um, but um thinking about her treatment um I just gave up. I sacrificed myself. Um yeah, but that funding helped me to find out. If I didn't get the funding, I was not um interested to carry on the therapy...Individually, if I, I, I was not able to start. It's expensive treatment. Each hour, they charge a lot. I know some of the people are rich, they can afford it. For me, it was not easy and still it's not easy."*

2b.2. Other Stressful Life Events. Besides the financial burden that families often experienced, other events within their lives may also cause additional stress for mothers.

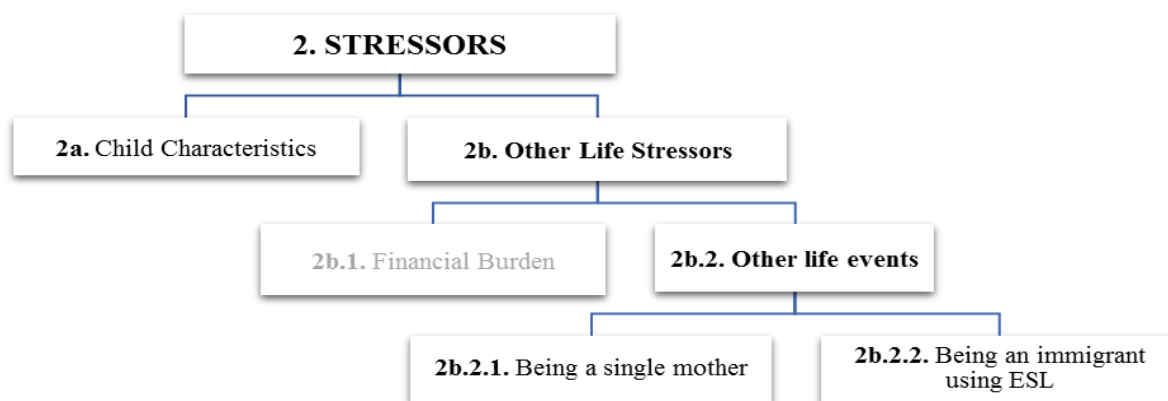


Figure 9. Coding diagram for Life Events as Other Life Stressors

2b.2.1. Being a Single Mother. One Canadian and two South Asian mothers who were single parents described their struggle to be exacerbated due to the absence of a partner who supported them. One of these mothers (S10) described: *“also I’m a single mother, I’m, I don’t have any income. I wasn’t able to get car. I always go on the bus. It was really hard.”* A second single mother (S4) reported that she had to go to school in order for her daycare subsidy to be approved by the government: *“I start also school 2 years ago. I, morning time I drop my kids in the bus and I go my school and I half-day I go to school because my, I no go to school, otherwise subsidy say don’t give me subsidy for day care. And I very needed day care because sometime I take for *Child in the hospital, sometimes I take my daughter diabetes clinic. Sometimes *Daughter go to [agency]. Who pick up my children? No somebody home because worker coming seven o’clock and bus coming four o’clock.”*

2b.2.2. Being an Immigrant and using ESL. Some Canadian mothers were thankful that they did not have to navigate the services system in a new country and with English as a second language. One Canadian mother (C1) expressed: *“I mean I also think that I’m very, I also feel that I’m fortunate because I am English first language and I, you know, I’m a fairly educated person and I have some experience working in government so I have an idea of how the system works. I don’t, I can’t imagine how you would navigate this without those things.”* In addition, several South Asian mothers described that challenges they experienced as a new immigrant or someone who speaks English as a second language. One of the South Asian mothers (S3) described her process: *“Mostly when you go for school meetings, like, um, my, my, I always don’t go alone. I go with my husband plus a, um, a social worker because there someone else who will listen to the same things the principal or the teacher is saying and they know the rules of the schools, they know the system. So we are not aware of anything because we just experienced, it’s new for us. But uh I go with her. That lady is a white lady so she, um,*

she had a son with autism and she went through the same steps. But it was easier for her because she's um, not Asian. Like she's uh white and she's strong and she, she can talk. She knows about the system."

In addition to these stressors, a couple of mothers expressed experiencing systemic and, on one occasion, explicit racial discrimination that added to their stress. With this regard, the South Asian mother (S3) above elaborated: *"if I go by myself, then they know I am Asian and they wouldn't like um, I, I know they do their best to help but they know that if we say no, she will accept it. She wouldn't push it. She wouldn't go through too far. But even I go with her or I know that, someone, they would, they would be afraid of her. They would not say anything that's not, not in the laws or not in the paper...So I, I feel like um Asian community, like, still they, even though they try to do their best, they would try not to go out of their way to help if you're Asian. That's what I have experienced and it's sad. But it, it's, that is the truth. When I go with her, I, I am more comfortable and I know that they would not say something that's not right."* Another South Asian mother (S4) experienced explicit racism: *"I go to my kid's doctor first and his secretary I'm [South Asian] and I talk to her and doctor, doctor say why you talking to this lady because this lady Muslim. He come to your home and he put the bomb. This one not fair. No every Muslim is bad...Sometimes people no accept because I'm Muslim. And some people so nice. Some people don't care I'm Muslim. Um, Muslim people, I have a single something, people don't care. I'm living alone, don't care. Some people so nice and some people don't understand."*

Unfortunately, the quantitative measures were unable to capture some of these experiences in their true form. The part of the questionnaire measuring other life stressors was basically a total tally of other possible stressors instead of actually measuring what aspects of these listed stressors or events might have contributed to negative or positive impact or to what extent did they influence parents.

In the presence of the stressors discussed above, several personal and family resources as well as formal and informal supports may influence the positive and negative impact mothers

experience on their journey of raising a child with DD. I will describe mothers' reports on these resources and supports in the following four sub-sections.

3. Mother's Personal Resources

3a. Self-Efficacy

Both Canadian and South Asian mothers discussed in detail how they dealt with the challenges they experienced in teaching and taking care of their child with a disability. Interestingly, even though self efficacy was not found to be a significant predictor of positive or negative impact in the quantitative section above, most mothers that were interviewed discussed their confidence or self-efficacy as being variable depending on their child's changing needs. Both groups described how they advocated for their child, but Canadian mothers discussed multiple roles that they played in their child's life in much more detail.

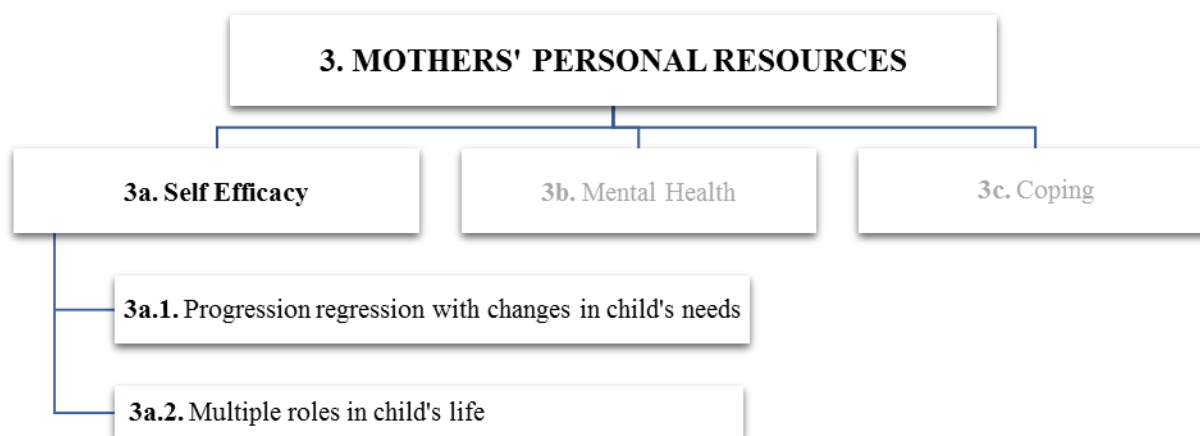


Figure 10. Coding diagram for Self Efficacy as Personal Resource for mothers

3a.1. Progression and Regression in Confidence with Changes in Child's Needs. Both groups of mothers related their confidence in being able to support and help their child as a

journey on which their confidence ebbs and flows based on the child's changing needs. A Canadian mother (C1) explained: *"I would say that's been an ebb and a flow thing because at first, yes, I didn't know what to do, I was completely, I just was at sea and I felt at a loss. Um, at the same time I felt that I understood my children better than anyone else... Um, but initially I thought I knew nothing, then after a short period of time I thought I knew everything - I was completely wrong. I only knew a little bit, so it's like, and also as the kids have developed the new challenges come up... you know I had been feeling pretty confident and then sometimes he would go through changes and then there's this short period of time of "oh my gosh" and then you have to, after a while start to feel more confident again and then you know, so I, it is difficult, it really is difficult. It's up and down."* In addition, South Asian mothers described more specific incidents where they felt successful in helping their child and other times when they did not. One South Asian mother (S1) shared a sense of success: *"Before commonly, we don't do certain things. After I went to classes, because I learned certain things, even if I apply them, he only takes it in sometimes. Sometimes, more than me, if someone else tells him, he'll do it quicker. For example, when we go to [South Asian agency], sometimes he'll enter, sometimes, he won't enter. We stand there and have a hard time sometimes. At the same time, if a worker or volunteer comes, they'll trick him and somehow bring him in. So, the way we tell him or speak to him is the key as well, I think. Even if I know how, it is only a success sometimes."*

Despite the ups and down in their confidence in being able to help their child, mothers reported knowing their child well and accepted their child as he or she is. One of the Canadian mothers (C1) expressed: *"we find with, it's really more like a circle with him because he'll go through period of times of being learning and then not, kind of progression, regression, progression, regression, progression, regression. So, you know, you'll make a little headway and then you'll lose little bit on the back end. So you really have to be willing to flow with that and I, I don't think I have - I have tried not to have too high expectations and tried to establish for him like a sense for him that whatever he can do is*

going to be okay with us. You know? That like we're, we're just kind of supporting what he's capable of doing."

In addition, mothers from both groups also reported additional challenges that they overcame or are trying to deal with as their child entered his or her teenage years. A Canadian mother (C4) of a teenage boy reported: *"Plus, he's also got the hormones going at this time. You know, it's kind of up and down, up and down, up and down. Because you know like, teenagers, they're really cranky all the time. But you know, he has moments. He has his moments...he'll be very stubborn. Very stubborn. That sort of thing. If I want him to come, then he'll just like, hold his ground and he won't move."* A South Asian mother (S1) reported a similar experience: *"now, she's becoming teenager. Although I was still, four months back, I was very, very worried about her teenage, how she's going to learn, how she's going to cope up with her periods. She has coped them up very nicely. So my next worry was her sexuality because I cannot talk to her because she's mentally only six years old. So I cannot talk to her about sexuality. So, it is still a worry for me and I am trying to work on the resources."*

3a.2. Mothers Played Multiple Roles in Child's Life. Mothers in both groups reported multiple roles that they had to play in their child's lives, A Canadian mother (C5) described: *"I've grown in a different way. I'd never thought I'd be doing this. I never thought I'd become a therapist, a teacher, a doctor. You know? And on top of that, a mother. You know? That's what, I became a lot of people for him. So I do feel, I'm more comfortable now. I know what my rights are, I know what I want. Before it's like, before it was, what, where do I go? Now it's like, okay, I know what I need for my son, I try to go and ask lots of questions so I've grown in the past few years. In regards to him, I feel more confident now, taking care of him."*

Both Canadian and South Asian mothers reported learning to be a strong and effective advocate for their child. They have had to coordinate their child's services and fight to get them the best services possible. A Canadian mother (C1) described: *"Finding the right thing, you know*

we were told: "No we couldn't have it, no we couldn't have it." Having to push and learning how to be like an advocate that wasn't going to offend the teachers in the school system. Like being able to stand up for him but not, you know, having to learn to temper how you feel and that's that's a real challenge. So that was hard." A South Asian mother (S3) also described needing to focus service providers on her child's abilities and advocate for appropriate services for him: *"then all these ten things, they would say that he cannot do. And I would say: "No, I know he can do it. He just needs some prompt." He needs a prompt. He's so independent. Because at the uh at the ABA, it's all independent, it's not independent, it's all directed. Like one-on-one, so this is like a whole new experience for him. So he needs the little push and gradually, he'll improve. So I was able to tell because I knew how he is and I knew that he can do it. So with uh with this experience, I'm able to become more stronger and I can fight for the kids, for their rights, for their whatever they need, right? Because every time they would say no and it's not right, because they need the chance."*

In addition to being an advocate, mothers from both groups emphasized the training and/or education that they underwent in order to be able to support their child's treatment at home. This training led them to assume the role of a therapist at home to extract the most benefit they could from the therapy their child was receiving, and/or as a monitor for the therapy he or she received from their in-home therapists and/or as a researcher who was able to weed through different treatment options to choose what is best for their child. A Canadian mother (C5) described: *"so luckily, in this day and age, you can go on google, you can research and see where you can take your child for extra, um, extra curricular stuff. Extra support...because of the [physical disability], he was hooked up with an OT, a PT...in the mean time, I took the responsibility, I took an ABA course from [agency]. And also that's another resource place too for children with autism, families with autism. I took a course to learn about autism first, first of all. Then about ABA and um, so now, plus watching the classes, the first sessions he had, I learned a lot as well."*

A South Asian mother (S1) described a similar journey: *“I have attended all these workshops, I have attended all these trainings of behaviour management and techniques...what I have finally realized over the years is now what the services are, no matter what they do, uh, it’s only you and your partner who have to actually um implement it. Like I paid for behavioural consultancy, hundred dollars an hour, she came here, she saw her behaviour, she made the whole plan. But what ended up happening is she will not be able to come and treat her or teach her behaviours. Because, behaviours can happen any time. So, we have to, like there’s still a long way to go between our own self and to tackle all the behaviours the way she wants us to tackle. We cannot, I won’t say I tackle all her behaviours that way.”*

3b. Mental Health Difficulties

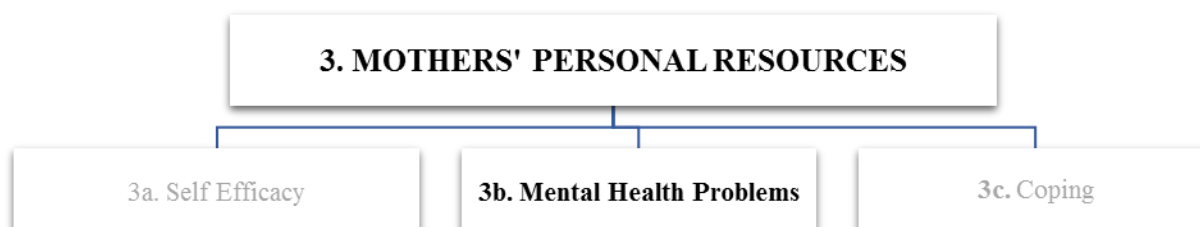


Figure 11. Coding Diagram for Mental Health Problems within Mothers’ Personal Resources.

Both Canadian and South Asian mothers named several mental health issues such as depression, sadness, anxiety and a feeling of helplessness and/or anger. They reported these mental health struggles adding to their overall stress and difficulties. A Canadian mother (C4) described: *“This past winter, I don’t know if it was just because of a long winter, um, I went through a series of depression. And, I went to my doctor and he did give me some pills for my depression but they did upset my stomach so I thought, I stopped taking them...it just got, it got to the point where I was just, I can’t take this anymore. But then I thought, if I did that, I would be selfish, because he needs me. My*

husband and my older son, they don't need me as much as he does." Another mother (C6) described her constant state of anxiety: *"I'm always on high-alert and I'm always anxious that I'm gonna get screwed over or that she's gonna get screwed over one way or another because that's been the experience."*

South Asian mothers described similar emotional struggles. Quantitative results demonstrated significantly higher levels of mental health issues in South Asian mothers compared to Canadian mothers. Perhaps, some of these aspects of their experience might explain this difference. One South Asian mother (S4) expressed: *"Sometimes I'm very – Helpless. I'm no nothing do. Sometime I cry. Sometime I cry. Again I see my two children face and then I stop cry."* Two of the South Asian mothers who had completed their graduate training and left successful careers to take care of their child also described an ongoing sense of depression that they think is related to their sacrifice. One of these mothers (S8) described: *"Sometimes, not sometimes, uh yes, most of the times, I get depressed. That what I'm doing, staying. Usually I used to work when I was in [South Asian Country] and here I did some work but uh about thinking *Child, I just sacrificed myself, stopped just um my side. Whatever I want to do, I'm not doing that one. So in that sense, I'm, I'm really, really depressed and uh sometimes in, in my uh country's people, community people, um they have different, like South Asian people, they, they think, they talk different, "Oh you did study, you're staying at home."*

Some of the Canadian mothers described physical health issues as well (e.g., high blood pressure, sleep issues, weight loss), some of which could be indicators of their overall stress and mental health problems. One Canadian mother (C3) described her sleep issues: *"It has affected my health a lot..I do take pills. I did. I don't anymore. To help me sleep, cause I need to wake up in the nights. *Child doesn't sleep. So when she wakes up in the middle of the night, I don't go back to sleep. My husband does. So I go to work bleary-eyed and everything like that but I used to take a pill and now I*

don't because if she wakes up I'm not in very good, so I just deal with it. With no medical, no medicine at all."

3c. Coping with Challenges

It is evident from mothers' reports that they lead a stressful life in which their child is their primary focus. Different people use different ways of dealing with such challenging situations to regulate the negative impact it has on their lives. In fact, based on the questionnaires, mothers from both groups reported stronger positive impact when they used positive coping strategies such as accepting their child's challenges, consulting people and getting help, planning and finding solutions for their child's problems, reframing difficult situations to focus on the positive, as well as accessing religious and spiritual support. When asked how they take care of themselves and deal with the challenges that came their way, mothers from both groups described several common ways of coping.

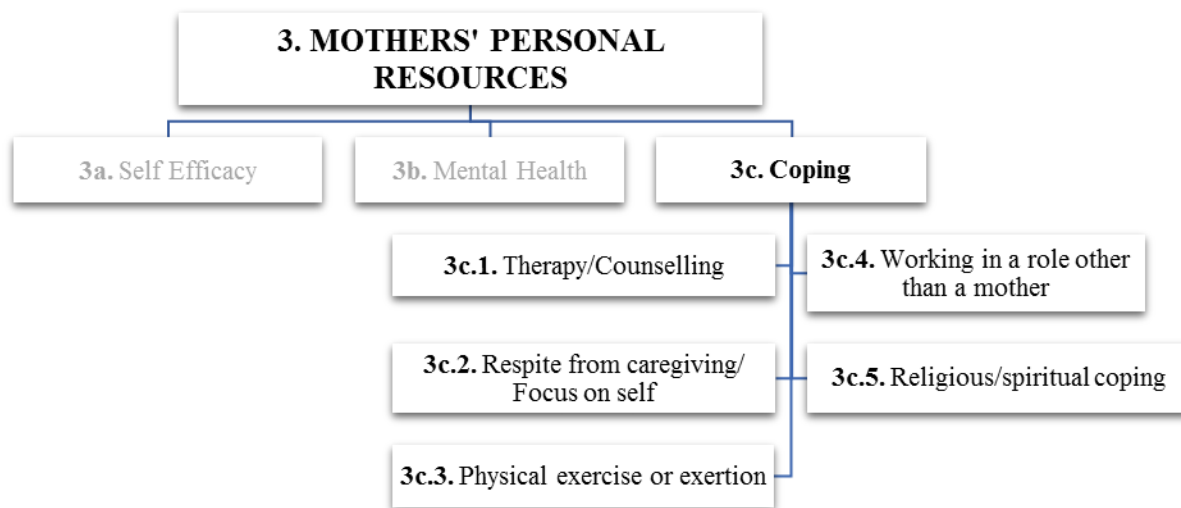


Figure 12. Coding Diagram for Coping as a Personal Resource

C3.1. Therapy/Counselling. A few Canadian and South Asian mothers reported that going for therapy was helpful for them to deal with the difficult feelings that they had regarding their child's difficulties and with their acceptance of their child's diagnosis. A Canadian mother (C1) reported going for counselling as a way of coping: *"I mean, well.. I mean... therapy and counselling has been really big. That's probably been the biggest thing that I've done. Um, yeah, that's probably thing I've done. Just kind of, because you have things in your heart that you need to get out because, but you can never say them, you have to say them in a specific environment, where it's like you can just put them in that closet and put them away but they have to get said and you have a right, you know, people have a right to those feelings. But, you know, those feelings would never be appropriate to give to other people. And not even really necessarily something you want to say. I mean I've had - I've felt a lot of anger about my life experience and you know, felt a lot of, you know, questioning: "Why is it like this?" and "What am I supposed to do?" and "Why don't I know what to do?" and you know, all of that stuff. So being able to vent that stuff in the right situation has been a huge difference for me."* A South Asian mother (S3) also reported: *"Um counseling too helped. I went for like five or six counseling sessions and when the counselor, she ask you things that you have never thought before and like that helped like mostly to be open to others. Like, I was not telling anybody at work about it. I was like trying to like I didn't want anyone to feel sorry for me. Or I didn't want anyone to ask questions. So I was like so like in to me, so that didn't help to heal, like you just um have to be open and little by little that helped a lot. Just to be open."*

C3.2. Respite from Caregiving/Focus on Self. Several mothers from both groups reported the need to get away from thinking about their child and focusing on themselves as important, as a way of coping with their challenges. Most mothers reported using at least one of these activities such getting out of the house and meeting a friend, talking to family or friends, writing their thoughts down, reading for leisure, doing some arts or crafts, or just being mindful or taking

a pause at the end of the day to relax their mind. A Canadian mother (C5) articulated the importance of this in her life: *“I said: ‘You know what? I have to leave this problem behind for a few hours once a week.’ So I told my husband: ‘Look, I’m going to meet my friend for coffee. And I don’t want to talk about kids, I don’t want to talk about ‘Did you know about this?’ I just want to go out, watch a movie. So at first, I thought, no, no, no, I’m his primary caregiver, I’m not gonna leave his side. I didn’t have much of a social life. Um, because I was scared no one could watch him as much as how I could. Even if it was my own mom. I would leave him maybe for two hours or whatever...But at the beginning it was hard. But now as I, when you get more comfortable with the situation, I can leave him alone. And that was the hardest part, too. But to cope, you need time for yourself. Everybody was telling me: ‘You need time for yourself.’ I said: ‘No, no, no, don’t. I’m okay, I’m fine.’ But you’re not fine. It creeps up inside you. It builds up slowly inside you until one day you lose it and you say: ‘Oh my God, I need to get out of here.’”*

One mother (C2) stressed the importance of being mindful and taking a moment to calm herself down: *“there’s nights I know, you know what? I need to calm down, I need to clear my head, I’ll just open the window and just do some deep breathing out the window. And I’ve told all the neighbours I’m not staring at them, I’m vegetating, okay? I just need that time. And, just try to relax and put it all out and say you know what: ‘We’ve got these issues on the table’”. And I put them on my little table upstairs so I visually have put the issues on the table. I am taking a minute for me. It doesn’t always work out because things are always on your mind.”*

Several South Asian mothers also described using some of these techniques as ways of coping. One south Asian mother (S8) reported: *“The thing is, specially, uh when I, when I talk with my family, close family members, it uh give me peace. Give some better uh feelings. So when I get time, I always talk with them and I, we do the Skype, use the Skype to communicate when I see them and uh and I like to read books. Books so uh when I get time, just I went through the uh E-book or try to borrow books*

from the library and watch some movies when I get time. I try to do that. I just, to get out some bad emotional things. It helps.” Some South Asian mothers also reported reading/researching about their child’s diagnosis and exploring intervention options as a way of dealing with their difficulties. One mother (S8) articulated: *“What to do next... it was just, really, unknown thing for me. So um they get lot of information, I started read lots of books... So that’s why I wanted to know that how she’s feeling? How her thinking working that time? So I started to read some more thingies um then I, I and some uh I read some of the books like uh those has, had the autism problem but now they are um recover. : Learned some the skills and they’re in uh regular life and they explain in the book their way. So then I understand, maybe I’m, I thought I understand, maybe I understand... So it uh these books and this type of information also helped me a lot.”*

C3.3. Physical Exercise or Exertion. Some mothers also reported physical exertion as a way of releasing some of their frustration and focusing on something productive. Canadian mother (C4) described: *“I go to the gym a lot. Well, I haven’t been to the gym for a while but I, after I drop him off at school, I’ll go to the gym and I’ll work as hard as I can. Just to get my frustrations out. This summer I had big [DIY project involving physical labor]project... And um, people go: “Well, doesn’t it take a lot out of you?” I say: “No, it doesn’t because when I’m doing that, I don’t think about anything else. And that’s what I need. That’s what I need... Because if I don’t focus on one specific thing, then my mind is going everywhere. And I can’t calm myself down. And then I’m up all night. I’m all night and I’m thinking, okay, what could this happen. What could this happen. What could this happen. You know, that sort of thing. So I need a project that I can do that’s gonna take my one focus, right. And it’s keeps me on the straight and narrow. So to speak.”* A South Asian mother (S10) also described using exercise as one of her coping mechanisms: *“Uh do some yoga. And uh the, but, the thing is, not regular but every mother have to do, I think, exercise. So, um, this uh exercise and yoga and even God, pray to God, so this is the thing. And uh never feel down. Always feel confidence.”*

C3.4. Working in a Role Other Than a Mother: This was a coping mechanisms that was not covered in the quantitative measure, and perhaps helps in providing mothers with a positive sense of self and a sense of control within a different environment. A Canadian mother (C2) also reported using work as a reprieve from caregiving, where she can interact with adults as someone other than a mother of a child with a disability: *“its not like I'm making money from it and I'm working but it is kind of social, you know, there's other people around and you've got your mind off the house and the kids...I'm a co-worker. One that some of the girls asks questions or the boss depends on me for certain things. But, my cell's in my pocket.”*

C3.5. Religious/Spiritual Coping: Eight out of the 10 South Asian mothers reported turning to their religion or faith as a mechanism for coping and attaining a state of calmness, whereas none of the Canadian mothers did so. South Asian mothers used religious/spiritual coping in two different ways. Some mothers explained their journey of having a child with a disability as destiny or God's careful plan such that they were given what they could deal with. One South Asian mother (S1) who decided to finally move to Canada after her child's diagnosis described her journey: *“For me, sometimes I do believe in destiny. I do believe in God. I actually believe that um it was all done in a way, it was all presented in my life to me, like, I'll never, after I finished my graduation and my degree in teaching, I never wanted to go for further education. But, I don't know. Somehow I wrote an entrance exam and I got through it. I'm like, okay, now I get into it, so let me just finish this course. Because it was more than ten thousand people sitting for that exam and only twelve got selected and I was number twelve. So I started this course in Masters in Child Development. So I did for two years for post-graduation. And then when the choice came to, to choose between the early child education or the special need, I went for special need. So I got all these expertise, education in hand and then I got married and I realized that my in-laws, they don't believe in working. Ladies working, like woman of the house working. So I'm like, it's okay, I will start volunteering and I volunteered in [South*

*Asian Country] too. Then she was born and um, before her birth, I got the immigration. Cause I wanted to move and in the meanwhile, by the time the immigration came, I was pregnant and I stayed back. So I'm like, I got the expertise, the education, immigration, everything, before. Before God gave me *Child to bring her up. So, it's all, it was in our destiny...So I like, for me I think it's all, God all planned it for me. So he chose us to, to bring her up."*

Another mother (S2) expressed her faith: *"same time I do therapies and then also I go to the temple, I go to [South Asian Country], this and like and you know how the Hindus do that, like you know? We do that too. And then also, I did it when he was seven, seven years old. I went to the temples, so like, I don't say like its oh, this is the thing. Like all those things, I will say. Yeah. Because like, I always believe in like okay, the God, he gave me this therapy. That's how I got it. Because we staying there. How many people, even if we like it, he like it, sometimes they can't do it. It doesn't work it out, like you know?"*

Other mothers surrendered to their faith in their God/Allah. They arranged for all the necessary services for their child(ren), but at the same time believed that it is in their God's hands and He will help their child if they have faith in him. One mother (S3) expressed her faith: *"Mostly, I believe in, in the God and I pray to God. So that, that's like a comfort, I know that even though we're going through this difficult time, God is looking at us and God will look after us. And um, so only that is the only comfort I have... no how much people to talk to you, still you feel really down. You're not going through that and you don't know how hard it is. So like, if, when you, but when, end of the day, you just say "God, I can only do this much. And like that's all like I can do. And everything else is in your hands." We just do what we can."*

Finally, a South Asian mother (S6) expressed that her faith, patience and love will help her child improve: *"I just pray to God. Like you know, I just put his hand, I just always tell him, like you know, I'm putting my son's hands in your presence, just please heal my son. Because I know, doctors cannot do anything. Only He can do. Miracles can happen, right? So I, there is hope, so, even that priest*

told me: "Don't worry, just have hope in your child and that's it. Faith, patience, hope." The more you have patience, the more faith you have, and this child just needs love. That's his medicine. Doesn't require any medication...Just love him and have faith in God. That's it. And talk to him. The more you, that's your medicine. Talk to him, love him and pray to God. These are three things he told me to do. And I do all those three things, yes."

4. Family Resources (Family's Adaptation to Child's Diagnosis)

As discussed so far, raising a child with a disability comes with its challenges, and mothers report experiencing a mix of positive and negative impact as well as positive or negative days as a result. A South Asian (S1) mother commented: *"see on a typical day as a typical family, we, we are very positive about it but there are days when, see, when you're upset, you don't think what you are saying. And you, you say things which you should not have said but those things happens but then we realize it very soon that this is not what reality is like."* Often all other family members adjust and adapt to the needs of the child who needs extra care and attention. Each family adapts to these changes and readjusts its dynamic and functioning in an attempt to achieve an equilibrium. A Canadian mother (C3) gave an example: *"You can't have people over to your house, your house looks a lot different than other people's houses because of the, of things you have to put in place and uh, you can't do things, we, I mean, she's 19 years old, I can't leave her alone. My older [child] has to put her on the bus in the morning if she's around hopefully and if she's not I'm gonna have to do it... I mean I guess you'd think when the child, when someone's 19, you're free and clear, as we were with my older [child] but um no. That's how it impacts us the most."* Mothers from both groups highlighted some of these changes that their families underwent.

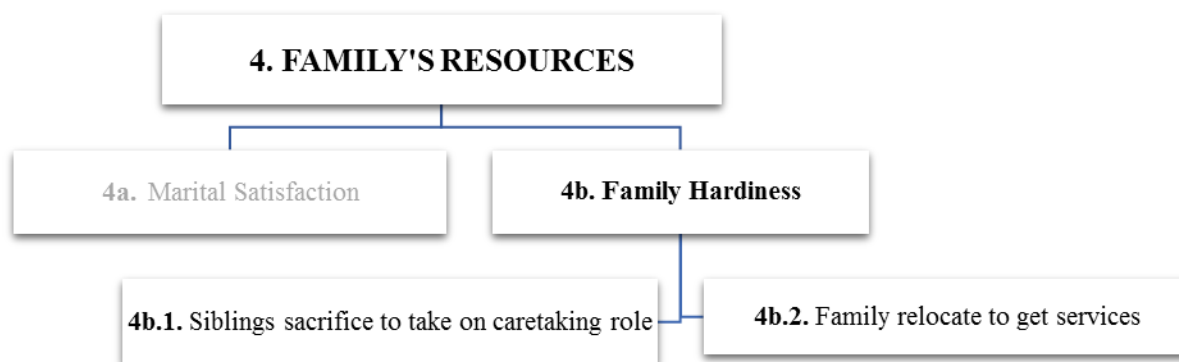


Figure 13. Coding Diagram for Family's Resources

4a. Marital Relationship

Mothers from both groups generally reported a change in the dynamics in their marriage. They described the challenges they had to overcome and at times went for counselling in order to help them improve their relationship. A majority of parents were able to work through the challenges and stay together. They reported their marriage as becoming stronger over time, and that being with their spouse helped them in dealing with the stressors related to raising a child with DD. A married Canadian mother (C1) described: *“It has certainly been a challenge and it has been, you know, within our marriage it has been a challenge. I mean, we, we have done, what we have done is we each did individual counselling and we also did counselling as a couple. Um, and so we've learned a lot about ourselves...I'm proud of the fact that we're still solid and together and a large part of the reason why we stuck together was because we knew that they really needed us to.”* South Asian mothers who were married also reported similar experiences. One of the South Asian mother (S3) reported: *“my husband, he's a support. He will drive us to anywhere we want and um he's, he's always there. Like lot of marriages don't end well when they have children with disabilities. So um, like*

it's always good to be like to have someone." Another South Asian mother (S1) described: *"I think I have, I am more closer to my husband"*.

For some families, dealing with the daily challenges took a lot from the individual parent and from the family, and the parents drifted apart and separated. This dissatisfaction with and at times separation from their partner added to the stress experienced by the mother, A Canadian mother (C2) expressed: *"I think as a couple, whether you're married or not, you, you need your date night. I look back over my 28 year old marriage and a date night would have been nice. It would have helped maybe gel things. We drifted apart, there was no yelling, no screaming because we had no communication. He did what he wanted and I was home with the kids. So I sunk myself into it – it's like oh yeah, okay."* Another South Asian mother (S4) who was married as a teenager to a much older man from a traditional family, explained the lack of support from her husband: *"my husband don't understand. Now, totally my husband don't understand. Like this, I keep it nice somewhere, I pen keep it somewhere. My husband say: "Why you keep it?" Like my husband come in, *Child play the iPad, computer. My husband does, same time my also want to computer. I say: "Now *Child play, can you play laptop?" My husband don't understand. That's why, husband no fighting with me. My husband don't understand my kids. That's why, my husband say: "You enjoy your life. I enjoy life." That's why I don't interfere."*

4b. Family Hardiness

4b.1 Siblings Sacrifice and Take on Caretaking Role. More often than not, mothers described that their immediate family members (spouse, parents, other children) united to share responsibilities and support the child with DD. Some mothers from both groups also described instances in which other children in the family sacrificed or modified their needs in order to accommodate the needs of their sibling with a disability. These siblings also assumed a care

taking role when needed. A Canadian mother (C4) explained: *“because I devoted so much of my time to him, it kind of affects my other child, you know? And I’ve actually had to sit with him and say: “Look, its not that we love you any less than your brother”, but I said to him, “You always succeed.” I said: “You need some guidance, but you don’t need the same guidance as your brother does.” Right? I said: “Look at all the stuff that you can do, that your brother can’t do. You can go and walk to the mall by yourself, whereas your brother can’t. He will always need constant supervision. Not constant, but I mean, he will always need someone there to guide him. That sort of thing. You know?”* A South Asian mother (S2) described: *“then also, like, my, my oldest son too. Because he’s, he’s supportive but he’s never fight or like... Sometimes, like you know, for the computer, they fight. But he wont, he understand. So only one year older than him. He understand, he doesn’t give me that much trouble. Now he’s volunteering here at [South Asian agency] ...So like he understand”*

Another South Asian mother (S8) explained how her younger daughter also supported her older sibling: *“*Child always gets the priority. Whatever [sibling] wants, I try to give her. She doesn’t, but she’s [sibling] 11 years old so I talk with her that mum, maybe just for the, for few years, everything will be okay. We’ll be well adjusted, we have to just help each other. And she also, when the therapist come here, she sit here or uh I stay in the kitchen to learn uh how they’re working. Because uh they’re only coming 2 hours or weekly 4 hours. So it’s not enough. So I, if I know the techniques or strategies, it uh, I can implement every day. She also know some of the uh yeah techniques. So I will requested her, something like that. Oh, just learn something, maybe you help. You know she likes you. That’s the way I try to involved her too. Though she’s 11 years, but I try to. I don’t know, inside, how she’s feeling, but she, she helps.”*

4b.2. Family (or members) Relocate to Get Services for Child. Canadian mothers that were interviewed were mostly from urban and suburban areas of Toronto and did not report necessarily moving residences to get better services. They advocated for their children to get the

best services possible in the region they lived in. One of the Canadian mothers (C3) reported having a vacation house that they like to visit as a family when they need to relax. She reported that one of the parents might retire and stay there with their child while the other travels back and forth: *“One of us will retire there and the other one will visit. So it’s really impacted your life. I mean you can’t do things that normally other people do.”*

On the other hand, several South Asian families either moved to Canada or travel between Canada and elsewhere so their child continues to receive optimum services here in the Greater Toronto Area (GTA). One of the South Asian mothers (S1) reported that they had completed their immigration process for Canada, but actually decided to move so their child could get appropriate services and supports: *“I was an immigrant just before she was born...But I never decided to move because I had a very small child who was going through challenges so I decided not to move to a different country all together and raise her up. So maybe I thought I need my family support during this time. But when I got the label, at that I decided that um raising a special needs child, living in [South Asian Country] will be okay for me, for my family, for my support but it will not be any good to her because there’s no, there’s hardly any resources there. And whatever they were, I already um tried to see, it was all um money that talks and even if we have money we can keep maids for her who can look after 24/7 even if she when she’s at school. Um, I can just, she can just sustain. She will not learn. So we took a decision of finally migrating but since in these three years we always were coming here to get our immigration status done, so we were able to come back here for permanent stay.”*

She also reported moving neighbourhoods within the GTA in order to get the best possible team for her child: *“I don’t mind, I’m not, I don’t mind living in any neighborhood as long as the school is good. I have done it earlier when we were living in rental accommodation.”* Another South Asian mother reported moving and requesting her husband to also move with her: *“Then um like this, we uh started doing this and that time my husband helped me a lot. He had job and I told him that if*

you and he was at that place, he was not with me. I requested him: "If you have to be with me for the kid's betterment, then you have to resign yourself." Otherwise, I cannot contact, I cannot manage this all. You cannot, so it's better, until or unless you just leave your job and you just be with us and follow the doctor's suggestion." In addition, a mother (S2) who lives in the GTA with her son, while her husband works outside Canada and visits often reported that they decided to do this as a family since her son was already getting services here: *"for my husband I'll say, like, because he's not here, he comes mostly every week...So like, financially, cause I don't have to go to like a full time job or like kind of thing."*

5. Formal Supports & Services

On their journey of raising a child with a disability, mothers try to access the best available formal supports and services for their child and family including assessment, treatment, case coordination, services within the school system. However, as reported earlier, Canadian mothers focused more time on talking about different services they knew about and that their child received compared to South Asian mothers, who spent lesser time discussing services. Regardless of the number of services they knew about or had access to, mothers from both groups reported spending a lot of time and energy on advocating on their child's behalf to get the most appropriate services for their child. Based on mothers' responses on the questionnaire, there was no significant difference in the helpfulness of formal social supports between Canadian and South Asian mothers. Both groups highlighted and emphasized their frustrations with this process and the current service delivery system, while also appreciating some of the positive experiences they have had with services.

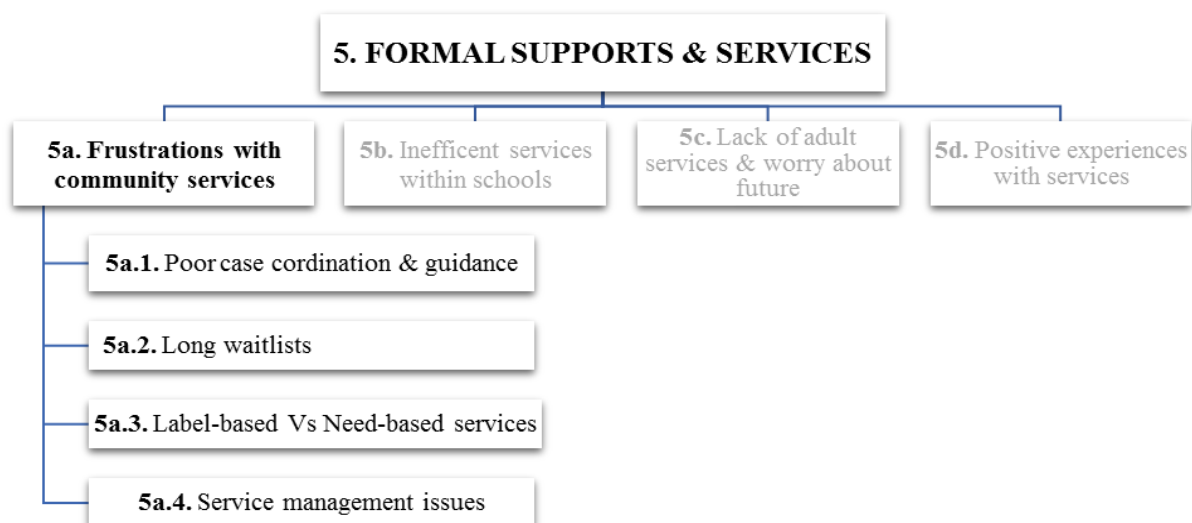


Figure 14. Coding Diagram for Frustrations with Community Services within Formal Supports

5a. Frustrations with Community Services

5a.1. Poor Case Coordination and Guidance. Mothers from both groups expressed their feeling of being lost and not knowing what to do after their child received a diagnosis, as described earlier. They felt that they were handed a list of things to do but were not supported or guided to navigate through the service delivery system. This lack of service coordination and support seemed to have been common throughout their journey until the present. A Canadian mother (C6) articulated her anger: *“And here’s where the problems start. Because when you tell, when someone says, well there is a delay but we’re gonna refer for a global assessment, you’ll get a phone call from [hospital] to book appointments and all this jazz, all right, you’re thinking okay, we’re going to get on top of this, right? So, you think you’re gonna get the help that you need. Right? Like I pay my taxes. So, you know, this is a healthcare issue, and then you find out you’re on your own... Cause I left that session, uh, being told that she needed some help, not knowing what kind of help but with a list of private [therapists] that I could hire in the mean time, while I’m waiting for help... every time you’re going to through a step, no one wants to tell you. You know? It’s all wink, wink, nudge, nudge, here’s a paper, you*

need this help. So I said, well, before I hire a [therapist], I don't even know how to start. How do I start? How do I interview them, how do I know they're qualified? How do I know I'm getting the type of [therapy] that I need for what she has, which no one really wants to tell me, wink, wink, nudge, nudge."

Several mothers (S6) also emphasized the need for service coordination right after a child receives a diagnosis: *"I'm telling you, from the beginning, when you go to a, when you get, when you think something's wrong with your child at the very beginning, that's where someone needs to step in...Because they miss you there and you're alone for the rest of the ride. Right? So whether, whether they pick you up 6 months or 8 months or 9 months down the road, it doesn't matter. Cause you're already twisting in the wind. Right? You need someone to help you from day 1, I think."*

5a.2. Long Waitlists. Almost all mothers also discussed the long wait times for getting services in the public system. At the same time private services are expensive and mothers reported feeling trapped and helpless about not being able to get their child services in a timely manner. A Canadian mother (C5) expressed: *"So that's the hard part too, finding therapists that will work with the child and if it's with the government, it's a huge waitlist. If you go private, it's expensive and you can have it right away. So the waitlist, that was very hard on us. Waiting for services. That was hard. So we paid for private, um, therapy. So we had an OT and a PT work on him...and um, so then, once he picked that up (in ABA group), that was only three months long. That class. Short sessions. Once that session was over, I said: "Okay, when does he come again?" "Oh, he has to go back on the waitlist." I said: "Oh my goodness." Like okay, so that was devastating for me. I wish he can go back in six months, or whatever. He goes: "There's a huge waitlist." You know when he went back again? ...Two year wait."* A South Asian mother (S6) described similar experiences with wait lists: *"So, we came when he was 2, or sorry, 1 and a half. So then he was on a waiting period for a longer period. I feel that was the time where he lost most, because he was on waiting for more than one and a half years"*

5a.3. Label-based Instead of Need-based Services. Most government funded services in Ontario are based on the diagnosis or label that the child has. This has resulted in niches of services that are provided to particular diagnostic populations and often do not overlap with each other. According to some mothers in both groups, often their child with more a severe presentation or with comorbid diagnosis was unable to get services tailored to his or her specific needs. Mothers from both groups expressed their dissatisfaction with the services their child received. Some felt that the system uses "cookie cutter" ways to provide services based on child's label or diagnosis and doesn't always take into account the individual needs of a child, especially when children have behavioural or medical issues. A Canadian mother (C3) expressed: *"it's been difficult because she is an aggressive child...It's always a problem finding childcare and before and after school care. There's not a lot of things out there."* Another Canadian mother (C6) described: *"what really kills me is that by the time you find out what she has, you realize, if you've done your research and you've started paying these professionals... It's the same darn thing. They give the same type of [therapy] to everybody with a developmental delay. No matter what the delay is."*

Often diagnostic or service delivery decisions made by the agencies are not communicated well to the parents. A South Asian mother expressed her frustration with the service system where his son was denied IBI because he was on the severe end of the autism spectrum. According to this mother (S5), this decision wasn't explained well or alternatives were not given: *"So she put for the IBI waiting list, my child's name. But they said: "No." If it is waiting list also, they have to take assessment after, like, six months. After that only they will tell whether my child is eligible or not. So we keep all the hopes for this IBI. We know, like, doesn't matter. However my child is ill, definitely, once he got the IBI, we know he will recover. Then, till that time, he's going to the special*

school. Like he's in senior, sorry, senior kindergarten. Senior kindergarten. Finally, they said: "No, he's not eligible." So it's very unfair, they have given very unfair reason. On that time, I'm just giving my child therapy, like IBI therapy...So we fight. Yeah. We fight a lot. And uh, finally, third time also, they're telling they're not going through... The third, the second time they have given they said: "He can't, like, you know that he's a little bit severe autistic kid." He said: "This IBI program not benefit for him it seems." This is what they said. But no one can tell whether child is benefit or not without, like, within an hour, no? They just checked the child in an hour. How they are going to tell that he's not benefit or not? At least they have to give this for six month of period."

Another South Asian (S4) single mother with two children with severe behavioural difficulties reported being told that she herself should be able to help her son: *"Sometime helpful, sometime not helpful. Now like this, my kids is uh damage clothes. Three time [agency] therapist come in, still my son, still he do damage the cloth and um last time this therapist come his clothes last week. She said: "I'm no possible. You can do yourself." I'm not a therapist. Therapist give me idea, I can try."*

In addition, a mother (C5) who had a child with ASD and a medical condition expressed her frustration with the lack of resources for children with multiple physical and developmental diagnosis and reported that she often had to choose what to focus his services on: *"Because it's hard with a dual diagnosis. Where does the CP end? Where does the autism begin? Vice versa...they said he doesn't qualify for IBI. He will be doing ABA services. And I said: "All right, no problem." I accepted it. I said: "Why not IBI?" And they said: "Well, I don't think he can handle a full day of therapy" and because of his of his CP, because he's in a wheelchair. Cause he needs a lot of care...what I am disappointed in is the resources for children with CP and autism. I wish there was more...not a lot of combination for him so it's either or. And then too as a parent, I came to realize at age about 5, 5 or 6, I said to myself: Where am I going to dedicate most of my resources? Towards the physical part of it or towards the communication, the autism."*

5a.4. Service Management Issues. Some mothers in the Canadian group expressed their frustration when they have to provide the same information to different people over and over again since their child often receives various different services in different agencies. A few mothers from both groups highlighted issues with the way services, health information and funding are managed by the government and service providers. One Canadian mother (C1) highlighted the lack of flow of health information between professionals, and described being frustrated by having to repeat herself over and over: *“it was stressful finding the way, especially initially, it was very frustrating because having to tell the story of like my pregnancy, my birth experience, how the - over and over and over again, at length. And there was no kind of constant, there was no transfer of that information to other professionals and it seemed to take so long before I was able to actually get to the, you know, being able to state what I wanted, it was very frustrating in that way”*. A South Asian mother (S7) described another aspect of a similar issue. She described how a constant change in the direct worker leads to challenging behaviours since the new workers are not aware of her son’s challenges and how he deals with them: *“sometimes, uh, now, the Tuesday one person and Thursday another person. It’s maybe, he wants to learn the new people. Different, different people meet, it’s sometimes means they don’t know what he knows and what he doesn’t want or what he does. That’s the problem, something happen. And today also, it’s a bit, because he’s new. I don’t know what’s going on.”*

In addition, a couple of mothers described their exasperation with the way government funds were utilized within the service delivery system. They felt too much money was being spent on administrative functions and not enough was reaching children who could actually use it for therapy. Along these lines a Canadian mother (C6) expressed: *“So then you find out the ABA is done by one agency. The IBI is a different agency. The speech therapy is a different agency. And the occupational therapy is a different agency. Are you kidding me? That aside, okay, do the math. You got*

*four agencies here, right? Four HRs, four CEOs, four, you know, times everything! Four times four times four. Well no wonder I'm on the waitlist for 18 months. Oh my God. Or like, seriously? Like, it blows my mind. So then, the anger sets in, right...You know, because how could this happen to my kid, right? But then, to get slapped in the face from 4 different agencies, you know? All sucking up the money that's supposed to be going to your kid. I gotta tell you. *Child is, turns [years] old in [month]. She got, maybe, out of all that, she didn't get uh one hour of occupational therapy itself from [hospital], because by the time her name came up on the waitlist, she was in school and so as soon as you're in school, not pre-kindergarten but kindergarten, then it goes to uh [agency] in Ontario. You know who [agency] is? Community Care Agency Number 5, right?"*

5b. Inefficient Services within Schools

Mothers from both groups also described their experiences within the school system. They expressed their frustration with the extreme variation in quality and quantity of services for children with any kind of DD within the school system. A Canadian mother (C1) reported:

"beginning of school was very challenging um because there is such, there's such a fluctuation in what is available where, you know... the idea of the community class...is that there is like a small ratio. So we that it would be ideal for him, we found one um - he did okay the first week. The second week he started having a lot of behaviours. The teacher called and said you know, if he keeps doing this he can't come back. I was, I had no idea what to expect. Well, I have come to realise after experience that this was a terrible community class. Really, badly managed, the teacher was not, it was her first year doing it... we didn't know at the time, we thought this is how it was and now having experiences with better classes, we see that in fact, it's very sad that he had such an awful first year, it was terrible and it took him such a long time to recover from that" Both South Asian and Canadian mothers pointed out several specific challenges they and their child had to overcome within the schools.

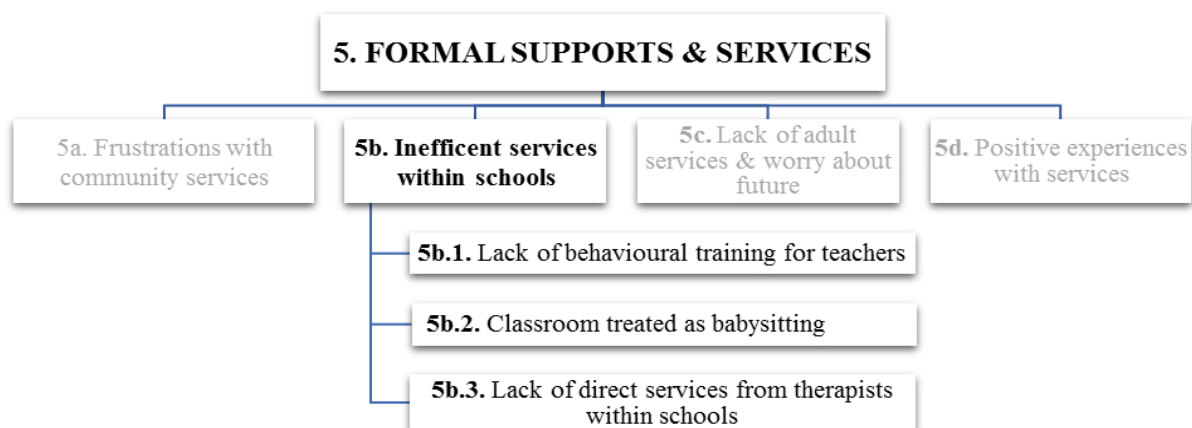


Figure 15. Coding Diagram for Inefficient School Services within Formal Supports.

5b.1. Lack of Teachers Trained in Dealing with Behaviours Related to DD. A majority of Canadian and South Asian mothers emphasized that there is a lack of classes that are equipped to deal with behaviours related to various DD including ASD. According to them, a lot of teachers are not trained to deal with the behaviours and often just send their child home disrupting his or her learning. As a result, children often get do not get the necessary services within the school system. A Canadian mother (C2) reported: *“I find there’s not the respect for these children in the school system. Oh, that burns me. That burns me. And I think I’m old enough now that some of these teachers coming in, even though they’ve got some experience at teaching, they’re still younger than me. And, I speak up. I’m not afraid to speak up.”* Another mother (C4) reported: *“then we had him in regular school and that’s a horror story right there. I mean, he got treated extremely bad from his homeschool. You know, his homeschool treated him like he had leprosy. It was so bad, I was, if I had known then that I had known, like, now, we could have had a lawsuit against this school and the teacher and the principal. Cause it was, it was, I was disgusted.”*

Several South Asian mothers also described similar frustrations. A South Asian mother (S5) expressed: *“In the school, also, they doesn’t have any professional teachers for autistic kid. They*

are just a special need teachers. But they doesn't know, when they have behaviour, how to like, solve that problem and all. Only thing they do, they call. "Come pick, he's crying. He scratching. He's biting. Come and pick him."

When teachers are trained and experienced, they seem to be able to handle the child's behaviour and support their learning. A Canadian mother (C3) reported: *"she was in a self-contained classroom from grade 1 on in [school] and that went well for a couple of years but um then the teachers changed and it was a big difficulty and they had a lot of problems with her and she went to um, the, um [segregated school]...all the problems that they had at [school] disappeared completely as soon as she was with people that knew what they were doing and she was like the poster child for that. She was one of the first ones that they transitioned into high school. And, uh, they helped me with that and that was very helpful."*

5b.2. Classroom Treated as Babysitting. Some South Asian mothers also described how the school, at times, focuses simply on looking after the basic needs of their child, and often dedicate minimal resources to teaching him or her. One of the South Asian mothers (S2) reported: *"Because that teacher, she teaching there in the same classroom for thirteen years, so she think like, we sending the kids there just for um relief. They don't have to teach anything...So when he was like six years, they didn't have any water play. No sand play. Nothing. *Child love like sand, okay, but water play, he will stay hour and hour...the occupational therapy, what she did, what we did it, like me and her and uh the vice principal, they say, like, "I want to see the kid, what he doing, and then I want to do it home. We want to see." So we stayed there. She doesn't do nothing. Nothing at all. Like half a day, we stayed there. Nothing...She didn't do anything. No circle time and then nothing."* Another mother (S5) explained: *"this autistic children, they need the therapy. Like one-on-one therapy. But school, just you know, the special needs school is like a, what do you call, it's like a day care. You know?"*

Like, we just put our child over there. They are just caring the children and send it back to the home. That is what they are doing.”

5b.3. Lack of Direct Service from Therapists within School. Some South Asian and Canadian mothers also discussed how Occupational therapist, Speech Language Therapists and other professionals were only allowed to consult with the classroom teachers, who may (or may not) then implement some of the recommendations from these professionals. They expressed their anger at the lack of direct therapy from these professionals within the school system. One of the South Asian mothers (S5) described: *“They are telling they are giving speech therapy. You know what the speech therapy? Just the speech therapy came and get the assessment, like big letters, like assessment report. After assessment report, she said: “Done, my work. I have given all the option what to do for the like task, for the child with the teachers. So how teacher knows to do with my child? Only the speech therapy know how to handle, no? ... speech therapy, she used to give some 15 or 20 tasks to do with the child. For the end of the year, how we are know the child do this or not? Whether the teacher do with the child or not? No one knows.”*

Similarly, a Canadian mother (C6) reported: *“So she has been getting occupational therapy, um, uh, oversight from [agency] but not actual occupational therapy. The therapist goes in the school, recommends things and then leaves. Then the EAs and the teachers are supposed to implement whatever the occupational therapist has said she’s needed. Okay, that’s not occupational therapy, let’s be clear. So my daughter is overseen by an occupational therapist from [agency] but she isn’t actually getting occupational therapy anymore and I can’t afford it.”* Another Canadian mother (C5) described the irony of getting this service at school: *“I’ve heard duplicate, duplication of services. I said: “What?” Or “Your son’s at school? He’s already seen speech, he’s already seen...” So if I go to another agency, some agencies, once they find out you’re in the school system, they won’t help you because they say:*

“Well, he’s receiving that service.” Because either outside of school, I’m trying to see what else can I do for him. That’s frustrating.”

5c. Lack of Adult Services and Worry About Future

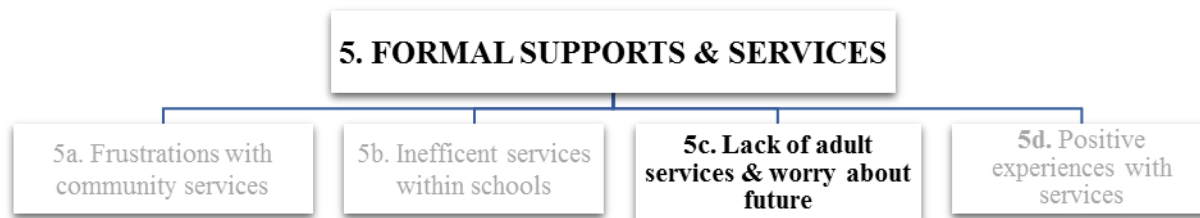


Figure 16. Coding Diagram for Lack of Adult Services & Worry About Future within Formal Supports

Most mothers from both groups described their worry about their child in the future once they are no longer there to care for their child. A Canadian mother (C1) expressed her worry: *“I have, you know, certainly a huge worry about what’s going to happen when I’m gone... And I mean the thing is the people in their lives who would be in a position to steward them are all my peers, you know, so, we’ll all be of a similar age, one assumes, and I yeah, I worry about that quite a bit.”* A South Asian mother (S3) discussed her worries about her son: *“So you know it’s really hard. Like thinking of the future and thinking of when we’re not there, who’s going to look after them, like that, those questions.”* Another South Asian mother (S9) expressed: *“One day, I will not be alive. There will be nobody. She has no siblings. No sister, no brother and she will be a burden to herself. How she will? So I have to do something. How can I do better?”*

Some mothers discussed these worries specifically in terms of services and supports for adults with DD, and at times planning how the other children in the family will have to take care of their sibling with DD. A Canadian mother (C2) described the ageing out process within

services: *“Children’s center, they only go to age 19 now because the funding’s cut back, it used to be 21. So that will tax now [community agency for adults]. Snowball effect. Domino Effect. Like George Do It, I like to call it. Let George do it, let George do it. And somebody has to stand up and say, you know, this is wrong. You’re passing buck? and nothing’s getting done. But it all boils down to money. They have to start throwing money at it but in a planned manner.”* Another Canadian mother (C3) discussed the challenges of respite services for parents of adult children: *“the issues that um, right now we’re finding is that now it’s not child, it’s adult care now. And now the problem is, the respite care has disappeared cause she’s not a child anymore and I haven’t had time to start navigating the adult system.”*

A South Asian mother (S4) discussed the need for better financial support for children with DD as they go for post secondary education: *“Child is very good, excellent student. He can don’t forget everything... very, very, very smart, my son. Yeah. That’s why I like to, yeah, this kind children like to study, more study. Go to university and then finish university. Government can give scholarship. Because I’m no possible, I keep it money, because I know go to university, lot of money. Next year, my son go to grade six and then high school finish, then go to university. Where I keep it money? I don’t have money. Not only me, yah. All autistic children. Because this children, lot of money needed.”*

Another South Asian mother (S9) described her worry about her child’s education as well: *“they have some spaces for the developmental disability but they have only the grade 5, up to 5. They didn’t have any plan after that. They, this child will go and how they will lead their life? No plan. That time I was getting worried that yes, it’s fine up to 5. What left? How will be her life? How she will lead her life?”*

In spite of mothers spending a significant amount of time and emotions on discussing their frustrations with services, this affect was probably difficult to capture in the quantitative measure for formal supports. It is quite evident that these qualitative themes give a much richer understanding of the actual experience of formal supports that mothers report, while the

questionnaire covers helpfulness of these formal supports in general, without going in depth about what was helpful and what was not.

5d. Positive Experiences with Services

Despite these frustrating experiences, or in addition to these challenges within services, mothers also reported several positive experiences with services. These positive reports were in almost all service areas as described in this section.

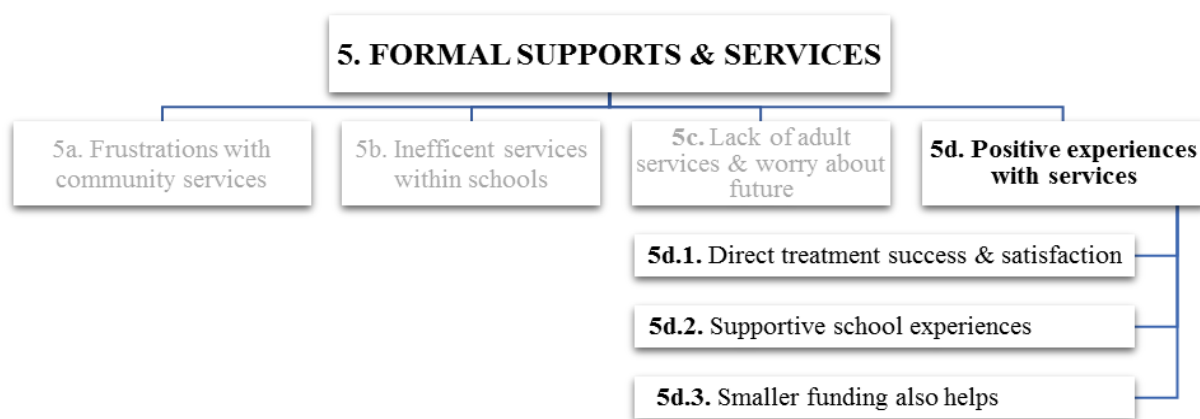


Figure 17. Coding Diagram for Positive Experiences with Services within Formal Supports.

5d.1. Direct Treatment Success and Satisfaction. A few Canadian and some South Asian mothers discussed some successful experiences with direct treatment that their child received in the form of IBI, ABA or other parent support. A Canadian mother (C1) reported: “*we had a great interventionist. I don't know if you know how that works. So you only have them until they transition into grade one basically. So she was super, she did a lot of work with us. When my husband and I were working full time she would go the sitters and do work with our guys there, which is great. Um, we had, so I would say our Preschool Speech and Language was a really good experience. We got a lot from them.*”

South Asian mothers discussed similar experiences with direct services. One mother (S2) described: *“ABA therapy she does, like more academic stuff and all the stuff...Still she comes...Now he’s going to be 18..Almost 9, 10, 2003 I think she started. So then 11 years..She like, when she started, he doesn’t talk at all. So she worked like, because like, in the first eight months, uh, she worked every day. Monday to Friday four hours through the [agency]. Thank God they gave me the same worker because I heard different mothers like either the parents, they don’t like the worker or the worker doesn’t like to go or something like that. So they always change...For him, I’m okay and then she was very good too.”*

South Asian mothers also discussed how helpful some of their family support workers or service coordinators were. One mother (S8) reported: *“the [agency], the therapist, they taught me um lot of uh techniques. Uh they give, they provided book, specifically, I, when I attending the session, um I asked um if I stuck, uh how can I help her or handle her? And they showed me different way. You can go this, this, this way. So one of them work and yeah, that’s why I’m really grateful.”* Another South Asian (S10) mother explained: *“now I’m getting help from RESPITE services. So if I sick, they keep him...the one lady, she really helped me, when he diagnosed...and uh she was, she, she’s for um special kids, like autism or disability. And she guide me. She guide me, that time. She helped me to apply in [agencies] all those things that time and the rest services... Yeah, they really helped. They really, um, guide uh how to deal and if we discuss the problem, they, they help us to how to deal with these problems.”*

On a trip to her country, one South Asian mother (S2) tried homeopathy as a treatment for some of her son’s difficulties and was asked to stay back for some time in order for her son to receive treatment. She decided to forego the treatment because he was getting good services here in Canada and would lose them if he stayed back. She reported *“then we decided no for the homeopathy because we have to stay for year and then like those things. So then we decided no because we don’t want to lose it over here. Because he’s in a school system. I know how hard is it to get it in all*

those things. And then like I know like his future is going to be here and then if he lose those things, not good, yeah."

A couple of Canadian mothers talked about their child's positive camp experience and how it kept their child learning throughout the summer as well. One of the mothers (C3) was particularly appreciative that her child could attend the same camp every year into her early adulthood: *"it's great cause it's a constant in her life. She know she has camp every summer. So even if she was in a group home, she'd just be bussed to the camp every day...we know everybody. She does a lot of things, like you know, we're a very close-knit group in [Regional Society]...They do everything and the parents, we all know each other. So, and she knows the kids. And uh, she's in school with quite a few of them and she's, I've know them from over the years so she recognizes them."*

5d.2. Supportive School Experiences. Some mothers from both groups also mentioned positive interactions and experiences with particular teachers within the school system. A Canadian mother (C5) of a child with ASD and physical disability described her experience: *"when he was 4 years old, he started JK. So he was in preschool from 2-4, which was a great help and then at 4, I registered him at [segregated school]. And um, I let them know, this is his condition. These are his, um, CP, autism and school took care of everything,...the school's amazing, they do the PECS, they do, they have um, they now have iPads, so, the education system has come a long way for, I believe, for children with special needs."* One of the South Asian mothers (S9) also described a similar experience: *"Right now she's regular school but she has the, under the special program. School is a normal school, regular school but they have full-time special program. And last year, she had uh another regular school but they didn't have that much, that's why, school actually helped me a lot. They provided lots of things. They provided support and they provided information too, district board. They assessed and they took decide, decisions and that she will her placement and that will be the right place for her."*

5d.3. Smaller Funding Also Helps. South Asian mothers also mentioned that having some of the smaller funding provided by private institutes or charitable organizations is helpful in getting the necessary private therapies for their child. One of these mothers (S3) expressed: *“because we get um we um, the services that we got from [agency] ...and um from [charitable organization] we used to get when the income was low, we used to get uh funding. And then from [other agencies], they used to give like thousand dollars a year. Now that we’re both working, we don’t get. Um so those funding and [Autism advocacy organization] has summer funding. It’s a raffle but sometime because I have two kids, I always get a chance at winning at this one. And March Break funding. So those fundings really help.”* Another South Asian mother (S8) reported: *“doctor gave the information, the funding, funding it was [charitable organization]. So they, [agency] helped me to apply and I, *Child was approved for the funding. So I started the um uh Intensive Behavioural Therapy, IBI...So that thing um that, it covers five months uh the funding. Three days, two hours each session.”*

6. Informal Social Support

Mothers reported being the primary caregivers for their child with a DD. They report feeling stressed, tired and frustrated. They reported seeking informal support in the form of help from their husband, parents, siblings and other family, as well as friends and other mothers who have a child with a disability. Overall they discussed two sides of receiving social support. They expressed that socializing was difficult and they managed their social life differently. However, they seemed to have chosen and surrounded themselves with friends who support them and accept their child.

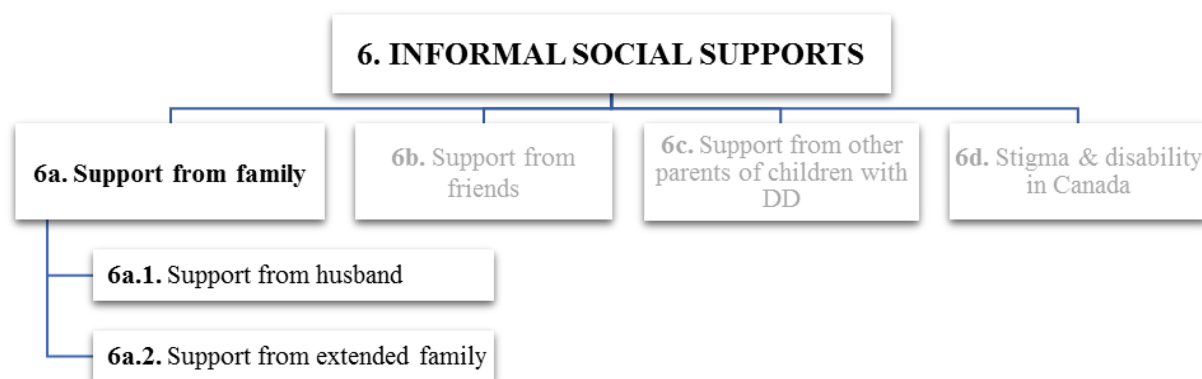


Figure 18. Coding Diagram for Informal Social Supports.

6a. Support from Family: Husband, Children, Parents, Siblings, and Relatives.

Most mothers from both groups reported that their immediate family did their best to support their child, while some reported low levels of actual help from their family due to low levels of understanding of the disability or how to help.

6a.1. Support from Husband. Mothers from both groups described mixed levels of support from their husband. Some mothers described a lack of support with household chores and emotional empathy from husbands. A Canadian mother (C4) reported: “*My support system is basically non-existent. Non-existent. Just me. Well, it’s mostly, basically it all falls on me. Like, we get the financial support from my husband, you know, but the emotional part is, is kind of lacking. Like he doesn’t understand what I go through on a day... My husband doesn’t understand that. I say: “You go to work everyday. You talk to adults. Who do I talk to? I talk to a child that can only give me one word answers.” You know? I say: “That’s not, that’s not being consistent.” I say: “Yeah, I know you work hard.” But I say: “So do I. I don’t get paid for my job.” Yeah. But he doesn’t understand as to why I don’t want to do anything.*” Single mothers report that their child misses having a male figure to help and support his/her interest at home. A Canadian mother (C2) described: “*He’s pining for a male figure and he looks up to *Ex-Husband with baseball. “Oh I’ll ask him that when he comes home”,*

*you know? He'll ask a baseball question or he'll run down and check the score when the Jay's are playing. Um, they're playing the League Baseball. When its Monday games *Ex-Husband can come and watch and he just loves that...But I mean, *ExHusband is busy."*

Most mothers talked about themselves and their husband as a team and did not always talk about their husband separately while discussing social support. They discussed receiving practical support from their husband in day to day tasks more than emotional aspects of support. One South Asian mother (S3) discussed: *"even though like my husband wouldn't do everything that I expect him to do, but it's still, like, I'm happy that he's there for me and he's doing what I want him to do. Where I want to, I want him to take us. He would do, like willingly. So I have no, I have no, that made a big impact."* Another South Asian mother (S7) described: *"If he has time, he'll help. For him, his time is occupied. For me, I won't go shopping and stuff, right? Because taking my son with me is hard. So Dad does the shopping and other work. So, he goes to work and comes home, time just goes. Saturday, Sunday, going anywhere."*

6a.2. Support from Family. Mothers reported both challenges and positive things about the support they received from their family (i.e., their children, parents, siblings and close relatives). Some mothers discussed the lack of understanding about the disability amongst family. Due to their child's behaviours or peculiarities, these mothers felt that they end up staying home with their child who often misses out on opportunities to socialize and learn from different people. A Canadian mother (C1) reported: *"we really didn't have much of a support, most of our family just don't know, didn't know what to do with us, you know I have [sibling] that live quite close to me who I never see. They, they just don't know what to do with us, so they've just left so we have so little support...So I think in those ways it has a big impact. Also, I think, you know, both of my [siblings] play hockey and skate so I would, like, they could have potentially taught the boys how to skate. You know, I don't know how to skate anymore, I, I'm not able to do that."*

Another Canadian mother (C4) explained: *“we have relatives that live down the street...So, um, you know, they tend to do more things with the older one than with the younger one. So that’s kind of a negative aspect because they don’t know how he’s going to react...I’ll give you an example where my other [immediate family’s] birthday at the beginning of the month and he went to a certain restaurant. So I looked it up and I looked at the menu and I thought, there’s nothing there for him to eat. So, I forfeited going to the restaurant so I could stay home with him. That’s another aspect of it. You know? I’ve actually had to forfeit going to certain things um because of that”* A South Asian mother (S3) also talked about similar experiences: *“they both used to cry a lot and have lot of behaviours uh when they were children, small. And um we couldn’t go out to any place unfamiliar. Like just the house they’re familiar. If we go out to anybody, relations’ place, soon as we park in the parking lot, they start to cry. Very loud. They’ll start crying. So we couldn’t take them anywhere...it’s still hard to take them out to, like, we wouldn’t go everyone who invites because we know like, I have to always be with them because you never know what they’ll pull or they’re not aware of danger or something like that. So um, I don’t go all the time out. Only like people that I trust who I know I’m comfortable with I take the children.”*

On the other hand, most mothers also gave examples of one or more of their family members as constant pillars of support which they found to be extremely valuable. A Canadian mother (C3) referred to her older daughter as a source of support, while another Canadian mother (C5) described her mother and family as playing a supportive role: *“everybody was supportive. We’re like an Italian family. So we were very, we’re all close to each other and uh, I had my parents. They helped. They helped a lot...I’m lucky I have my mom. I’m very close to my mom. Um, I only, I have a [sibling], And he has [kids] of his own so he, him and his wife give me a lot of support too. You know, shoulder to cry on, to talk to. My mom too. My mom’s my number one help and um for everything, support emotionally, financially. Um so and that’s been a great help. For five years.”* Several South Asian mothers also described receiving similar support from their families who are here in

Canada. A South Asian mother (S2) reported: *“if you look at like a relatives side, they are like a really helpful. Like my mom and my sister...I think if I don’t have it, probably, like couple more, like, uh, some other moms. Like more, like frustrated. Because like uh I will say, like still when he born, I started my home business...before one month, I started. So, still I’m continuing because of my mom and my sister...So like it is like they giving me like a little bit relief too. So that that’s, oh, I have somebody, oh, when he does something...you know, like, like, inside, you feel more confident.”*

It is important to note that some of the South Asian mothers reported feeling supported by their families back home. At times, their parents or siblings have travelled to Canada to support them, and at other times they have been able to provide emotional support over the phone by being open to discussing issues and helping problem solve. One of these mothers (S6) described: *“my family is back home, right? I don’t have any extended family here. But my dad came twice, like you know, when I was going through this depression. My sister came with her kid. Just to give me some time. But later on they explained to me, you know: “Don’t worry, everything will fall in place. Just a matter of time, patience, trust, everything.” And really, things, like, you know, was falling in place. Like gradually. Like you know, and then I thought, you know, okay, so there is hope. I never gave up... They used to call me twice in a week and sometimes, like, you know, even twice in a day, you can say even, initially when he was diagnosed. I’ll tell you it was too good... You can share with your family and stuff. And you get a feedback also. What to do next, right? So that’s the reason, like I got lot of good advice, feedback from my family members. Okay, do this, do that, do that, do this, like you know.”*

6b. Support from Friends and Community

Just like with family, Canadian and South Asian mothers described challenges with socializing with friends due to their child’s challenges. However, they reported surrounding themselves only with friends who accept their child and support his or her learning and

socialization. They removed themselves from friends or social groups where their child was not accepted. A Canadian mother (C3) reported: *"You lose friends but then you don't need them to begin with, the ones you lose."* A South Asian mother (S1) described choosing her real friends: *"If, if people don't accept, we will not be in that company. We can, we can change, we have build up our, our friends in a way that those friends who can deal with us, who are there for us, uh, they are true friends, if they think that by bringing my child to their house and she spoiled anything or if they are back-biting, they go off our list"*

Thereafter, for most mothers these friends act as constant sources of support in these their lives. A Canadian mother (C3) described her friendships: *"And all my friends have been great supportively. Everyone adores *Child. They've been very good. So I guess it just makes you appreciate. So, maybe, we're a closer group than we would be normally...and I have been so, it's kind of nice, you feel grateful for your friends a lot more and you find out who your friends are because the ones you keep are the ones that are the real friends too."* A South Asian mother (S1) discussed her friends as sources of support: *"Like I do miss my family, my, my support but I got much more support here. My, when I moved here I had no, I had no clue where I was going. I had no personal, I had no friends, no family. But at this point, ten years in the country, I have enough friends whom I can look for, who can support me, who upport my child."* A South Asian single mother (S10) described her friends (ones who accept and love her son) who support her within her community: *"I choose friends who like us how we are and uh I go to the temple, I never feel and never allow people to feel, I, something is different...Uh, in our community, people sometimes don't like the single ladies, single mothers, so... And uh, um the son with autism. So, I have friends, I have group. I choose the group, which one, which they really accept us, how we are."*

6c. Support from Other Parents of Children with DD.

In addition to the above discussed sources of social support, a number of mothers from both groups reported receiving support from, as well as giving support to, other mothers who have a child with DD. They described sharing information and resources with each other. A Canadian mother (C3) reported: *“I feel, you know, the [Regional Society] has been great. So I would never even, before my child was diagnosed I don’t know if I would even joined anything like this or been as close to these people...we get together for coffee like couple of times a month and our kids are in school together and they go to camp together and we can always get back and forth, you know, we help each other. She helps me because she can’t work so she’s there to drive *Child back and forth to camp every day. You know, and if she has a problem, she definitely, everyone shares resources.”*

However, another Canadian mother (C5) expressed mixed feelings about these parent groups: *“I would meet moms and try to, like okay, I want, like I want to go out meet other people but the people I met were other moms with special needs kids. So it’s like you couldn’t escape it in a way. But in a way it’s nice to talk to somebody who’s going through the same thing that you’re going through.”* South Asian mothers also reported mixed feelings about sharing their feelings and talking to other mothers from their own country/culture compared to other Canadian mothers. Some mothers felt more comfortable sharing with Canadian mothers since they are more open and understand the disorder better. One South Asian mother (S8) reported: *“when I met some of the people, uh, those have autistic child or, or some Canadian people uh those grown up here or they stay for long here, they have different view than that, yeah. They don’t think like that way. They don’t think like that way so I can share with them um my uh about my child. Yeah. How she’s doing, uh how I’m feeling, how I’m doing...as well as I’m sharing my feelings that I cannot share with my country’s people.”*

On the other hand, some South Asian mothers reported that they prefer talking to other South Asian mothers since they share a common language and culture and are easier to talk to.

One of these mothers (S2) reported: *“since I’m coming to [South Asian agency] like about a year...the thing I like it about it, because we can stay here and then seeing and then talking to the other parents [in their own language]. Because other agencies also he goes, like Saturdays...there uh, 2 things, it’s a different language moms. Them, because like usually we don’t open our like you know, not the open talks and then all the things...So when we’re having like over here, when we’re talking...especially like for me, I’ll say, like, I feel, like, more confident.”* Another South Asian mother (S6) described: *“This is only when, you know, when I, uh joined this South Asian, like my community thing, where I got to know this other parents, first I thought it was me and my child. But I went there, I said, oh, yeah. I have somebody, where I can, you know, rely on, so. That was a time where I came to know so many... And *Friend helped me a lot.”*

Overall, quantitatively, informal social supports were not found to be significantly different between the two groups, while overall helpfulness of all available sources of social support was significantly higher in the South Asian group. As mentioned earlier, these qualitative themes helped with teasing apart the possible reasons why South Asian mothers reported experiencing strong social support.

6d. Stigma and Disability in Canada - Mixed Support from Community at Large

Even within the context of Canada, where developmental disabilities are widely recognized and accepted, several Canadian mothers described a need for better awareness and true acceptance of individuals with a disability. A Canadian mother (C1) reported: *“I don’t know what we need to do but the thing is that there are more people affected by that and we have to as a population, have to be, we have to learn real acceptance. Not awareness, but real acceptance because this different way of being is not going away.”*

According to mothers, people in Canada as well, still do not completely understand the scope of these childhood disabilities, especially when the disorder is not physically evident. This becomes a more common issue when children get older and society in general expects more from them. One Canadian mother (C4) described: *“he’s really good. Um, and when he was about seven or eight and I would take him grocery shopping. I would still have to put him in the grocery cart. Now this is the downside. People’s always looking because he is a big boy. You know? Oh, why is he in the shopping cart? ...Like even now, I get looks when I take him to the ladies washroom. I can’t let him go to the men’s washroom cause if something were to happen, he wouldn’t tell me. So, I would rather get the looks. I just take him into the washroom. He goes into his own stall by himself. That sort of thing. You know? I don’t care. I mean, if people say things, I mean I’ll turn around and say something back. I go: “Just because you can’t see it, doesn’t mean it doesn’t exist... But I mean like, I have no problem of people coming up to me and asking questions. What I have a problem with is people looking and staring and commenting. You know, that’s the problem I have.”*

She further alluded to the stereotypes people often still carry about children with a disability, particularly when they are having a behaviour "meltdown" in public: *“People just, as soon as I say that, they’ll turn. Or I’ll say: “You’ve never seen a kid have a fit before?” And people, you know? It’s harder in the older generation. Like grandparents, cause they don’t understand. But even like, people of my age, they find it hard. They kind of shy back. You know? It’s almost, it’s almost like, I don’t want to get near them in case I catch it. It’s not that sort of thing. But I mean, that’s the kind of stereotype I’ve had to go through. Because I’m with him all the time.” Therefore, there is a need to promote better awareness and acceptance of the diversity of challenges that children with DD can have.”*

However, South Asian mothers might experience additional challenges related to the understanding of disability within their culture back home [South Asian Country] as well as within their community here in Canada.

7. Culture & Disability

As evident from the discussion of qualitative results so far, culture seems to be influencing multiple aspects of South Asian mothers' experience of raising a child with DD in Canada. In order to get a better understanding of cultural understanding and influence, South Asian mothers were also asked how being South Asian influenced their experience of in terms of both challenging and helpful aspects about their culture with respect to disability.

7a. Additional Challenges Related to SA Understanding of Disability

South Asian mothers described various challenges parents face when raising a child with a disability in a South Asian family in their country of origin, some of which they also experience now when visiting from Canada.

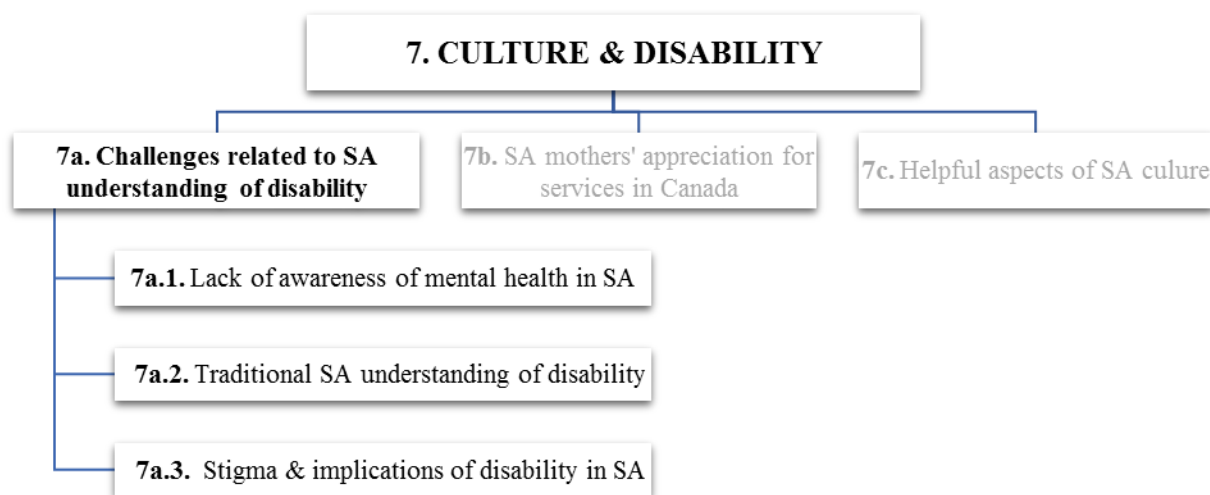


Figure 19. Coding Diagram for Challenges Related to SA Understanding of Disability.

7a.1. Lack of Awareness and Understanding of Mental Health Problems in SA.

According to mothers, there is a lack of awareness and understanding of mental health problems or developmental disorders in South Asian countries. A mother (S4) described her experience

when she goes back to her country of origin: “my family also I go to [South Asian Country] uh so many questions. Why can't do your daughter? Why can't do like this your son? You know? I don't like it. Question, answer, I no feel good. I'm alone here, my two children, I'm happy. I don't like it interfere someone question, why you like this your children? What happened your children? This one no my children fault. God give it to my children...My family also, my family also, he's mentally problem, mentally problem. I say no, this no mentally problem. This autistic children, that means is brain, his age like this ten years old, her brain work three years old. Understanding very down. And again, again, one question, again, again, repeat. My family, my mommy also. That's why I don't like it.”

Another mother (S8) reported on this lack of information: “one more thing that is that they, our, in South Asian people, um the autistic, autistic mean uh they think very, I, I never had any positive aspect from the, my community people. That they always have some, something negative, as I mentioned, that lack of knowledge or information, they're thinking that way. So they think uh this child, child is behind or below. Um, as a mom, I feel bad that I want to see, I don't want to see my child uh to be like downgraded or below, something like that...the negative thing is that uh as I grown up in [South Asian Country], you know, that is developing country, they don't have enough funding or money uh to giving or post the information to the people. Just regular people, public people. So we, we didn't learn that uh this type of information, that if I, if I knew that, um, it was more easy for me.”

7a.2. Traditional SA Understanding of Disability. Some South Asian Parents (and by extension their family and friends) try to identify other reasons for their child's challenges (e.g., boys talk later), try to deny there is an issue, that the child will catch up and at times go to faith based or naturopathic healers in order to find remedies for their child's difficulties. One of the mothers (S3) described her feelings: “It was really hard for um our family to tell anybody about our children having autism. It was really hard. We just hid it for a long, long time. Uh like for about, till they were about six, no, five. Maybe five. Till 2 and a half to five we never told anybody about autism. We only

said that they have a uh speech delay. Because anybody can see at four years, they 're not talking. And um we just said they have speech delay only. And but after I went for counseling, we had counseling at [agency]um for individual counseling. And um, I was able to understand it's good to tell um people."

Another mother (S5) reported a similar experience: *"So still his [husband] parents doesn't know that he's having a problem. We didn't tell them. We were just telling he's having a speech delay. So it's very hard time, like, with myself and my husband and child because we don't have anything."*

Another mother (S6) described the process her family went through when they went back home: *"I went, when I went back home, back home for my brother's wedding, and then like you know, my cousin husband, so he just saw him and he said, like you know, I said so-and-so is a problem. He said: "Oh! Nothing is wrong. He's perfect." This and that. "It's just in your mind that something is wrong." I said: "No, he has, he really has a problem." "What problem?" I said: "He has autism." He said: "No just uh..." Like you know, how we take it easy, right? "It's nothing, man, just a small thing." I said: "No, it's a big thing, man." It was because he looks so handsome, doesn't mean, he has a big problem, speech... "Don't worry man, don't worry, just pray to God"*

7a.3. Stigma and Implications of Disability in SA. Some mothers also described how children are often kept home due to the stigma attached to a developmental or mental disorder, and fear of others saying negative things about their child. A Mother (S1) reported: *"And it happened with me initially when I was [South Asian Country], when she got the label and I used to take her to um to Play Park. And uh, so like all my neighborhood, whoever was there. So I was talking to them, like a casual chat, you're meeting person and I'm talking about my child and her diagnosis and they were like: "Oh, what is autism." So I was like telling them about autism and I'm coming back home and my in-laws are like: "Why do you keep talking about it? Everything is going to be okay. Don't keep talking about autism to a stranger." I'm like, if I don't tell them, who is going to tell them? I need to make them aware that my child is not mad, my child is not um like developmentally, any major disability, like*

um, she's only autistic...if I cannot explain it to you, if you don't accept it, how will I make the whole world accept it? So that was the time when I told my husband like she has immigration. We have the resources. We can still go and make a life for her. Instead of staying back and then everyday we will be having the same issues. Because there is no acceptance there."

Some mothers also reported that their society at times considers that parents have a child with a disability due to their past sins. South Asian mother (S2) reported: *"like still people say like sometime they say because of their sins, they got this son. And all, all different kind of things"* Another mother (S9) described a similar attitude: *"So our country, it's, you know, it's a kind of different. What can I say? It's a taboo or stigma, like this, people always the disabled people, they think that it's a kind of the consequence or sin, the forefather sin. They did any mistake to God and that's why your kid is like that. Even though, very higher educated family, when they find, they are not that much positive. They cannot uh show the similar sympathy, the similar uh responsibility on disability."*

Another mother (S2) described how people around her suggested she should send her child away: *"Because back home, if it's a back home, they were really bad. Like if it's a, if it's some kids, if it's like that, they will, like, they will, it's a mentally ill. It's already, put them down, kind of thing... Like and then so many people that's also hurt me like sometime they: "Oh, why you keeping him?" You could put him in the residence, they have a places to go, like, kind of thing."*

7b. SA Mothers' Appreciation for Services in Canada.



Figure 20. Coding Diagram for South Asian Mothers' Appreciation for Services in Canada

Most South Asian mothers compared the services their child would have received back home, and described the differences. They also discussed that they often tried to increase awareness about their child's disability by talking to other people from her culture. One mother (S1) described: *"people from my culture, they don't understand autism. Canadian parents, Canadian kids, understand autism. Like they know, even they're young, they're small, five, six year olds. They, they know what autism is. But um a typical growing um [South Asian] parent, sometimes parents have also told me: "What is autism?" So, I just describe them in few words but I always try to tell them, instead they making joke of *Child, bullying her or talking anything negative about her, I would always prefer that I would just go and tell them."* Another mother (S3) discussed the limited services available in her country of origin: *"If we were in [South Asian Country], we wouldn't get the help that they need uh because I have a friend who came to Canada two years, two years ago. And she said she could only get speech therapy, like they didn't have anything or ABA or IBI therapy. Like children um with this special needs, they think that they're really bad and they don't have the skills. And people talk about uh people talk negative about it and lot of people, like, they would gossip... also back home, we wouldn't have the, the finances to do the speech therapy.."*

As reported earlier, a handful of families had moved to Canada in the hope of receiving appropriate treatment and other services for their child with DD. Even though these mothers had to advocate for their child in Canada, and experienced frustrations like Canadian mothers, they expressed appreciation for the services they did receive, especially when they compare them to what they believe their child would have received back home. One of these mothers (S4) reported: *"Because this country, I thank you for this country. My kids, before to now, very helpful. Everyone can have doctor, [agency1], [agency2]. Everyone. My case worker, everyone help me. My son's school, my daughter's school. Principal. I like to more help for people can understand this kind of*

children... And thank you God. I'm here in Canada. This country lot of help for me and my children, before to now, my kids now 80% okay."

Another mother (S5) described: "But I'm really happy in Canada. Only thing, I'm getting, uh, like, for my child, getting so much supports and everything. Only thing, we have to go, like, find out the things. In back home, for those children. We don't have any support. Even, they doesn't know what is autistic. Normally, they got to know. In this country, so many, like, opportunities to, like, grow up with my child. At least, they can go school. You know? In my country, for those children, they can't go school. They don't have any special school, nothing. But here, I'm really appreciate to this country, like, they have so much uh like things. At least they're getting child tax and disability supports and you know, special services at home. So those things, we can use for the therapy or whatever the things. But I think it's very good opportunity, I live in Canada with my child. Like a disabled child, it's a very good, getting very good support in Canada."

7c. Helpful Aspects of SA Culture

South Asian mothers discussed a few different helpful aspects of their cultural background that helped them deal with the challenges associated with raising a child with DD.

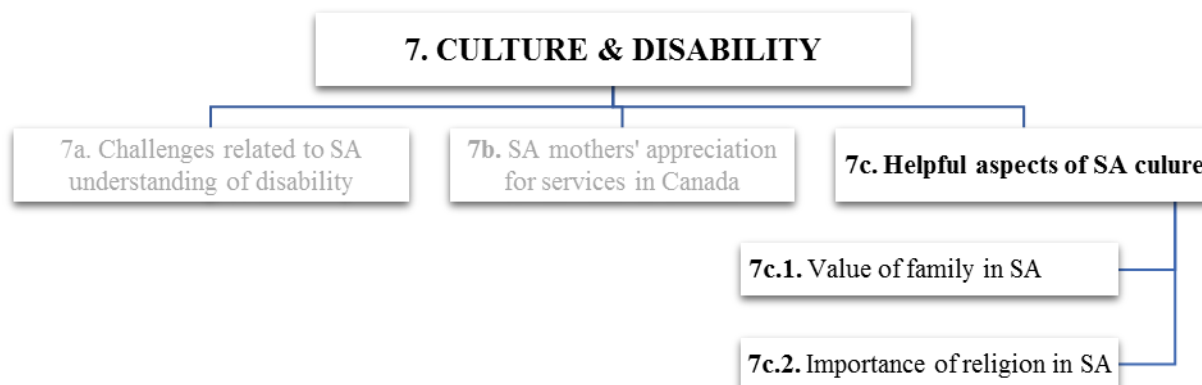


Figure 21. Coding Diagram for Helpful Aspects of South Asian Culture.

7c.1. Value of Family in SA. The most common positive cultural value highlighted by mothers was the value of family and staying together no matter what. Several mothers discussed how being from a South Asian background meant that family was of utmost importance to them, that they got through the tough times with their partners and immediate family including parents and siblings. One of the mothers (S1) reported: *“support, family, family values. Like, no matter what, uh, this is for us together. This is a challenge, like it’s not, the value which is given to us that this is marriage. You cannot come out of it. You have to stay and face all your challenges. Don’t look back and think that you will be able to... Although that those values are getting changed in [South Asian Country] now. People are really, marriages are really breaking. Um but for me, that value, that’s, that’s, um, that really helped me. Like uh I know no matter what he says, what his family says, I have to be here. I have to stay here with them. Change them. Make them accept her. And still be here.”*

Another mother (S3) reported a similar set of values: *“We still have, we still have the [South Asian] cultures. Like we, we think family is important. Like we value my mother-in-law. We value my husband. We value, we always um like we don’t do something just because we want to do it. We will ask permission or we will ask someone for consent before we do it. Like those things are still there...because we are a family, we stick together, no matter what. That’s the way we are. We never like we wouldn’t like just uh we would fight the battle together. Like kind of. So we would um, I think the South Asian community, the way that we were brought up helped us through this situation and um we wouldn’t give up easily. Like we have a way of fighting it. And somehow, like going through it, not um, like, not being uh enduring it. So it has been good, being South Asian.”*

7c.2. Importance of Religion in SA. Some mothers also mentioned religion/faith as something important in their culture, as a source of strength and calm, even though they may not spend long hours praying. Mother S1 explained: *“the other thing was I think faith is, every religions helps so...I’m not saying that um, I’m, I have become more religious. Like people do tell me, start doing*

this, go to that. I have done it a few times. Like people tell me, okay go take her in that particular temple. Go do this. Sometimes, um, just to please them up, I have done it. But I know, my inner self, that no matter what, it's behaviour challenges...I believe in God but I'm not that, like, I cannot explain, I, I, I know that by chanting this ...Yeah, if I really need. But, uh, I don't think I'm, I don't even follow those routines anymore... I just bow my head once in a day and that's it. That's my only time, the only second that I, I think about God. But otherwise, God is there." Another mother (S10) expressed a similar sentiment: *"just pray. I, when I grow up from, with my culture, I know whenever we have problem, pray to God. This helped me."*

Overall, the cultural influence did not emerge in the form of acculturation in the quantitative analysis. Perhaps the acculturation measure was focused on aspects of cultural adaptation that are more salient for typically developing immigrants or immigrant parents of typically developing children. For immigrant parents of children with DD, specific challenges related to cultural underpinnings of disability and a change in their approach to disability might better capture acculturation within disability.

Discussion

The purpose of this dissertation was to explore the experiences of South Asian immigrant and Canadian mothers raising a child with a developmental disability using the Perry (2004) model of stress. I attempted to understand the similarities and differences in the experiences of the two groups by answering two main questions: 1) Is there a significant difference between the two groups on any of the stressor, resource, support or outcome variables, and 2) Are there different predictors of positive and negative outcome in the two groups? In addition, to answer a third mixed methods question, I attempted to explore the similarities and differences in the way

Canadian and South Asian immigrant mothers of children with DD articulate their experiences when asked about the challenges they faced, the resources and supports they accessed and how these impacted them as a person, a parent and family. Through the use of quantitative questionnaire data from 56 Canadian and 51 South Asian immigrant mothers of children with a DD as the primary source of information and of qualitative data from semi-structured interviews with a sub sample of mothers from both groups, I will summarize the factors influencing outcomes in both these groups.

It has been well established in the literature that the diagnosis of a disability in their child has a great impact on parents. Right from the time they suspect something is different in their child, parents go through a dynamic and almost cyclical journey of dealing with the challenges that their child's diagnosis presents to their child and to the family (Bingham et al., 2012; Blacher & Baker, 2002; Blacher et al., 2013; Hill, 1949; Lazarus & Folkman, 1984; Lutz, Patterson & Klein, 2012; Perry, 2004). The current study examines a cross section of this experience at one point in time.

During the interviews, mothers from both groups reported that this journey included searching for the right diagnosis for their child, coping with their own grief about losing their ideal child as well as adapting their expectations to accept a "new normal", finding and obtaining the most appropriate supports and services for their child, adapting or changing these supports and services with their child's changing needs, adapting and finding a new balance within themselves as well as their family. This process occurs at various times during their lives as their child goes through developmental changes (Bingham et al., 2012; Lutz et al., 2012).

Even though all mothers went through this process, most Canadian mothers reported having heard about developmental disabilities and autism, even if they did not have direct

experience with them. Some Canadian mothers suspected that their child had ASD and, in some ways welcomed the label, since they could then get appropriate help for their child. On the other hand, most South Asian mothers had never heard of these disabilities and initially looked for alternate and often traditional explanations such as boys talk later. Mothers in both groups initially tried to search for a cause including something that they might have done wrong. While Canadian mothers seemed more aware of the cause as being medical, South Asian mothers shared their understanding of their child's disability both in medical/biological terms as well as more religious/traditional terms such as "will of God", result of "past sins", and so on. These mostly similar but somewhat different experiences around understanding of disability in the Canadian and South Asian mothers is in agreement with previous findings of studies with both Caucasian as well as South Asian mothers (Harry, 2002; Mandell & Novak, 2005; Welterlin & LaRue, 2007). Masood et al. (2007) explored the attributions of their child's diagnosis in parents in Pakistan and the USA. They reported that parents in Pakistan tended to attribute their child's diagnosis to God's will or personal failure, while parents in USA tended to attribute it more to genetic and medical factors.

In the current study, both Canadian and South Asian mothers experienced anger and sadness at first and researched as a way of learning more about the disability. However, some South Asian mothers reported going to traditional healers and spiritual leaders on the suggestion of elders in the family and at times, hid their child's diagnosis from family to avoid being shamed by their community. These findings are congruent with almost all the South Asian literature on parents' reports on their understanding of causes and experience with raising a child with a disability, including several studies done in South Asian countries (e.g., Daley, 2004; Das et al., 2017; Desai et al., 2012; Divan et al., 2012; Minhas et al., 2017; Mirza et al., 2009; Maloni

et al., 2010; Heys et al., 2016) and some done in western countries (Bywaters et al., 2003; Daudji et al., 2011; Gabel, 2004; Heer et al., 2012; Jegatheesan, Fowler & Miller, 2010; Zechella & Raval., 2016).

On this journey of getting a diagnosis, accessing services and establishing their child within the community, parents reported experiencing both negative and positive outcomes simultaneously as a result of their process of dealing with stressors (e.g., child's age, adaptive skills, maladaptive behaviour, diagnosis, as well as financial burden and other stressors present in the family), with the help of personal (self efficacy, mental health, coping strategies) and family (family hardiness, marital satisfaction) resources and supports (helpfulness of formal and informal sources of social support). I explored the differences and similarities on each of these aspects between the two groups.

Differences and Similarities between Groups.

The results of this study suggest that the reported experiences of Canadian and South Asian immigrant mothers within the Canadian context are quite similar overall but with some key differences.

1. Maternal Outcomes.

Mothers from both groups reported experiencing moderate to high levels of stress or negative impact in the process of taking care of their child, with South Asian mothers reporting higher parenting stress. This is congruent with results obtained by John (2012) who collected parenting stress data from Indian mothers with a child with DD and compared it to parenting stress scores of Caucasian mothers with a child with DD obtained by other studies done in

Canada, the USA and the UK, and reported significantly higher mean parenting stress scores in Indian mothers.

However, in the current study, differences in positive and negative outcomes between the two groups varied based on the measure used. While on the QRS-F, South Asian mothers reported significantly greater levels of parenting stress related to raising a child with a DD as compared to Canadian mothers, this difference was not significant on the FICD Negative Impact scale. This difference might be due to a somewhat different focus and tone of items within the two measures. The QRS-F includes more items about daily hassles and how their child's challenges affect their family and social interactions, whereas the FICD Negative Impact scale focuses on parents' perception of the impact of their child's disability on their family. During interviews, South Asian mothers tended to discuss their child's behavioural challenges and skill delays in a greater detail than Canadian mothers, and perhaps, this focus might be translating into the different scores on the two measures. In my master's thesis (Luthra, 2010), I conducted a file review study and compared seven different cultural groups on parenting stress and positive impact. I did not obtain a statistical difference between the South Asian and an English Speaking or a Caucasian group in Canada on either of those variables.

Several researchers have reported significant levels of parenting stress (on several different measures) in Indian (Das et al., 2017; Gupta et al., 2012; Kishore, 2011; Bhargava & Dhiman, 2007) and Pakistani mothers (Mirza et al., 2009), even though they did not compare South Asian mothers to another cultural group. Some other researchers in South Asian studies have conceptualized negative impact in terms of subjective burden and have reported high levels in mothers in South Asian countries (Kandolkar & Kechappanavar, 2014; Sabih & Sajid, 2008; Singh et al., 2017). There is much variability in the selection of negative outcome measures in

the literature on Canadian and South Asian mothers. Moreover, the measures used in South Asian countries were often quite different from those used in the west, focused directly on the child's challenges and how stressful it was for parents (e.g., NIMH-DIS and FISC-MR), and were often completed in a semi structured interview format or based on observer ratings. Therefore, perhaps there is a need for validation studies to be conducted in eastern cultures in order to be able to validly use universal measures for parent outcomes.

In the interviews, both groups reported that their journey had been “stressful”, “hard”, “challenging” and that they had been “stretched like a rubber band” at times when there was too much to cope with. In addition to these comments, some South Asian mothers also described their experience dealing with the stigma, negative attributions and beliefs about their child's disability in their country of origin, as stressful for them. They described how there is limited acceptance and a general assumption of a bleak future for their child there. They reported limiting their visits to their country due to these stressful situations, and some reported such attitudes here in Canada within their community as well. Previous research conducted in South Asia as well as South Asian immigrants in USA, UK and Canada (Daley, 2004; Heys et al., 2016; John, et al., 2017; Kharti et al., 2011; Mirza et al., 2009; Maloni et al., 2010; Ravindran & Myers, 2013; Zechella & Raval, 2016) also report these beliefs and attitudes as contributing to parent stress.

In addition to parenting stress, mothers from both groups also reported positive outcomes in the current study. This finding in both groups adds to the growing literature that emphasises the coexistence of both negative and positive impact on parents of children with a developmental disability (Blacher & McIntyre, 2006; Hastings & Taunt, 2002; Lloyd & Hastings, 2009; Luthra et al., 2014; Myers et al., 2009; Perry, 2004; Summer et al., 1989; Trute et al., 2010). Even

though most mothers reported moderate to high positive impact, South Asian mothers reported significantly higher Positive Impact on the FICD, while their scores on the Positive Gain Scale were not significantly different. Part of this difference in results between measures could be due to the way items are worded. On the Positive Gain Scale, all of the seven statement starts with a version of “Since having this child...” followed by a positive change mothers may have seen in themselves. All mothers might have had a tendency to score high on these items, as indicated by a somewhat negatively skewed distribution of scores in both groups. Whereas, on the FICD Positive Impact scale, positive statements are interspersed with negative impact statements, and have more variability in scores, even though South Asian mothers still continued to report more positive impact on these statements.

Although in the last decade, there have been some qualitative discussions around positive perceptions in South Asian parents of children with a disability (Gupta & Singhal, 2004; John, 2012; Lakhani et al., 2013; Minhas et al., 2015; Rajan & John, 2017; Zechella & Raval, 2016), there is no previous research quantitatively comparing positive impact in South Asian mothers to any other groups. Kishore (2011) and Rajan & John (2017) examined positive impact qualitatively amongst other variables in the experience of mothers raising a child with a disability in South Asian countries, and found that most mothers reported significant positive impact or positive change in themselves as a person and a parent.

Mothers from both groups in the current study reported several different ways that raising their child with a disability has affected them positively. In congruence with a lot of the qualitative research and reviews into positive impact (Hastings & Taunt, 2002; John, 2012; Myers et al., 2009; Stainton & Besser, 1998; Summers et al, 1989; Turnbull et al., 1988), mothers from both groups discussed a number of positive characteristics and strengths of their

child, reported focusing more on smaller achievements of their child and experienced an overall change in their perspective towards life. Mothers reported that they developed a better understanding of disabilities and reported becoming more patient, tolerant and accepting towards others.

It is interesting to note that South Asian mothers, who belong to a more collectivistic culture with a strong focus on family, specifically highlighted themselves as being better and stronger parents and persons as a result of their experience of raising their child. They also stressed family as one of the strengths or helpful aspects of their culture, and that family stays together and supports each other no matter what. Several studies done in South Asian countries also highlight the importance of supporting their child and that South Asian parents might be more likely to normalize their child's challenges and focus on the positives due to the stigma attached to disability in this culture (Croot et al., 2012; Daley, 2004; Gupta & Singhal, 2004; John, 2012; Maloni et al., 2010; Mirza et al, 2009; Zechella & Raval, 2016).

As suggested by existing models (Perry, 2004), perhaps a combination of factors might be related to higher negative and positive outcomes reported by South Asian mothers. I explored the differences between the two groups on all the stressor, personal resource, family resource, as well as social support variables before investigating them as predictors of these outcomes.

2. Stressors

Amongst stressors, children's adaptive behaviour or the level of their daily life skills was the only variable that was significantly different between the two groups. Even though there was no significant difference between the ages of children in the two groups, Canadian mothers reported their child as having more advanced adaptive skills (a mean difference of about 26 months in age equivalence between the two groups). John (2012) reported that the majority of

children with DD in her sample of Indian families had moderate to severe adaptive skills deficits, while about 20% had just mild deficits. A lot of the skills measured on adaptive behaviour measures aim towards making the child more independent in their daily lives. Higher adaptive skills scores in the Canadian group might indicate an overall lower level of skills in the South Asian group compared to Canadian group. However, there might also be a cultural underpinning of these differences since there may be differences in expectations at different ages.

Research suggests that the time table to normal development and as such, the expectations of children at different ages is different across cultures (Harry, 2002; Minhas et al., 2015; Mirza et al., 2009; Ravindran & Myers, 2012; Welterlin & LaRue, 2007). In cultures such as South Asia, where there is a strong value of interdependence amongst family members (Schwartz, 2006), especially between parents and child, it is considered normal for parents to do things for their child until the child is older compared to more western cultures where there is a strong focus on making the child independent as early as possible. In addition, some previous research suggests that South Asian parents may tend to be over protective about their child, may encourage their child to be more independent, but at the same time they may be doing things for their child due to lower cultural expectations from a child with a disability (Bywaters et al., 2003; Gabel, 2004; Hussain et al., 2002; Ravindran & Myers, 2013). In fact, two mothers shared their faith in God as central to their child's development, and that they tried their best to get services for their child, but ultimately they would leave it up to God. Their focus was for their child to be happy instead of always pushing their child to do things that made them unhappy. This does not imply that one way is better than the other, but only suggests that there is a difference. This might be contributing partly to this difference between Canadian and South Asian groups.

3. Mothers' Personal Resources

Amongst personal resource variables, South Asian mothers reported significantly greater mental health issues than Canadian mothers. There is strong support in the literature for the presence of serious mental health issues such as depression, anxiety or lower psychological well being in parents of children with DD (Baker et al., 2002; Beckman, 1991; Blacher et al., 1997; Hastings, 2003; Hastings et al., 2005). Comparisons of other cultural groups such as US Latino and African American mothers with Caucasian mothers have found higher mental health issues such as depression in the first two groups as well as higher positive impact in the Latino group (Blacher et al., 1997; Blacher & McIntyre, 2006). Despite growing awareness of mental health issues experienced by parents of children with DD in the last decade (Singh et al., 2017), there is almost no research comparing South Asian parents' experiences with those of parents in other cultures (Gupta & Singhal, 2004; Ravindran & Myers, 2012), and thus comparisons with my findings are not possible.

Canadian and South Asian mothers in this study reported using both positive or adaptive or problem focused (active coping, planning, positive reframing, acceptance, religion, using emotional and instrumental support) and negative or maladaptive or emotion focused coping strategies (self distraction, denial, venting, behavioural disengagement, and self blame). It is well established that both kinds of strategies can be used by parents depending on what the stressors are, and can be used concurrently for dealing with different stressors (Croot et al., 2012; Folkman & Lazarus, 1984; Kishore, 2011; Lopez et al., 2008). In their interviews, majority of mothers from both groups discussed that they researched their child's diagnosis and available services in order to decide the best course of action, tried to access emotional and practical support from family, went for counselling themselves, used physical activity to release stress

(e.g. working out, finishing furniture, cleaning garden) to get respite from caregiving. There is limited literature that explores coping strategies quantitatively in the South Asian group.

Interestingly, in one of these studies with Indian mothers in India, John (2012) reported that 37% of mothers reported using positive coping strategies while 27% also used some negative strategies. In addition, Gupta, Mehrotra, and Mehrotra (2012) reported that Indian parents in their sample (from New Delhi) turned to religion as a source of coping, comfort and finding meaning in their child's disability, and tried to get support from family and friends. They also used negative strategies such as turning to media as a way of distracting themselves.

However, in the current study, South Asian mothers reported using both positive and negative strategies significantly more often to cope with the daily challenges of raising their child with a DD. So far, there is very limited literature comparing the use of these strategies between South Asian and other groups. The only study I found that compared the use of coping strategies between Caucasian and Asian parents of children with DD in the USA reported that the two groups use somewhat different strategies to cope (Tway et al., 2007). While most parents depended on close family and friends for help, Caucasian parents tended to use passive appraisal strategies more often while Asian parents used reframing more often. Moreover, when divided based on whether they spoke English as their first or second language, ESL parents reported using religious or spiritual coping mechanisms more often than the English-speaking parents (Tway et al., 2007). Although the actual measure used is different in that study and my current study, the positive coping factor included reframing and religious coping strategies.

In fact, several studies have highlighted the role of religion in coping (Gray, 2003; Krageloh, 2011; Newton & McIntosh, 2010; Scorgie & Sobsey, 2000), and more so in South Asian families of all religions and socio-economic backgrounds (Croot et al., 2012; Daley, 2004;

Gabel, 2004; Gupta, Maloni et al., 2010; Mehrotra & Mehrotra, 2012; Minhas et al., 2015; Mirza et al., 2009; Ravindran & Myers, 2012). In the current study, Canadian mothers did not report religion as a coping mechanism in their interviews, while about 80% of South Asian mothers interviewed for the present study emphasized the role of religion in their process of dealing with their child's challenges. Some South Asian mothers explained their journey of having a child with a disability as destiny or God's careful plan such that they were given what they could deal with. Other mothers surrendered to their faith in their God/Allah. They arranged for all the necessary services for their child(ren), but at the same time believed that it was in their God's hands and He would help their child if they had faith in him. This highlights the importance that religious beliefs and practices can play in South Asian mothers' journey of acceptance and action, in addition to more problem focused mechanisms.

4. Family's Resources

Besides mothers' own personal resources, South Asian mothers reported significantly more satisfaction with their marriage than Canadian mothers. This finding needs to be interpreted with caution, however, since this marital satisfaction score was computed using mothers' responses to just two items and had a small range of possible scores. In addition, more mothers in the South Asian group (90%) were married compared to Canadian (78.6%) mothers. In their interviews, both Canadian and South Asian mothers reported having some challenges within their marriage since their family's entire focus is on supporting their child with DD. However, they described being proud of having "made it" and still being married to their child's father in spite of all the difficulties. Some mothers shared that they have become closer with their spouse in the process of navigating their child's supports and sharing both challenges and successes with

each other. This was particularly true of the South Asian mothers as they emphasized the role of their culture that teaches them to value family and staying together forever even when it is hard.

5. Formal Services and 6. Informal Social Supports

Regarding informal and formal supports, mothers reported on the helpfulness of their husband, immediate family, other relatives and friends as well as more formal services that their child and family received over the years. South Asian mothers reported significantly higher overall helpfulness of social supports compared to Canadian mothers. This might seem counter intuitive at first glance since one would reason that South Asian mothers may have fewer supports here in Canada as they are away from their family. There might be a few factors contributing to this difference. In their interviews, South Asian mothers emphasized the value of family and supporting each other through everything, and a more collectivistic/family approach to deciding their child's diagnosis and accessing services. Some mothers would often discuss the diagnosis and possible causes, services etc with their parents (living with them or back in their country of origin) and decide what steps they should take for their child. Secondly, even though their families are "back home", some mothers highlighted how their parents and siblings at times travelled to support them or spoke to them regularly on the phone to provide them with emotional supports.

In their interviews, mothers from both groups expressed that, even though their social interactions were limited by their child's challenges, most of them found some emotional and practical support from family and friends. They did consciously choose their friends based on who accepted and cared for their child. They also reported getting some support and help from other mothers who had a child with DD. John et al. (2016) asked parents of children with DD to rank order sources of stress and support, and found that positive support from their spouse, and

support from family and friends were ranked as the top 3 supports. Similarly, South Asian parents may be able to avoid the negative social interactions within their community in their country, and experience more acceptance here in Canada. While some South Asian mothers reported that they preferred to be with a Canadian group of mothers of children with a DD, most of them expressed having found a true source of support at the South Asian agency since they could interact with other mothers from the same cultural background speaking the same language.

Most South Asian and Canadian mothers' experience of getting support from formal services was mixed. They experienced a lot of frustration with getting consistent, timely and appropriate services for their child within services in and outside of the school. Mothers expressed their frustration and helplessness around long waiting times for publicly funded evidence based therapies for their child. Within the school board, mothers highlighted the need for better training for teachers to deal with the specific needs of children with DD and for better access to therapists within schools.

In addition, some South Asian mothers described experiencing racism from doctors and teachers, and some felt that they would get better services if they were accompanied by a white Canadian social/case worker. Such issues have been reported by other researchers in the USA and UK that have worked with South Asian immigrants (Bywaters et al., 2003; Jegatheesan, Fowler & Miller, 2011) as well as by researchers working with a diverse immigrant sample in Toronto, Canada (Khanlou et al., 2017; Su et al., 2018). Some mothers also expressed their regret in not being able to speak better English, and felt that perhaps then they would have been able to better convey what their child actually needed.

In spite of the many frustrations that South Asian mothers expressed towards formal services, they described the services that their child was getting here favourably in comparison to those he/she would have received if he/she were back home, and expressed their gratitude for what their child was receiving (Jegatheesan, Fowler & Miller, 2011; Zechella & Raval, 2016). Some South Asian mothers shared their decision to either stay in Canada or move to Canada hoping for better services here. Even though there is more awareness and advocacy for services for children with DD including ASD in South Asian countries than in the past, the reality is that this progress is slow, there is immense variability across countries and within countries between rural and urban areas. Even in urban areas, doctors and teachers have limited understanding and training in dealing with specialized needs of some of these children (Barua et al., 2017; Divan et al., 2012; John & Montgomery, 2016; Maloni et al., 2010; Mirza et al., 2009; Parvin et al., 2015; Yousafzai et al., 2011; Heys et al., 2016).

Predictors of Maternal Impact

Interestingly, when positive and negative impact on mothers was individually predicted based on all of the child related stressors (child's age, adaptive behaviour, maladaptive behaviour), other life stressors (financial burden, total other life events), personal resources (mother's self-efficacy, mental health, coping), family's own resources (family hardiness, marital satisfaction) and overall helpfulness of all formal and informal sources of support in a hierarchical regression model, some trends were similar between the groups while others were quite different.

Predictors of Negative Impact.

A) Adaptive Skills and Maladaptive Behaviour (both groups). For both Canadian and South Asian mothers, initially their child's adaptive skills and maladaptive behaviour were the strongest predictors of negative impact such that higher adaptive skills and lower maladaptive behaviours were related to lower levels of negative impact on mothers. These findings are quite congruent with the current literature. It has been consistently reported that children with DD start experiencing significantly more behaviour difficulties than their typically developing peers even in their pre-school years (Baker et al, 2002; Lopez et al., 2008), and at times these difficulties continue well past their childhood into adulthood (Blacher & McIntyre, 2006). Some of these behaviours are quite challenging for mothers to deal with, especially since they often are the primary caregivers and it gets harder to manage these behaviours as their children become older and bigger in size.

Even though research over the years has suggested that mothers of children with autism (over 80% of the current sample has ASD) experience higher stress than almost all other specific diagnoses such as Intellectual Disabilities, Down Syndrome, Cystic Fibrosis, etc. (Bishop et al., 2007; Bouma & Schweitzer, 1990; Donenberg & Baker, 1993; Eisenhower et al., 2005; Hartley et al., 2012; Karst & Van Hecke, 2012; Kasari & Sigman, 1997; Rao & Beidel, 2009), it is well established that when maladaptive or challenging behaviours are present, they are consistently related to higher levels of stress in mothers at any given point (Baker et al., 2002; Baker et al., 2003; Manning et al., 2011; Paynter et al., 2013). Therefore, it is not surprising that maladaptive behaviour emerged as the strongest and most consistent predictor of negative impact in the current study. Mothers in both groups described some of these behaviours with a lot of affect

during their interviews, and reported these behaviours as stressful not just in their current situation, but also expressed worry over how these behaviours will be managed in the future.

Besides maladaptive behaviours, their child's adaptive or daily life skills, including communication, socialization, self help, and community skills, were also significant predictors of parenting stress, such that higher adaptive skills predicted lower levels of negative impact. This finding is also consistent with other studies conducted in the past (Bishop et al., 2007; Minnes et al., 2015; Plant & Sanders, 2007; Weiss et al., 2003) with community samples in the USA and UK. Similar results were obtained by the two studies that I came across that explored this factor quantitatively (John, 2012; Sethi et al., 2017) in South Asian parents in India, such that adaptive behaviour scores on the Vineland II (John, 2012) or overall skill level reflected by severity of ID (Sethi et al., 2017) significantly predicted parenting stress in mothers.

Moreover, amongst all the variables tested, adaptive skills and maladaptive behaviours were the only significant predictors of Negative Impact in the South Asian sample. During the interviews as well, there was a definite focus of mothers on these behaviours and skills. South Asian mothers focused a lot of time during the interview describing each behaviour and relating incidents that occurred over time, or things that stood out for them. Even though some progress has been made in South Asia with regards to their understanding of the causes and appropriate intervention for various DDs, the lack of awareness and acceptance of disability in the South Asian community is still deeply rooted. The extent of this stigma is probably stronger within the South Asian community because of traditional beliefs regarding causes (e.g., punishment for past sins, evil spirits etc.) that place the blame on the child as well as the family (Daley, 2004; Gabel, 2004; Gupta & Singhal, 2004; Ravindran & Myers, 2012; Maloni et al., 2010; Mirza et al., 2009; Zechella & Raval, 2016). Perhaps, the presence of these visible maladaptive and/or lower levels

of adaptive skills cause these children to appear different in society and cause a more negative impact in South Asian parents.

B) Mental Health Problems (Canadian group only). In Canadian mothers, their level of mental health problems was also a strong predictor of negative impact such that when mothers reported more mental health issues in themselves, they also reported greater negative impact. In general, mothers of children with DD are reported to experience greater psychological distress or mental health issues such as depression and anxiety (Baker et al., 2002; Beckman, 1991; Blacher et al., 1997; Hastings, 2003; Hastings et al., 2005). When mothers experience depression, it becomes more challenging for them to care for their child and manage their complex needs, thus causing more stress for them (Downey & Coyne, 1990; Gelfand et al., 1992). Several studies have reported maternal depression and even change in depression over time to be significant predictors of maternal stress (Davis & Carter, 2008; Hastings, 2003; Hastings et al., 2005; Hastings et al., 2006;). One study with South Asian mothers in India (Kishore, 2011) reported that mother's overall health predicted lower stress. Interestingly, instead of negative impact, mental health problems predicted positive impact in South Asian mothers, as discussed in a following section.

However, the quantitative scores from questionnaires did not pick up on some additional potential contributors to negative impact, that were highlighted in the interviews. Some Canadian, and a number of South Asian mothers also discussed their sadness about giving up their careers and their desire to work, but also their guilt for feeling this way. This seemed to be stressful for them since their family or friends also commented on these issues at times. This has been reported in some previous studies as well where mothers have reported these feelings as contributing to their overall negative impact (Das et al., 2017; Divan et al., 2012; Mirza et al.,

2009; Yousafzai et al., 2011). Moreover, almost all mothers also expressed their constant worry about the future when they are no longer there to care for their adult child. Even though these mothers have shared this worry in past research, the questionnaires have probably not captured this aspect of mothers' experience.

Predictors of Positive Impact.

Positive impact is still a relatively new outcome being studied quantitatively within the DD population. There has been extensive research about predictors of negative impact. However, there are few studies that examine these variables as predictors of positive outcome. There has been some research with it in Latino and African American samples, but close to none with South Asians. There were a few differences in predictors of positive impact between the Canadian and South Asian groups. Child's age, mother's use of positive coping and family hardiness emerged as significant predictors of positive impact in Canadian mothers, whereas positive coping and maternal mental health problems were significant in South Asian mothers.

A) Child's Age (Canadian group only). Canadian mothers of younger children reported lower levels of positive impact in the questionnaire. However, this was no longer a significant predictor once resource variables were added to the regression. Two of the Canadian mothers interviewed had preschoolers with autism and both expressed that it was difficult for them to think about any positive outcomes for them or their life besides the fact their child was medically healthy. One of these mothers was quite emotional and expressed her sadness about not being able to think of positive things to say yet. Mothers of young children with DD are still often grieving for the loss of their ideal child (Bingham et al., 2012; Lauchlan & Boyle, 2007; Lutz et

al., 2012) and might have not experienced successes with their child yet, that are thought to contribute to mothers' resilience as well as positive perspective and view about themselves.

B) Mental Health Challenges (South Asian group only). On the other hand, maternal mental health issues predicted positive impact only in South Asian mothers. It is interesting to note that mental health issues predicts negative impact in Canadian mothers, which is well supported by existing literature. However, there are mixed reports in the limited research that has examined the relationship between mental health difficulties and positive impact. Blacher and McIntyre (2006) reported that more severe levels of maternal depression significantly predicted lower positive impact in mothers, after controlling for mother's health, education, marital status, income and diagnosis. Paynter et al. (2013) reported a moderate but not significant negative correlation between FICD positive impact and depression. As discussed above, South Asian mothers also reported significantly higher mental health difficulties on the questionnaire. Moreover, there is significant stigma attached to mental health issues within the South Asian culture. Perhaps, these South Asian mothers who had lower mental health issues might be able to avoid some of that stigma and may be reporting greater positive impact. However, there is no previous research that I have come across that has examined this relationship in South Asian mothers.

C) Positive Coping Strategies (Both groups). In addition, as expected, Positive Coping was a strong predictor of Positive Impact in both Canadian and South Asian mothers. Positive coping includes strategies such as active coping, planning, positive reframing, acceptance, religion as well as using emotional and instrumental support. In both groups, frequent use of these strategies predicted better positive impact on mothers. Research in the past has examined these specific strategies individually and consistently predicted higher positive impact (Hastings

et al., 2005; Minnes et al., 2015). Hastings, Kovshoff, Brown, et al. (2005), in fact, reported that greater use of reframing strategies predicted different aspects of positive impact such as personal happiness and fulfillment, strength and family closeness as well as personal growth and maturity. In addition, some South Asian studies have also reported greater positive impact in parents who used more problem focused (Kishore, 2011) and reframing (Rajan & John, 2017) strategies, since they lead to better acceptance and a focus on rehabilitation.

Some researchers in the west (Gray, 2003; Newton & McIntosh, 2010) have emphasized that mothers often utilize religion/spirituality as a coping mechanism and find it to be helpful, especially when they use it in an adaptive manner. Several studies with South Asian parents have highlighted the consistent use of religious/spiritual strategies as ways of making peace with their child's diagnosis, and as hope for a better future for their child (Daley, 2004; Daudji et al., 2011; Mirza et al., 2009; Ravindran & Myers, 2013). In their interviews, South Asian mothers more than Canadian mothers discussed their faith and religious beliefs as providing them relief from the constant stress.

Family Hardiness (Canadian group only). Few studies have actually explored family hardiness as a factor in successful adaptation and functioning of a family with a child with DD. Although the results from several studies have consistently shown that family hardiness can help parents deal with stressors and reduce negative impact on mothers (Failla & Jones, 1991; Weiss & Lunsky, 2011; Weiss et al., 2013) there is almost no literature on whether hardiness as a family would be related to a stronger positive impact. The results of the current study help fill this gap. Interestingly, family hardiness was a significant predictor of positive impact only in the Canadian group, and did not predict negative impact in either group. These findings suggest that when Canadian families were able to reallocate resources, as well as change and adapt to the

diagnosis of a family member, and successfully deal with crises together as a family, mothers reported more positive impact.

Acculturation as a Predictor

All South Asian mothers in this study were first generation immigrants to Canada. Some have been here for only a few years while others have been here for over 20 years. As they started their lives here in Canada, they adapted to the new beliefs and values inherent in Canadian culture, while at the same time trying to maintain their heritage culture's practices. This process of acculturation was the last predictor tested in this study. Neither mothers' Canadian cultural identity scores nor their South Asian cultural identity scores emerged as significant predictors of either outcome. Interestingly, the majority of mothers' scores on both Canadian and South Asian identity were quite high. Based on these scores, close to 80% of South Asian mothers were Integrated according to Berry's (1980, 1997) classification of acculturative strategies, which is considered to be the best outcome. Thus, perhaps there was not enough variability in scores in the sample to obtain a significant relationship. Moreover, when I completed the questionnaire in person, mothers were often quite surprised by these questions and did not quite understand how they were related to their child with DD. This concept of acculturation needs considerably more exploration within clinical populations as perhaps their child's diagnosis and related challenges are more prominent in their experience rather than adapting to the culture. It is possible that if we focus on more specific questions related to cultural adaptation in the disability context, we may get different results. For example, focusing on acculturation in terms of their understanding of disability, treatment options chosen and treatment goals would better reflect acculturation within the disability context. This could be

useful, especially in light of a reported lack of utilization of services in studies with South Asian immigrants in the USA and UK.

To summarize, results of the current study suggest that Canadian and South Asian mothers have a somewhat similar experience while raising a child with a developmental disability, with some interesting and differing trends that emerged with variables within the framework of the Perry (2004) model of parent outcomes. While Canadian mothers reported stronger adaptive skills in their child, South Asian mothers reported greater Negative and Positive impact on some measures and discussed their child's behaviours in great detail. South Asian mothers also expressed greater mental health difficulties, but also more frequent use of both positive and negative coping strategies. Surprisingly, they also rated the helpfulness of their formal and informal social supports to be stronger than those of Canadian mothers. Overall, the regression models computed in this study accounted for close to 51% of variability in negative impact in South Asian mothers and almost 62% in Canadian mothers. Higher negative impact was significantly predicted only by lower adaptive and higher maladaptive behaviours in South Asian mothers. In addition to these, mental health problems emerged as a significant predictor of negative impact in Canadian mothers. Interestingly, mental health difficulties along with positive coping mechanisms emerged as significant predictors of positive impact in South Asian mothers, while positive coping and family hardiness proved to be significant in Canadian mothers. The final model accounted for 54% and 58% of variability in positive impact scores in South Asian and Canadian mothers respectively. There is still a significant amount of unexplained variability in both groups, more so the South Asian group. Some of the culturally influenced challenges raised by South Asian mothers in their interviews might help explain some of this in future research.

Clinical Implications

As suggested by most modern-day research and clinical reports in the field of DD, while working with any family who has a child with DD, it is important to take a strength based approach, as all parents experience challenges raising their child. Mothers from both groups in this study focused on strengths of their children, but at the same time, their child's skills and behaviours were significantly related to the negative impact on them. Therefore, it should be helpful to provide families the support they need for dealing with their child's difficult behaviours, but also highlight their child's skills, progress and their strength as a family.

In order to do this well with immigrant families, it will be helpful for professionals to receive training in providing culturally sensitive service, so that they can learn to explore parents' understanding of their child's disability which turned out to be somewhat different in the South Asian group in this study. This doesn't imply that they need to know everything about every culture there is. Instead, it means that they should be cognizant of the fact that different cultures define typical development, disability, its causes, and appropriate treatments differently, and that having a child with a disability may have different personal and social implications for parents and families. Most mainstream professionals interacting with immigrant families are trained in the western medical model of disability which predisposes them to assess and treat children within the bounds of a western timetable of development. South Asian mothers in this study as well as in other studies have presented with a mixed model of disability which partly subscribes to mainstream causes and treatment, while partly still believing in spiritual/religious causes and treatment. Some, but not all, South Asian mothers in this study initially used traditional (e.g., boys talk late) or religious (e.g., result of past sins, or will of God) explanations

for their child's disability, and after research and guidance from professionals, some came to understand it as a biological disorder, while others still believed it was up to God to help them.

In addition, South Asian mothers in this study and in past research did not always volunteer this information readily. They may have a tendency to do as they are told due to a cultural hierarchy that results in a strong belief in doctors knowing best. Moreover, as indicated by parent interviews in this study, they are aware of the lack of services back in their country of origin and may feel grateful for the support they are getting. Therefore, when working with immigrant families, it is essential for professionals to consider cultural practices and be more deliberate in their efforts to ask culturally relevant questions, to be more curious and non-judgemental in understanding parents' journey, experience, expectations and goals.

Similar to complimentary and alternate treatment practices used in the west (e.g., special diets, sensory exercises), South Asian parents may want to try alternate traditional treatments as well, such as Ayurveda and Homeopathy (used by a few South Asian families in this study). If parents consult them on the use of these treatments, professionals need to discuss these options openly with parents, while presenting them with any evidence for its potential harm. This could be used as an opportunity to explore their understanding of causes and why they are choosing to opt for these alternate treatments, and negotiate for a trial period or limits with doses etc., if there are any known harms of these treatments.

Several mothers expressed that their ability to speak English better would have helped their child as well. Professionals at all levels of services need to be aware of this, and check in with parents about their understanding of process/paperwork for different services. In addition, they need to focus on avoiding jargon in their interactions with families in general, and more so with ESL families.

Mothers from both groups experienced mental health difficulties, with South Asian mothers reporting significantly more mental health issues. It is essential to provide parent support and do frequent check-ins with all parents who are dealing with the daily challenges of raising a child with DD. However, there is greater stigma associated with mental health issues within the South Asian community, and mothers are less likely to bring up their mental health challenges in their interactions with professionals, and less likely to get help for them. Since lower mental health issues were found to be related to better positive outcomes in South Asian mothers, it becomes even more important for professionals to be aware of changes in mothers' affect, and to check in with them, and possibly provide them with parent counselling or refer them to a clinician who works with immigrant parents of children with DD.

Positive coping strategies were one of the most consistent predictors of positive impact in both Canadian and South Asian groups. It would be helpful to not just develop and implement treatment plans for the family, but also to empower parents by educating them about their child's disability, the terminology, causes and treatment, so that ultimately they are able to accept their child with his or her strengths and challenges. It will also be beneficial to provide some parent counselling and supporting parents in creating a network of support around them to promote more positive outcomes. For example, connecting them with cultural service organizations in DD such as the South Asian Autism Awareness Centres (SAAAC), Smile Canada etc., or parent groups and counseling at community agencies serving children with DD. Clinicians could support parents by targeting specific goals as problem solving real life challenges, relaxation exercises, improving sleep etc., using a CBT type intervention, and promote overall compassion and acceptance of their child's challenges using mindfulness and acceptance approaches

(Anclair, Lappalainen, Muotka, & Hiltunen, 2018; Cacia, Anderson & Moore, 2016; Neece, 2014; Singh et al., 2014).

Strengths, Limitations and Directions for Future Research

This study was exploratory in nature and comes with certain strengths and limitations.

Sample Characteristics and Representativeness

Strengths: There is lack of cross cultural research across most variables examined in this study, particularly with South Asians in Canada. Especially in a city like Toronto where immigrants make up close to half of the population, and there is such immense diversity, one would expect there to be more research done to understand experiences of clinical populations as we try to provide appropriate services to families. Most clinical research just lists ethnicity as a demographic descriptor. This is the first study that has examined multiple variables related to parents' outcomes in raising a child with DD in the South Asian immigrant population in Canada. There has been some research in the USA and UK with South Asian immigrants, and some Canadian research exploring immigrant experiences as a whole, but none that has studied South Asian mothers with a child with DD within the Canadian context. I was able to capture the immense diversity of the South Asian sub continent within my South Asian sample as there were participants from five countries, speaking 11 different languages, and practicing different religions including Hinduism, Islam, Sikhism and Christianity. A lot of the existing literature has focused on a particular country or religion, and the snapshot of diversity that I have captured in this study is one of the first in the DD literature

Limitations and Future Research: The diversity within my South Asian sample, though a strength in some ways, might be influencing the results as well, since there might be some within group differences that were not captured in this study. Moreover, there might be some statistical

limitations affecting my results. Even though the sample size was acceptable based on power analysis, a bigger sample would provide better power especially when examining so many variables. The regression analysis involved a large number of predictor variables for sample of 51 or 56 participants. This might be affecting the power of the model to predict outcomes. If there was a larger sample, perhaps some of the expected variables would significantly predict outcomes. Therefore, there is a need for future studies to duplicate or further examine these differences between a larger sample of South Asian immigrant parents and other cultural groups, and to examine within group differences in the South Asian group. Moreover, it would be very interesting to examine differences between South Asian parents of children with DD in their country of origin and South Asian immigrant parents here in Canada, along with studying understanding of disability within South Asian parents of typically developing children.

In addition, like most studies, this study required voluntary participation, and was not a part of a regular procedure within a clinical program. Therefore, there might be a bias in terms of who volunteered to participate in the study. The participants in my study might be inherently more empowered to share their experiences and frustrations, might be coping better and might have wanted to participate in order to promote more research and further enhance services for their children and future generations. Even though recruitment flyers were distributed locally within the GTA and across Ontario through social media as well, most participants in my study were either from urban or suburban areas around the GTA. This might reflect the concentration of services around these areas, and may not reflect the experience of mothers who are navigating services in rural communities.

I was not able to capture the socio-economic diversity within either sample. Even though there was variability in their scores on the Barratt measure, it was really challenging to score

parents' education and occupation in the South Asian sample, since many parents were highly educated, but working in low wage jobs. Since I completed close to half of the South Asian questionnaires with mothers in person at their homes, I witnessed some variability in overall socio-economic status, however, a number of these families were living in low SES areas and a few in public housing as well. There is no way for me to report on the Canadian group in a similar manner since they all completed the questionnaire online. Their Barratt scores however, did not reflect differences between the groups. Perhaps future research could use a different, more effective measure of SES such as median income to examine its relationship with outcomes of parents raising a child with DD

In addition, since the children in the two groups had significantly different adaptive skills, it is possible that the children were inherently different in the two groups, and thus may be confounding some of the results. I did enter their adaptive behaviour in the first step in my hierarchical regression, however, so this concern is negligible since any effect of child skill level should be controlled for.

Comprehensive Theoretical Model

Strength: Most of the existing South Asian literature on parents experiences of raising a child with DD focuses on two or three variables at the most, and I have not come across a study yet that uses an established comprehensive theoretical model to examine multiple inter-relationships between variables affecting parent outcome in this cultural group. I did not focus on one variable affecting outcomes, but used a well researched Perry (2004) model to understand the dynamic process of adaptation of South Asian parents dealing with challenges on an everyday basis. Moreover, I compared the nature and magnitude of these relationship between a

South Asian immigrant group and Canadian group receiving services within the mainstream service system in Canada.

Methodology and Measures Used for Data Collection

Strength: While a large majority of the existing literature on South Asian parents of children with DD has used qualitative methodology only, I used a correlational embedded mixed methods design, in which I collected quantitative questionnaire data as my primary source and semi-structured interview data as a secondary source of information, thereby providing a richer understanding of mothers' experiences. The quantitative questionnaires I used have been well researched and had mostly moderate to strong internal consistency reliability in my sample. Even though a number of these variables did not differ significantly between Canadian and South Asian mothers, I used my interview data to better understand and explain similarities and differences in mothers' experiences. In addition, only one study in the past with South Asian immigrants in the west has actually attempted to measure acculturation, and it did so using one question. I measured acculturation within a clinical population whereas most of the existing acculturation literature focuses on typically developing populations.

Limitations and Future Research: Even though I collected both forms of data concurrently, the sub-sample I purposely chose for the interviews was composed mostly of participants who completed the questionnaire early on and provided consent for an interview. Once I obtained saturation, I did not interview some of the mothers who participated in the later time frame of data collection and consented to be interviewed. It is possible that some of these similarities and differences between groups may have perhaps become more distinct. Perhaps without the time constraints that I had for data collection, a future research project could

intersperse interview participants a little more such that some of the later participants could be included in the pool of prospective participants to be interviewed.

Moreover, all the measures used in this study were developed, normed, and tested for reliability and validity in North America or Europe. A lot of these measures have not particularly been tested for cultural sensitivity. Even though most measures had acceptable to good reliability in the South Asian group, these measures may not be very sensitive to or be measuring similar concepts in South Asian mothers. Some of the measures involve a lot of jargon and confusing wording. This was challenging for some Canadian mothers, but presented with a significant limitation with the South Asian mothers. Even though a lot of mothers were proficient in English, they had difficulty with understanding certain culturally loaded phrases in the questionnaires. In addition, there were quite a few who either had the questionnaire translated by a family member or I translated it for them when completing in person, which might have affected the margin of error in responding to questions. Since there were multiple languages involved, it was not plausible to translate and back translate these measures in multiple languages, given the time constraints of my dissertation project. A future research project could compare and contrast some of these North American measures with those used in some quantitative studies done in South Asian Countries to determine a more valid and culturally sensitive measure for these constructs.

In addition, the acculturation measure was perhaps not sensitive in capturing the issues specific to immigrants with a child with DD. It has been used only with typical adult immigrants and most mothers were confused about the relation of the statements in the measure to their experience around their child's disability. I am not aware of a disability specific acculturation measure yet, but perhaps that will capture the nuances of cultural adaptation better than this

measure. Since acculturation has not been measured within parents of children with disabilities, a future project could conduct a participatory action research project to further understanding of how adaptation to a new culture would manifest itself in changed disability perceptions. It might also be interesting to examine if there would be differences between the understanding of first and second generation South Asian immigrants regarding disability in their child. This could be a true test of acculturation regarding disability over a generation.

Methods of Analyzing Data

Strengths: I used rigorous, mixed methods for analyzing my data. Less than 5% of my data was missing, therefore a limited amount of imputation was needed. In addition, the score distributions of most of my variables were within acceptable limits of normality and homoscedasticity. Most importantly, having conducted all the interviews myself and having access to rich qualitative data gave me the opportunity to present a unique perspective to the quantitative findings. For certain variables I was able to understand and explain differences between the two groups based on the data obtained from interviews.

Limitations and Future Research: Even though scores on most variables used in the t tests and regression analysis met guidelines for acceptable normality of distributions, some of these variables, including adaptive skills and positive impact measures had somewhat high levels of skewness. I made an informed decision to not transform these variables, but perhaps, transforming these variables might have lead to somewhat different results.

Moreover, even though my descriptive qualitative analysis was initially data driven, I finally presented my descriptive analysis of these interviews within the framework provided by the Perry model of parent outcomes, and combined these findings with the quantitative ones at the end. Perhaps if I did not bind myself to an existing model, and approached my interview data

using more interpretive data driven methods, such as grounded theory, I would have obtained a more sophisticated level of codes/themes.

Conclusion

Past research and the current study have established the fact that mothers of children with DD experience significant negative and positive impact simultaneously on the journey of dealing with the challenges in raising their child. As aptly described by some mothers in this study, it is a roller coaster ride with constant changes in their child and their circumstances. This impact of child related and other stressors on mothers was found to be significantly influenced by maternal mental health problems, their use of coping strategies and at times family hardiness. However, the current study uniquely contributed to this model by placing it within a cross cultural context in Toronto, Canada, where immigrants make up close to half of its population. South Asian mothers in this study encountered some additional challenges and barriers to successfully adapting to their child's disability. In spite of the importance of being culturally sensitive, most community service providers do not have formal means of training their staff in this practice. By comparing the predictors of positive and negative impact in mothers between Canadian and South Asian mothers, this study has further highlighted areas to focus on when working with South Asian mothers, and has taken a major step at filling this gap in research. However, it is important that future research continue to examine ways of providing culturally sensitive services to culturally diverse families of children with DD.

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Appendix A: SEMI-STRUCTURED INTERVIEW GUIDE

GENERAL EXPERIENCE

First I am going to ask you some general questions about your experience so far in raising a child with a disability.

1. How has your journey been so far since your child was diagnosed with _____ .
 - a. How old was he/she when he/she was diagnosed?
 - b. So its been _____ years since he/she was diagnosed
 - c. How would you describe your experiences in the past _____ years since his/her diagnosis

2. Please tell me about what it was like for you when he/she was diagnosed?
3. What was your understanding of _____'s diagnosis?

Probe: When did you first notice something was different in your child and what did you notice first?

Probe: What process did you go through once he/she was diagnosed?

Probe: What professionals did you go to initially, and since then?

4. Tell me a bit about any challenges that stood out for you during this time.
5. Tell me about some highlights or positive changes you might have experienced as a parent or as a person.

STRESSORS (*Do not say these headings out loud to the parents, these are only to guide you in covering the different sections*)

Maladaptive & adaptive behaviour (*If the parent has ALREADY talked about these items,, then DO NOT REPEAT these questions, only ask the questions that you don't yet have an answer for).*

- a. Describe some of the stresses that you have experienced over the years.
- b. Did your child have any behaviour difficulties?
- c. Tell me about your experience in dealing with his/her behaviours
- d. How independent is your child in daily life skills like personal care, helping at home, interacting with people etc.?
- e. How much do you think your child's skills and behaviours influenced your overall experience in raising him/her

from *No influence at all* (1) to *Extremely influenced* (10)by it.

Other life events:

- a. Did your family experience any big changes or major life events that added to your stress? How did you deal with it?

MEDIATORS (*Do not say any of these headings out loud to the parents, these are only to guide you in covering the different sections*)

Coping

1. Tell me a bit about what helped you cope with the challenges that are related to raising a child with a disability?

Probe: What kinds of things did you do in order to cope with the challenges you experienced on the way? (Only if needed)

2. How did these coping strategies work for you OR how much did you think they influenced your overall experience?
 - a. from *No influence at all* (1) to *Extremely influenced* (10) by it.

Self-efficacy

1. How confident did you feel in your own ability to be able to help your child?
2. Has this changed over time?
3. This confidence in your ability to help your child - how much do you think it contributed to your experience and feelings about it overall?
 - a. from *No influence at all* (1) to *Extremely influenced* (10).
 - b. Tell me more about it.

Mental Health Problems

1. How have you been feeling yourself? How have your experiences with your child affected you.
2. At different times, did your own state of mind and emotions influence your overall experience?

Family hardiness

1. In the event of any stressors or challenges, different families can cope in different ways
 - a. How do you think your family adjusts and copes?

2. What were some things that you as a family had to adjust with in order to deal with the daily challenges that your experience?
3. Were any of your relationships effected by the time and energy you had to dedicate to your child? How so?
4. To what extent do you think family's togetherness, adaptability and adjustment as a family influence
 - a. from *No influence at all* (1) to *Extremely influenced* (10).

Supports

1. What kinds of family supports did you have - from your spouse/partner, his/her family, and friends.
 - a. Was it helpful or did it add to your stress at times?
 - b. How much do you think it contributed to your experience and feeling.
2. What about more formal services - what kinds of services have you or your child received over the years?
 - a. How helpful have you found them to be?
 - b. What kind of challenges, if any, did you experience?
3. How much do you think it contributed to your experience?

CULTURAL INFLUENCE (South Asian only)

1. In what ways do you think being from the South Asian culture has influenced your experience of raising a child with a disability?

Probe: Were there ways in which it made things more difficult for you?

Probe: Were there ways in which it helped you with adapting and coping?
2. What was your family's reaction to your child being diagnosed and the following challenges you faced as a parent?
3. How did other people in your community react to your child's diagnosis? Have you experienced any difficulties socially?
4. Do you think your cultural background had a significant influence on any of the different aspects we talked about?

Appendix B: Information Letter used for the Current Study



Experiences of South Asian Immigrant and Canadian Mothers of Children with a Disability Information Letter

Dear Parents,

My Name is **Nidhi Luthra** and I am a PhD student in the Clinical Developmental Psychology Program at York University. I am writing to invite you to participate in a research study that I am doing as part of my PhD Dissertation, under the supervision of **Dr. Adrienne Perry**. The study is about the impact of raising a child with a Developmental Disability such as **Autism, ASD, PDD-NOS, Asperger's Syndrome, Intellectual Disability, Global Developmental Delay, Down Syndrome etc.**, on **South Asian immigrant** and **Canadian** mothers. This letter will describe the study and let you know how you can participate if you choose to do so.

This research has been reviewed and approved by the York University Human Participants Review Committee. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

What is the Study About?

Past research has suggested that having a child with a developmental disability has a great impact on the mothers. As you well know, mothers may experience stress due to the everyday challenges associated with taking care of a child with special needs. In addition, they may also experience some positive results such as increased self confidence, strengthening of family bonds etc. There are a number of different personal, family and support factors that may influence the overall experience that mothers report.

Although most mothers experience both challenges and gains in the process of taking care of their child with a developmental disability, their experience may vary somewhat based on their cultural values, beliefs, understanding of their child's disability, knowledge of the service system as well as social acceptance of their child in their own community. Therefore, the purpose of this study is to explore whether these differences between cultures influence the mothers' experience of raising a child with a developmental disability.

The goal of this study is to understand the commonalities and differences in the experiences of South Asian Immigrant mothers and Canadian-born mothers, in order to identify ways to help mothers cope better and to have a positive experience with their child. There has not been much research done in order to explore these variations, and it is extremely important to do so because it could help professionals do a better job of understanding families' needs and responding to them individually and more effectively.

What is Involved?

- If you choose to participate, we ask that you complete the questionnaire found in this package. It will take about 30 to 45 minutes to complete.
- You can also choose to complete this questionnaire online.
 - If you are a **South Asian Immigrant** mothers, please go to this link (**Password: matexsa**) to access the questionnaire https://www.surveymonkey.com/s/matex_sa
 - If you are a **Canadian** mothers, please go to this link (**Password: matexcan**) to access the questionnaire https://www.surveymonkey.com/s/matex_can
- In order to understand your experience in more depth, we will also be conducting some individual

interviews with mothers, which would take about 30 minutes on average. If you choose to participate in this interview, we will arrange for a time to meet you in person or talk to you over the phone.

- Your child with a Developmental Disability will not be directly involved in the study.

What are the Potential Risks and Benefits?

As a token for giving us your time and supporting this research, we will be providing you with an honorarium of \$35. We will be mailing the honorarium to you.

- If you are completing this questionnaire using the hard copy attached, please fill out the receipt included with this package and return it to us in the envelope provided.
- If you are completing this questionnaire online, please fill out your name and address in the space provided at the end of the questionnaire

The questionnaire and interview will involve providing information about difficult times as well as successes that you have experienced on this journey of taking care of your child. We do not anticipate any significant risks associated with participating in this study.

Will it be Confidential?

Yes, we will maintain your privacy throughout the study and afterwards. All information you provide will be confidential within the limits of law (e.g., if a child is in danger we must break confidentiality).

We will only be asking for your name on the consent form, after which you will be assigned a participant number and your consent form will be kept in a separate file, and only Dr. Perry, I and the researchers closely involved in this study will have access to it. All of the actual questionnaire and interview data will only have your participant number on it.

We will be audio recording interviews in order for us to have accurate interview data to summarize. We will transcribe the audio recordings without names and then destroy the audio files. All information will be stored securely in a locked filing cabinet at York University for 10 years. When presenting or publishing the results of this research, we will never use your name or identifying information without your written permission.

Do I have a Choice about Participating?

Yes, your participation in this study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future. You will still receive the same services from any agency that you are involved with.

You can stop participating in the study at any time, for any reason, if you so decide. If you decide to stop participating, you will still be eligible to receive the honorarium of \$35 for agreeing to be in the project. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible

What is the Next Step if I want to Participate?

If you are willing to participate,

- **please sign the consent form (there is also a copy for you to keep).**
- **If you would also like to participate in the interview, please check off the box on the consent form, and sign the consent form for audio recording.**
- **Please complete the questionnaire and return the questionnaire, consent forms and receipt (if**

completing a hard copy of this questionnaire) to us in the envelope provided. Postage has already been paid. Please return your completed questionnaire within two weeks of receiving this mailing.

If you have any questions about the study, please call our lab at **(416) 736-2100 ext. 40266 (leave a message for Nidhi)** or Dr. Adrienne Perry at ext. 33765 or email me at perrylab@yorku.ca.

Thank you for reading this material and considering this request.
Sincerely,

Nidhi Luthra M.A.
PhD Candidate
Clinical Developmental Psychology
York University

Adrienne Perry, Ph.D., C. Psych., BCBA-D
Psychologist, Associate Professor,
York University

APPENDIX C: Consent Form Used for the Study



Experiences of South Asian Immigrant and Canadian Mothers of Children with a Disability

Parent Consent Form for Study

I have read and understood the description provided to me about the research being conducted by Nidhi Luthra and Dr. Adrienne Perry. I understand that the research has been approved by the York University Human Participants Review Committee.

I understand that my participation in the study is completely voluntary and I may choose to stop participating at any time. My decision not to volunteer will not influence the nature of my relationship with York University either now, or in the future. I understand that I will be provided with a \$35 honorarium. If I decide to stop participating, I will still be eligible to receive the honorarium of \$35 for agreeing to be in the project. My decision to stop participating, or to refuse to answer particular questions, will not affect my relationship with the researchers, York University, or any other group associated with this project. In the event that I withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

I understand that all information collected as part of this study will be kept confidential, except as required or allowed by law, and that specific information about myself and my child will only be seen by those directly involved in the research. I also understand that when results are shared in papers or presentations, no information that could identify my family will be used.

I have been provided with the proper information to contact someone if I have any questions about this study.

- I agree to participate in the study by completing a questionnaire.
- I would also be willing to participate in the individual interview (**Please read the Consent for Audio Recording Interview, and sign if you agree**)

Signature of mother

Name (please print)

Date

This consent is valid for maximum of one year from the date of signing

- I would like to receive a summary of the **results** of the study
- I can be contacted in the future for other research projects.
 - Email: _____
 - or
 - Mail: _____

Appendix D: INTERCORRELATIONS WITHIN BLOCKS

(White boxes – Canadian; Grey - South Asian)

Parent Outcomes: Correlations				
	Stress	Positive Gain	FICD Positive	FICD Negative
Stress	1			
Positive Gain	-.309* (p=.021)	1		
	-.380** (p=.006)			
FICD Positive	-.155	.742** (p=.000)	1	
	-.402** (p=.003)	.452** (p=.001)		
FICD Negative	.734** (p=.000)	-.088	.135	1
	.696** (p=.000)	-.395** (p=.004)	-.067	

*. Correlation is significant at the 0.05 level (2-tailed).
 **. Correlation is significant at the 0.01 level (2-tailed).

Child Stressors: Correlations			
	Child's age calculated in years	SIB-R adaptive AE scores	SIB-R general maladaptive index
Child's age	1		
SIB-R adaptive AE scores	.299* (p=.026)	1	
	.377* (p=.016)		
SIB-R general maladaptive index	-.054	.040	1
	-.299* (p=.033)	-.008	

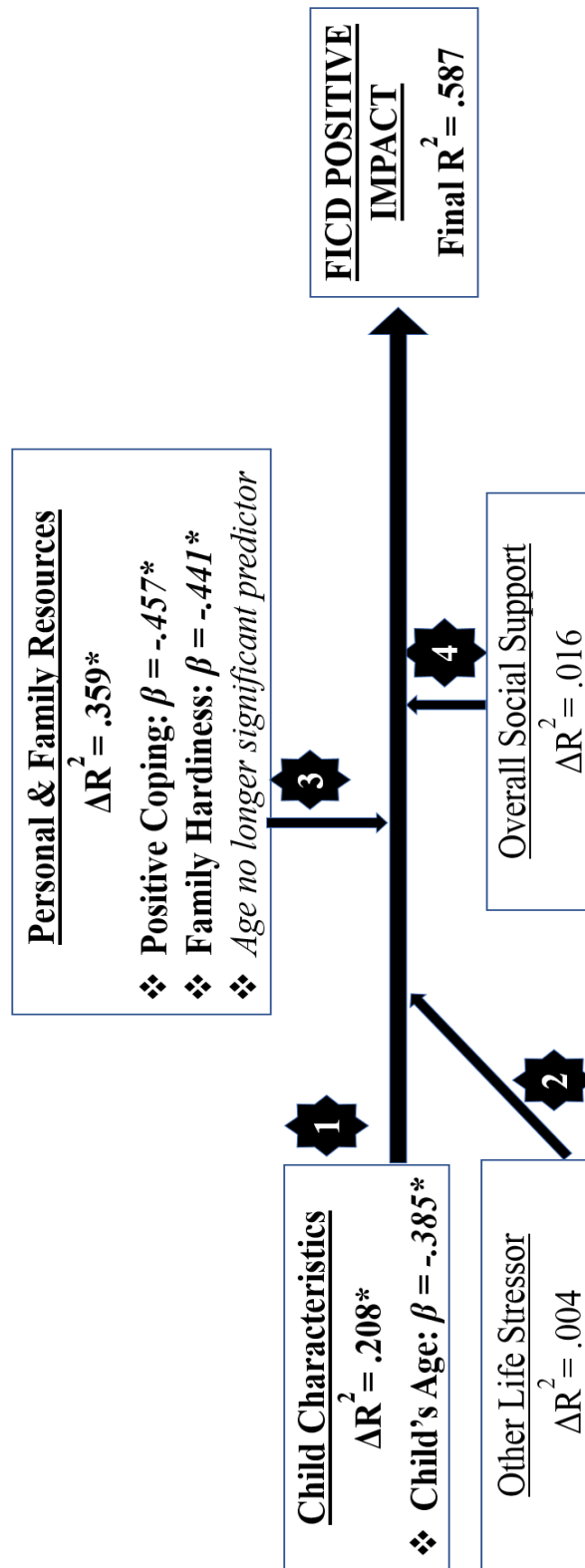
*. Correlation is significant at the 0.05 level (2-tailed).

Other life stressors: Correlations	
	Grand total number of other life events for the family
Number of financial effects or things family had to do without	.309* (p=.021)
	.460** (p=.001)

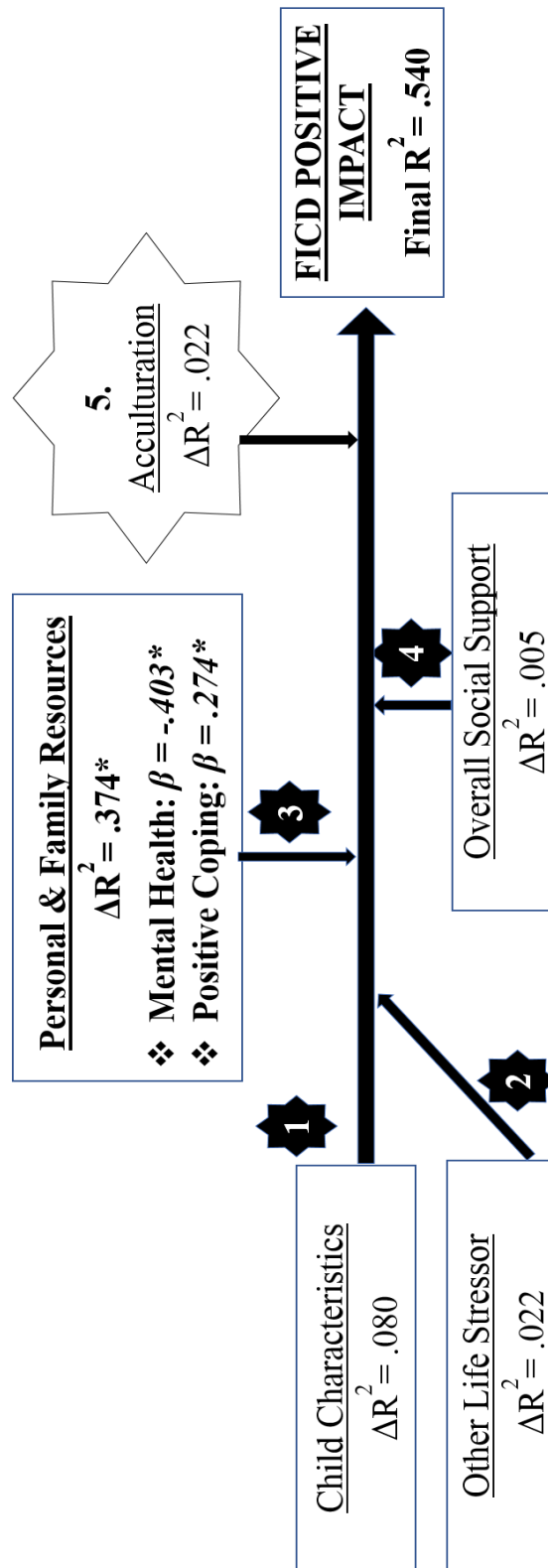
*. Correlation is significant at the 0.05 level (2-tailed); **Significant at 0.01 level (2-tailed)

Resources – Personal and Family: Correlations								
	Self Efficacy	Mental Health	Positive coping	Negative coping	Family Hardiness	Marital Satisfaction	South Asian Identity	Canadian Identity
Self Efficacy	1							
Mental Health	-.451** (p=.000)	1						
	-.426** (p=.002)							
Positive coping	.287* (p=.032)	.188	1					
	.387** (p=.005)	-.234						
Negative coping	-.277* (p=.039)	.573** (p=.000)	.274* (p=.041)	1				
	-.470** (p=.001)	.570** (p=.000)	-.174					
Family Hardiness	.655** (p=.000)	-.315* (p=.018)	.193	-.195	1			
	.629** (p=.000)	-.330* (p=.018)	.396** (p=.004)	-.289* (p=.040)				
Marital Satisfaction	.102	-.327* (p=.030)	-.040	-.286	.242	1		
	.316* (p=.034)	-.465** (p=.001)	.348* (p=.019)	-.477** (p=.001)	.329* (p=.028)			
South Asian Identity	.378** (p=.006)	-.235	.490** (p=.000)	-.072	.332* (p=.017)	.485** (p=.001)	1	
Canadian Identity	.152	-.152	.073	-.180	.138	.331* (p=.026)	.275	1
Correlation is significant at the 0.01 level (2-tailed).								
*. Correlation is significant at the 0.05 level (2-tailed).								

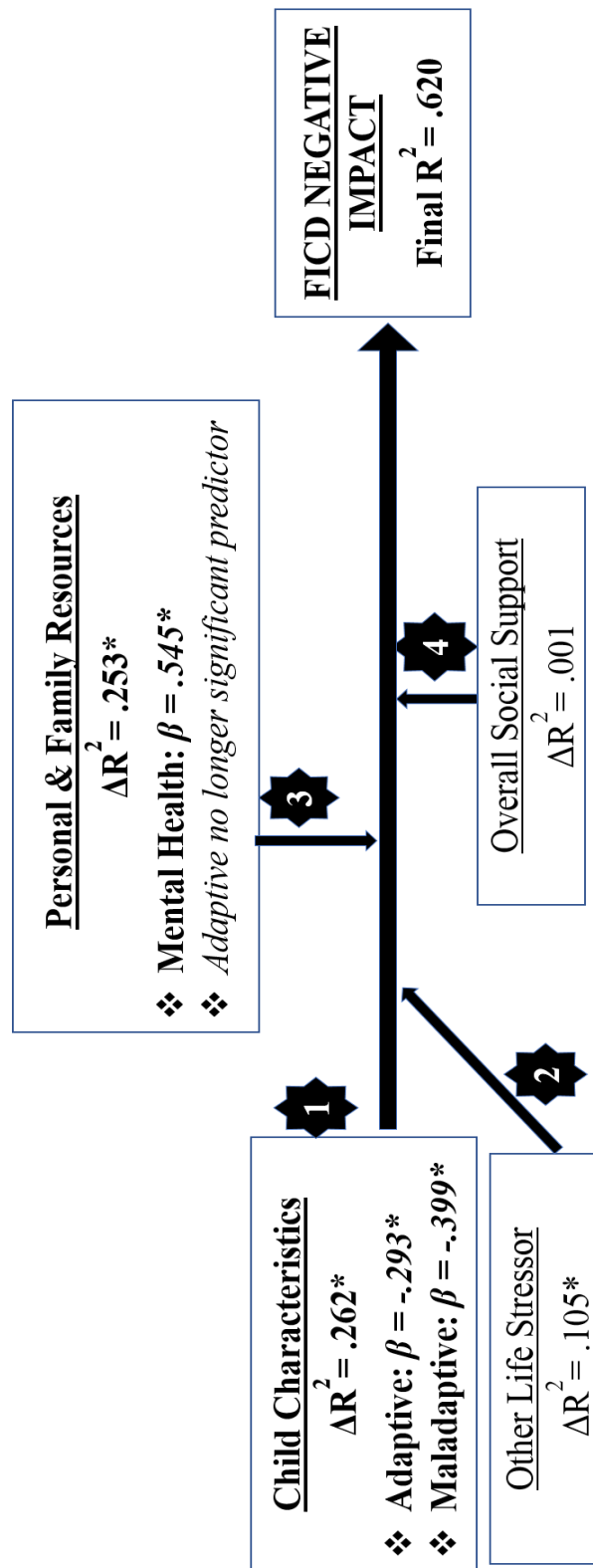
APPENDIX E: PREDICTORS OF POSITIVE IMPACT IN CANADIAN GROUP



APPENDIX F: PREDICTORS OF POSITIVE IMPACT IN SOUTH ASIAN GROUP



APPENDIX G: PREDICTORS OF NEGATIVE IMPACT IN CANADIAN GROUP



APPENDIX H: PREDICTORS OF NEGATIVE IMPACT IN SOUTH ASIAN GROUP

