

Exploring the Experiences of Mothers
of Children with Developmental Disabilities

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ABSTRACT

This qualitative study explores the experiences of mothers who have children with developmental disabilities. I sought to understand both the positive aspects of mothering a child with a disability, such as feeling love, joy, and pride for their child; as well as to understand the potential negative aspects of mothering a child with a developmental disability, for example, experiencing stress, guilt, and sadness. I also explored how the mothers reflected on this experience of mothering a child with a disability. Furthermore, I sought information on what services and/or supports these mothers found helpful, and why.

Six mothers were interviewed for this study. From these interviews, six themes were identified: 1. positive experiences and emotions; 2. mothering a child with a developmental disability as difficult, stressful, and overwhelming work; 3). mothers' fears for their children; 4). mothers' sense of loss; 5). mothers' relationships with their non-disabled children; and 6). mothers' perceptions of the helpfulness of formal and informal supports.

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Chapter One: Introduction

This study explores the experiences of mothers of children with developmental disabilities. As an overall focus, I sought to understand what it is like to *mother* a child with a developmental disability. While it would be difficult to touch on every topic related to mothering a child with a developmental disability, I attempted to look at different aspects that are related to it, including the mothering role, and what responsibilities these mothers take on while caring for their child. I explored not only the negative feelings, such as guilt, sadness, loss, and stress, but also the positive experiences for these mothers, including feelings of love, happiness, joy, and pride for their child and/or children. I also sought to understand how the mothers reflected on this mothering experience, and what supports, if any, have assisted them throughout the experience of mothering a child with a disability, and what support and/or services they require from helping professionals.

It was also my intent to gather from this research the stories that have possibly remained unheard by others, as I did not believe that mothers of children with disabilities have been given the opportunity to discuss and share their overall experiences. It was my hope that through the information I gathered, I would not only add to the literature on mothers of children with disabilities, but also suggest improvements to social work practice to better assist mothers and their children. Further, I hoped to support and validate the mothers I interviewed in sharing their stories and by acknowledging their caregiving role.

This thesis begins with a discussion of the research problem and the study objectives in Chapter Two. Chapter Three presents the current body of literature on children with developmental disabilities and their mothers. Following this, in Chapter Four I present the methodology used to carry out the research project, including the theoretical framework and

specific methods/techniques utilized. I also discuss the data analysis, including the methods of coding used, as well as how the results were interpreted. I then present the study results of this research in Chapter Five. Chapter Six discusses the themes found, including an interpretation of the findings. I conclude in Chapter Seven, with my conclusion and recommendations to social work practice and research.

Chapter Two: The Problem

Overview of Children with Developmental Disabilities in Canada

In Canada, the past few decades have shown an increased societal awareness for those who are living with some kind of disability (Human Resources and Skills Development Canada [HRSDC], 2010). In 2006, approximately four million people in this country reported living with a disability of some kind, which may include challenges with: vision, pain, mobility, memory, learning, hearing, emotions, development, communication, and agility/dexterity (HRSDC, 2010). Of these, less than 4% (or 200,000) were children aged 14 years or younger. Of the 200,000 Canadian children living with a disability, slightly less than 34% of boys and 25% of girls have been diagnosed with a developmental disability (HRSDC, 2010). Furthermore, the disability rate among children aged 5 to 14 years (not specific to developmental disabilities) has markedly increased. In 2001, 4% of children in Canada were considered to have some kind of a disability, and in 2006, the number increased to 4.6% (HRSDC, 2010). The reason for this sizeable increase was not stated in the report; however, due to the increase in disability rates in children, there has been an increase in various strategies used to ensure that these children are treated respectfully and protected from discrimination. This includes the use of inclusive education, allowing children with disabilities to learn together with their peers who do not have disabilities and ensuring teachers working with students with disabilities are given training, so they may do so in the most appropriate and effective manner (Sharma, Forlin, & Loreman, 2008).

While there is an awareness of those who live with disabilities in Canada, supports and resources are offered primarily to the disabled child (e.g., occupational therapy, speech and language services, physiotherapy, etc.) and not to their caregivers. Obviously providing services

to children with developmental disabilities is important, but it is also necessary, if not critical, to acknowledge the struggles and challenges caregivers face when caring for a child with a disability, and to provide them with supports to help cope with these struggles.

As a social worker working with families of children with disabilities, the majority of people whom I have met have been biological mothers. In my experience, it is mothers who are primarily responsible for the caregiving responsibilities, including making and attending the numerous appointments with a series of professionals (e.g., doctors, therapists, social workers, etc.). I have found it is the caregiving mothers who bear the greatest amount of responsibility while often receiving little assistance. Mothers seem to be neglected and not particularly well-served by professionals or workers with which they are involved. It is this observation that prompted me to explore mothers' experiences, with the intention of listening to their stories and understanding how they could be better served in the future by helping professionals.

Additionally, I was interested in exploring the experiences of mothering a child with a developmental disability. While many researchers have examined how mothers are affected (usually negatively) by having a child with a developmental disability (Cameron, Snowdon, & Orr, 1992; Eisenhower, Baker, & Blacher, 2009) they have not examined the mothering experience of raising such children. In other words, I wanted to know what it is like *to mother* a child with a developmental disability. Moreover, many of the studies conducted to date tend to focus on one area or issue related to parenting a child with a disability, such as parenting stress (Cameron et al., 1992; Eisenhower et al., 2009; Meirsschaut, Roeyers, & Warreyn, 2010) or difficult child behaviours (Boström, Broberg, & Bodin, 2011; Eisenhower et al., 2009). What appears to be missing in the literature is an examination of the overall or global experience of mothering a child with a developmental disability.

Purpose of the Study and Study Objectives

The overall purpose of my study is to explore the experiences of mothers who have children with developmental disabilities. While doing so, I explore mothers' emotions and experiences (both positive and negative) of raising a child with a developmental disability, as well as the type of supports (both formal and informal) that they received and their perceived helpfulness. I also explore how these mothers' experiences of raising a child with a disability may differ from raising a child without a disability, as all women in my study had at least one other child without a developmental disability.

I chose to examine mothers of children with developmental disabilities, in particular, because in my experience these mothers receive different treatment from family members, friends, and even professionals than mothers of children who have more obvious or visible disabilities, such as a physical disability. I believe the "hidden" or invisible nature of a developmental disability can present a unique or additional challenge to mothers. For instance, children with less obvious developmental disabilities often receive more criticism and judgment from the public than children with developmental disabilities that are more obvious to the observer (Gill & Liamputtong, 2013). As such, onlookers can often make misinformed or inaccurate assumptions about a child with a developmental disability and her/his behaviour. Consider the following example. A mother enters a hospital with her child with autism, and her child immediately begins to yell and cry due to the noise and overwhelming stimulation. It is quite likely that those around her, including other patients, visitors, and medical staff may believe, and perhaps even comment, that that child is behaving 'badly'. They may attribute the outburst to poor parenting or an out-of-control child. They likely would not consider that the child has a disability, as the child "looks" to be developing at a typical level. These kinds of

public perceptions/reactions might also lead to different emotions from the mother, including embarrassment for her child's behaviour, anger, and frustration towards those judging her and her child, or even feelings of shame due to not being able to control her child in public. It was my hope that by interviewing mothers of children with developmental disabilities, I would be able to share their experiences in my research in order to allow others to better understand what this experience might look like.

While many authors have explored the physical and emotional experiences of mothers who have children with disabilities (Cameron et al., 1992; Eisenhower et al., 2009; Meirsschaut et al., 2010), most have explored these experiences in connection with the child's difficult behaviour, which might be intensified due to their disability (Eisenhower et al., 2009). While this information is useful, it was my intent to explore the emotional reactions that mothers experience parenting a child with a disability more broadly (i.e., from first learning or suspecting a child's disability to well after the initial diagnosis). I wanted to understand how the mothers felt about having a child with a disability, what they were proud of while discussing their child, versus what they might be frustrated with. I also sought to understand how these mothers felt others supported them, and what they thought was helpful from professionals compared to what was not. Although it is important to understand how a disabled child's behaviour may impact their mother's emotional wellbeing, it is also important that researchers and practitioners recognize and understand the emotions that mothers experience simply from having a child with a disability. These emotions or feelings might include pride for their child with a disability; a sense of loss due to not having a child who will develop like mothers might have expected; joy in the accomplishments they witness in the child; or perhaps fear of what their child's life might be like as they get older.

A second objective of the study was to explore the various external factors that may contribute to mothers' emotional reactions, such as the lack of adequate assistance from both formal supports (e.g., social workers, staff at daycares and/or schools, doctors, etc.) and informal supports (e.g., family and friends). As a society we do not often seriously consider the voices of women in situations where they could provide valuable information and perspectives. If we are to work effectively with children with developmental disabilities and their mothers, it is critical that we have a full or holistic understanding and appreciation of their mothering experience.

Finally, as a personal goal, it was my hope to gain a better understanding of the mothers with whom I work, specifically to develop a stronger awareness of the additional resources and supports that may be required to assist them. While I am not a mother myself, I hold an interest in the unique experiences mothers seem to have. I also have always wondered, in general, why women are put in a position where they are ultimately responsible for their children, more so than fathers. When I started working with families with children with developmental disabilities, this observation became even more apparent, as I was able to see firsthand how mothers are often the ones who stay home with their child, plan and take them to appointments, and organize their programs. Through these observations, I was motivated to look more closely at the topic of mothering, and specifically what it is like to mother a child with a developmental disability. Although while meeting with a number of different mothers I have noticed similarities in their stories, I have also found that all of their stories are different and unique in some ways as well. While it is difficult to be able to completely understand what it is like to be a mother of a child with a disability unless you are one, I appreciated the opportunity to be able to meet with these women, and hear their personal stories and perceptions of what it was like when their child was first diagnosed, and what it has been like since that time for them.

Chapter Three: Literature Review

This section begins by discussing the experiences of children with developmental disabilities. I then discuss research that focuses on the experiences of caregivers of children with disabilities. Although my research is directed towards the mothering experience, much of the literature does not focus on mothers specifically but rather on caregivers, generally. As I did not wish to exclude any information that looked at the mothering experience, I chose to include relevant articles that focused on caregivers, which often includes fathers. Despite not being specific to mothers, this body of research does offer significant insight into the experience of mothers of children with developmental disabilities. Therefore, while these findings may not be only about mothers, I believed it would be important to include them in this literature review.

Following this section, there will be a review of the literature on the specific experiences of mothers of children with disabilities, which explores the daily experiences mothers go through when raising a child with a developmental disability, the stressors they may face, as well as the emotional and physical reactions they might have. Following these sections, I present the literature on the challenges and criticisms mothers of children with developmental disabilities encounter, and discuss ideas from mothering theory, including mothering blame, unfair expectations, judgment from others, and the intensive mothering ideology.

Children and Developmental Disabilities

A developmental disability is a disability that a person is born with or that begins before he or she turns 18; permanently limits a person's ability to learn; and can be mild or severe (Developmental Services Ontario, 2013). Developmental Services Ontario explains that, "People with a developmental disability may learn, understand or remember things at a slower

pace than others. This can affect their personal care, language skills, and their ability to live without support” (Understanding Developmental Disabilities section, 2013, para. 2).

The most common type of developmental disability is autism, which falls under autism spectrum disorder (ASD) and is a neurological disorder (Autism Society of Canada, 2010). Autism affects the functioning of the brain, which can create challenges with both social interaction and communication, and can result in unusual patterns of behaviour, interests and activities, with some being destructive or harmful (e.g., skin picking, head banging, and biting) (Autism Society of Canada, 2007). Of all the neurological disorders affecting children, autism is the most common (Autism Society of Canada, 2010).

It is important to note that having a developmental disability is not the same as having an intellectual disability (ID), which is a term that has replaced the outdated (and offensive) term “mental retardation” (The Arc, 2011). One important difference between the two disability types is the fact that the definition of a developmental disability does not include an IQ limitation, whereas the definition of an ID requires that the person experience significant limitation in both adaptive behaviour, as well as intellectual functioning (The Arc, 2011). However, it is also important to recognize that while these two terms differ, they can co-occur. That is, a child with a developmental disability may also have an ID. A person should not, however, assume that if a child does have a developmental disability, she or he automatically has an IQ limitation.

While there might be a certain expectation that a specific developmental disability presents itself in the same way for each person, this is not the case (Autism Society of Canada, 2007). For example, one child with ASD may display completely different symptoms than another child with ASD. For instance, a person with Asperger’s Syndrome may do well academically, and require little or no assistance from professionals. On the other hand, there

may be a child with a more severe form of autism who, due to sensory, behavioural, or communicative issues, is unable to function without the assistance of a specialized plan both at home and at school. In any case, it is important to understand that no two children are alike simply because they have both been diagnosed with ASD, or any other developmental disability.

Caregivers of Children with Developmental Disabilities

While this thesis focuses on mothers who have children with developmental disabilities, as discussed above it is appropriate nonetheless to begin this discussion with a review of literature on the experiences of mothers and fathers, or the caregivers of a child with a disability. Overall, the literature on children with disabilities often does not focus on mothers specifically, but instead, is gender neutral, and looks at “caregivers”. Although these studies are gender-neutral, they offer insight into the experience of mothering (and fathering) a child with a disability nonetheless. The discussion below examines the experiences that mothers and fathers face when they have a child with a disability, as well as their perspectives on this experience of parenting. There will also be some exploration of the positive experiences noted by caregivers, as well as the challenges or difficulties.

Within the body of literature on caregivers’ experiences of caring for a child with a developmental disability, studies tend to focus on the negative experiences or the burdens of caregivers (Bristol, 1987; Feldman, McDonald, Serbin, Stack, Secco, & Yu, 2002; Heiman, 2002; Nankervis, Rosewarne, & Vassos, 2011; Stuart & McGrew, 2009). In terms of negative emotions and experiences that are associated with parenting a child with a developmental disability, caregivers often report higher levels of anxiety, stress, and depression than caregivers of non-disabled children (Bristol, 1987; Feldman et al., 2002; Heiman, 2002; Nankervis et al., 2011; Stuart & McGrew, 2009). Feldman et al. (2002) examine the onset of depressive

symptoms in parents of children diagnosed with, or at risk of being diagnosed with, a developmental disability (of the 178 caregivers who participated in the study, 153 were biological mothers). The study found that 20% of caregivers of toddlers who either had, or were at risk of having, a delay scored over the clinical cut-off on the Beck Depression Inventory (a scale to assess depressive symptoms). Overall, 40% of the participants experienced depressive symptoms that ranged from mild to severe. The authors also found that depressive symptoms were higher for parents when the cause or reason for the delay was unknown, versus for parents who were already aware of what syndrome their child had. The authors argue that by understanding the effect of a child's diagnosis on a caregiver, more appropriate (and effective) services can be identified for the family.

Heiman (2002) examined parents' perspectives on having a child with a disability. Although not specific to developmental disability, Heiman (2002) found that parents' realization that their child had a disability was often the hardest and most shocking experience for them, often including negative emotions similar to those of bereavement. Heiman (2002) also noted that both mothers and fathers of children with delays experience greater stress, higher levels of depression, feelings of restriction, and more health problems than parents who have non-disabled children. This is not surprising given that not only do parents who have children with disabilities face the typical pressures of family life, but they also are required to adjust to having a child with special needs. Although mothers and fathers in the study reported feeling negatively about the diagnosis initially, approximately 75% of the parents reported these negative feelings became more positive over time, and resulted in the parents feeling acceptance, love, and joy for their child.

Bristol (1987) whose study focused on children with autism or with severe communication impairments, found that more severely disabled children seemed to have less adverse effects on their caregivers' marriage than did children with less obvious handicaps, or mild symptom severity. While this was not discussed in-depth in the article, Bristol suggests that this may be due to the fact that when a family has a child with a severe disability there is less ambiguity about the diagnosis and, therefore, they may experience less stress than parents who do not fully accept their child's (less severe) disability.

On the other hand, Stuart and McGrew (2009) examined the experiences of 78 caregivers of children diagnosed with autism within a six-month period. Findings from this study showed that the greater the symptoms of autism, the higher the burden was for mothers, fathers, and families as a whole. However, there did not appear to be a relationship between marital burden (the parent's adjustment to the diagnosis) and symptom severity. When focusing on the social support that parents received from both friends and family as well as care providers, there was evidence that suggested families with more support have lower levels of caregiver, marital, and family burden (which looks at how well a family is adjusting to the diagnosis of a child with ASD). The authors note that, "...caring for a child with an ASD presents very intensive and stressful challenges that tend to stretch the resources of the caregiver to near breaking point, and may be easily overcome by additional stressful events" (p. 94).

Woodgate and Ateah (2008) discuss the experience of parents (both mothers and fathers) who have a child diagnosed with autism. The authors interviewed 16 families in total, with a total of 21 participants. The parents were asked what their lives looked like before, during, and following their child's diagnosis. The parents in this study described parenting a child with autism as "living in a world of our own" (p. 1078), and talked about feeling that they needed to

be responsible for every aspect of their lives, especially surrounding challenges of caring for a child with autism. The parents also discussed feeling isolated, and noted that they felt this isolation was due to a general lack of understanding by society; not having a ‘normal’ way of life; feeling they were disconnected from their families; and feeling they were dealing with an unsupportive system, which referred to all child-related agencies that were in place with the goal of advancing the development of their child with autism. For this last point, the parents talked about feeling that services were inaccessible, and involved unsupportive professionals who lacked knowledge (and training) in autism, and who made the parents feel they were being separated or isolated from their own child. In order to combat these feelings of isolation, parents became vigilant, monitoring all aspects of their child’s world, in order to ensure they, as parents, were doing the best they could for their child. The parents also talked about protecting them and their family’s sense of self. That is, to not “...let autism get the better of them or their family, or else this would only lead to further isolation” (p. 1080). The final way that the parents stood up to feelings of isolation was by “fighting all the way” (p. 1081), and ensuring that the system was working for them, and offering their child appropriate and useful resources. The authors of this study note that the parents they interviewed exemplified how having a child diagnosed with autism can ultimately define how they live in their world.

In reviewing the sometimes stressful situations presented when raising a child with an intellectual disability, Nankervis et al. (2011) investigated factors relating to stress that might lead to relinquishment (the family placing the individual in a care facility outside of the home). The authors collected their data by reviewing the case files of individuals with a disability who had been placed in a care facility in the past year, and by interviewing the staff members working with these families. Generally, the factors related to stress fit into three categories: 1. individual

characteristics of the disabled person; 2. characteristics of the family; and 3. the level of and nature of support received by the family. A common theme found within the case files was the emotional state of the primary caregivers (most of whom were mothers). The staff at the facilities reported the mothers suffered from exhaustion, depression, stress, and isolation. Nankervis et al. (2011) note that these symptoms were likely due to the fact that the caregiving role primarily fell onto them, consequently leading to higher levels of stress. The researchers also reported that mothers received little support from their families.

Although it appears that the literature on caregivers of children with developmental disabilities focuses primarily on the negative aspects of the caregiver experience, including children's challenging behaviours and parenting stress (as noted above), it is important to note that many researchers have attempted to explore the positive aspects of parenting children with developmental disabilities (Boström et al., 2011; Hastings, Beck, & Hill, 2005; Kayfitz, Gragg, & Orr, 2010; Stainton & Besser, 1998; Trute, Benzies, Worthington, Reddon, & Moore, 2010; Trute, Hiebert-Murphy & Levine, 2007). Kayfitz et al. (2010) remind us about the importance of looking at the more positive aspect of parenting children with autism:

Much of the literature on parents of children with disabilities to date has focused on the negative aspects (e.g., parenting stress) of raising such children... We believe it is equally important and useful to examine the positive aspects of raising a child with autism for both mothers and fathers if one is to achieve an accurate understanding of the complexities of such a process. (p. 337)

In their study, Kayfitz et al. (2010) set out to gain a better understanding of the relationship between parenting stress and positive experiences for parents raising school-aged children who have autism. The authors found that parents who reported positive experiences

also described experiencing lower levels of stress related to parenting. Interestingly, the authors found that mothers reported more positive experiences than fathers, and that mothers tended to be more aware of people who have disabilities, and had a greater sensitivity towards these individuals.

Hastings et al. (2005) interviewed 140 mothers and 60 fathers of children with intellectual disabilities and noted that mothers and fathers describe their positive experiences differently, with fathers showing less positive perceptions about their son or daughter than mothers, when looking at the contributions the child offers to the family. The authors used a Positive Contribution Scale (PCS) and formed nine subscales for this, which looked at topics related to positive contributions. Of the nine subscales, five showed significant differences between the mothers' and fathers' scores. These included the mothers', more than fathers', perceptions that having a child with a disability was a source of family closeness and family strength, offered feelings of happiness and fulfillment, and helped to expand social networks. However, of the nine themes, fathers scored higher on the last one, which talks about the parent feeling proud of their child when they acted in a way that showed cooperation. This was the only subscale that the fathers scored higher on.

Stainton and Besser (1998) interviewed a small number of families (nine families, with 15 participants in total) to better understand the positive outcomes associated with the caregiver experience, and consequently developed seven core themes based on participants' personal stories. The authors also noted two additional themes, although one was not based specifically on positive caregiving experiences, while the other theme related to negative experiences, which were mentioned by every family interviewed, therefore, warranting attention in the article. The seven themes surrounding positive outcomes include: 1. increased feelings of happiness and joy;

2. increased sense of priorities and purpose; 3. expanded community involvement and personal and social networks; 4. increased spiritual beliefs or faith; 5. greater family unity and closeness; 6. increased tolerance and understanding; and 7. increased personal growth and strength.

Through these themes, parents described the satisfaction they felt when their child challenged or contradicted others' preconceived views of their child's (dis)abilities. Additionally, parents reported learning advocacy skills and becoming adept at challenging professionals for the sake of their children's best interest. The eighth theme, as noted above, was related to the positive impacts children with disabilities have on others (outside of the family) and on the community, more broadly.

Finally, although the authors' purpose was to explore the positive aspects of having a child with a disability, they noted a common concern raised by families, and thus identified a ninth theme: dissatisfaction with the service system and professionals (Stainton & Besser, 1998). The families interviewed shared the negativity they received by professionals, many of which were doctors. Some stories included the underlying message from professionals that to have a child with a disability was a negative thing, resulting in feelings of sadness and grief. These findings further highlight the need for professionals to work well with families, and understand the parents' perceptions of having a child with a disability.

Positive caregiver experiences were also noted in a Manitoba-based study conducted by Trute et al. (2007). The authors found that parents experienced joyful moments (in addition to sad ones) when caring for a child with a developmental disability. Moreover, the authors noted that while parents of children with developmental disabilities do experience greater levels of parenting stress than parents who do not have a child with a disability, they respond to these challenges in a positive and resilient manner. In this same study, the authors explored mothers'

and fathers' appraisals of how childhood disability impacts the family, as well as the implications for family adjustment. Data were collected from mothers and fathers at six months following their entrance into childhood disability services and again at 18 months following their entrance into these services. The study found that although fathers had more difficulty assigning positive meaning to the impact childhood disability had on the family initially (i.e., during the first six months after receiving services), the fathers' perceptions did converge with the mothers' by 18 months. Also, both mothers and fathers held similar perspectives on the negative impacts that childhood disability may have on the family. While mothers in this study did show significantly lower levels of self-esteem than fathers at both six months and 18 months, both parents' scores were within normal range, and consequently not considered clinically significant. The authors also pointed out through this study that, although having a child with a disability can present feelings of sadness, parents could also experience positive or happy emotions at the same time (Trute et al., 2007).

Trute et al. (2010) also note that parents of children with disabilities experience both positive and negative emotions simultaneously, although their study did not examine children with developmental disabilities exclusively, but rather a range of different diagnoses including those with physical disabilities and mental health concerns. In their study, Trute et al. (2010) started out examining mothers' interpretations (or appraisals) of how their child's disability impacted family functioning, including how the mothers' level of positivity influenced this interpretation of the overall family functioning. The authors found that "positive appraisal combined with a positivity score... emerge as salient predictors of family adjustment; negative appraisal failed to predict family adjustment when controlled by level of mothers' positivity" (p. 41). The authors also noted that although caring for a child who has a developmental or

intellectual disability may be considered stressful, this does not mean that the family will suffer from maladjustment. However, when a mother perceives that her child's disability has brought positive aspects to the family's life, for example spirituality or stronger values, there tends to be a higher level of overall adjustment for the family.

In Hoogsteen and Woodgate's (2013a) article, the authors focus on how Canadian families living in rural areas embrace their children with autism. These authors looked at both the positive and negative aspects of parenting a child with autism in a rural area. The interviews were held with both mothers and fathers of children with autism who lived between 15 and 800 kilometers from any city or urban centre. The parents' children were between two and 23, and were diagnosed with autism, Asperger's Syndrome, or pervasive developmental disorder- not otherwise specified (PDD-NOS). The findings from this study noted that for parents living with a disabled child rurally, although they had less services and resources than in the city, they did offer safety and familiarity within their communities, and over time, their rural communities became a family of support for them and their children. Regarding safety and familiarity, the parents noted that the school had smaller class sizes (which they considered beneficial for their children), and a smaller, quieter environment in general. One parent talked about not having to worry if their child ran out onto the front yard, as there likely would be few cars to pose a threat to their child. Overall, the parents believed that while rural services may not be as accessible as those found in the city, the support families received from their rural communities far-outweighed the downfalls.

Hoogsteen and Woodgate (2013b) also looked at the experiences of parents with children with autism who live in rural areas of mid-Western Canada. In this study, the authors interviewed 26 families, and asked them to describe the experience of parenting a child with

autism while living in a rural community. The parents in this study talked about feeling like they were in a battle to make their child's invisible condition visible, as they fought to get their child the best quality of life, while also being supported and valued. The parents talked about feeling the other community members considered their children's negative behaviours (meltdowns, yelling, tantrums) as a sign of bad parenting, or simply having an uncontrollable child, versus seeing these behaviours as a consequence of the child having autism. Furthermore, the parents talked about their community's lack of understanding and knowledge surrounding their children, which led to the stigma of being different. This feeling of stigma led the parents to teach their communities about autism, as they also continued to advocate on their child's behalf. The parents explained that in order to combat this stigma, they tried to be open and honest about their child's autism, which ultimately assisted with the community becoming more supportive. Lastly, the parents in this study talked about feeling they were handling their child's autism on their own, and receiving little assistance from services. Sadly, the authors explain that all of the families received their child's diagnosis (autism) and never saw the specialist (or any other medical professional) again. This left the parents feeling frustrated, as they would have appreciated support following the initial appointment where their child was diagnosed with autism. Unfortunately, these parents were instead expected to do everything alone, including learning more about the diagnosis, and seeking out appropriate services for their child.

Boström et al. (2011) examined both the positive and negative impact that children with various intellectual delays specifically can have on parents. The purpose of their study was to examine the different temperaments of disabled children, and explore how they may positively or negatively affect parents. The authors determined three different clusters of children with regard to temperament: active and outgoing; disruptive; and passive and withdrawn. The authors noted

that children with motor impairment and Down Syndrome were generally found in the outgoing cluster, while children with developmental disabilities were found in all three clusters.

Furthermore, the children specifically diagnosed with autism were all considered to fall within the passive and withdrawn or disruptive clusters. Of these three clusters, the disruptive group appeared to affect mothers most negatively, compared to the children cited as passive and withdrawn, or active and outgoing. Interestingly, mothers of disruptive children were more negatively impacted than fathers, who showed little difference between temperaments. Boström et al. (2011) noted that this could be the case because mothers typically are the primary caregivers and spend more time with their children.

The Experiences of Mothers of Children with Disabilities

The review of the literature on parenting children with disabilities, including those with developmental disabilities, reveals that the bulk of the work to date focuses primarily on parents or caregivers. Given the centrality of mothers in the lives of children, and that women are socially constructed as the natural caregivers of children, surprisingly few studies examine the specific experiences of mothers of disabled children (Home, 2008). Home contends that research on children with disabilities rarely distinguishes a mother's experience from a father's experience. This represents a significant gap in the literature. Home concludes that there needs to be better understanding and support offered to mothers of children with disabilities, particularly children with an invisible or hidden disability (such as a developmental disability), who are often in a difficult caregiving role. As Home notes in her article:

Disabilities such as ADHD and autism spectrum disorder (ASD) are invisible one moment but obvious the next, as their manifestations vary according to demand, setting, and situation... While the era of "refrigerator mothers" is gone, some professionals still

hold mothers responsible for behavior problems related to these disorders now known to be neurobiological in origin, which only increases their burden. (p. 148)

In her study, Home focuses on the daily experiences of mothers who have children with hidden disabilities (e.g., ADHD and ASD), including getting children ready in the morning and preparing them for school; and for many mothers, getting themselves ready for their paid jobs outside of the home. Although many of the experiences reported by the participants were similar to the daily tasks required by most mothers (i.e., who do not have children with disabilities), there were some key differences. While Home (2008) acknowledges that mornings can be difficult for any mother, she notes that for these mothers, getting their children to complete simple tasks such as getting dressed and eating breakfast can take an enormous amount of emotional resources. For example, some participants recalled in detail how they would need to sit with their child and give verbal cues to get them dressed - first with one sock, then the other sock, then pants, then shirt, and so on. For some mothers, the daily routine of caring for their children often involves dealing with distraught and violent children. One mother in the study talked about the negativity that every morning starts with, as her daughter screams at both parents, telling them they are terrible, while refusing to listen to instructions. Another mother explained that although her son has settled down over the years, she still worries that his emotional and physical challenges will worsen again, and result in the same violence she saw in the past, which at some points resulted in the police being called. While this study is important in that it attempts to understand the routine of mothers of children with disabilities, and make visible their daily experiences, it again focuses on only a small area of the mothering experience (i.e., daily routine), as opposed to a larger, more holistic or global picture, which looks not only

at one pertinent section of a mother's life, but at her whole life as a mother of a child with a disability.

Another area related to the experience of mothering a child with a disability is the topic of single parent mothers. Levine (2009) argues that single mothers of children with disabilities receive minimal attention in research, and when they are looked at, this often involves the researchers looking at family deficits of this family system. By only looking at mothers who are within a two-parent system, the author argues we are also creating an assumption that a family is only present when there are two parents involved. Levine (2009) interviewed 15 mothers of children with developmental disabilities. This study discussed the resilience these mothers exemplified, and noted four themes that were introduced through the interviews that displayed resiliency-building. This included the mothers transforming the stigma of being a single parent into the perspective that they are chosen mothers, who preferred being single as opposed to being in an unhealthy or unsatisfying relationship. The mothers were able to discuss positives of being a single parent, including getting to be the sole decision maker, and not needing to worry about conflict with the father. A second theme discussed was these mothers' perceptions of their child's disability as normal. The mothers talked about not focusing on the disability, but rather, on their child, and what she or he needed because of who he or she was (with or without a disability). The third theme is surrounding family support, and discusses how these mothers' resilience increased by utilizing their available resources, or finding new ones to support them in managing their children's needs. This support often came from the mothers' families, which was considered critical when looking at the children's future needs. The last theme surrounding the resiliency-building process was "authoritative knowledge" (p. 411), which discussed the mothers' shift from listening to others, to valuing their own personal and subjective knowledge

surrounding their children. The mothers talked about how, when their children were initially diagnosed, their parenting practices were often dominated by others. However, over time these mothers began to see themselves as experts of their situation, and consequently began to trust their own thoughts and opinions, as opposed to only listening to others' viewpoints. Through this research one is able to understand why it is inappropriate to assume that a family must be comprised of both a mother and a father in order to be whole. It must also be understood that these women did not consider themselves unfortunate in their circumstance, but rather, gained strength, and indeed resiliency through it.

Meirsschaut et al. (2010) looked at whether mothers' experiences of caring for and raising their child with ASD differed from their child without ASD. The authors found that the mothers in this study talked about feeling their children with ASD affected the overall, daily life of their families and made normal family activities such as going to the park, visiting friends, or planning a vacation more difficult. The authors also discussed that the families must develop well-structured plans to deal with everyday life, such as discussing when they will leave, when they will be home, and whether or not the child can attend a certain function, as it might be too overwhelming for him or her. Mothers in the study also discussed their decision to leave their jobs, as they felt it was impossible to care for their child with ASD while also working full time. When comparing how these mothers felt their roles might differ between caring for their child without a disability, and their child with ASD, these mothers were noted to feel less confident in their care for the child with ASD. These results were formed by asking the mothers how well they felt they did certain tasks with/for their child, including having the child pay attention to them, helping the child to have fun, and feeding, bathing, or changing the child. As was hypothesized by the authors, mothers reported much lower self-efficacy when parenting their

child with ASD than their child without ASD. However, contrary to the authors' expectations, when looking specifically at feelings of guilt, these mothers more often felt guilty towards their child without a disability. These feelings of guilt often revolved around feeling they were not doing as much for their child without a disability as for their child with ASD, such as giving them enough attention.

Cameron et al. (1992) found that mothers who have had a child diagnosed with a developmental disability experience a range of negative emotions, including shock, loss, disbelief, guilt, anger, sadness, and frustration. Importantly, feelings of sadness, loss, and guilt are among the three emotions that mothers tend to experience for the longest period of time after learning of the diagnosis (Cameron et al., 1992). In fact, the feeling of guilt not only lasts for months by many mothers, but for some, it can be quite profound, lasting years after the child is diagnosed. Feelings of guilt may relate to many different things, often with the mothers focusing on what they did to cause their children to be delayed in some manner (Cameron et al., 1992). Cameron et al. (1992) also found that mothers could think of a number of reasons for why they might be responsible for their child's disability.

Although these negative feelings of guilt, loss, and sadness may decrease over time, for many mothers, they still remain present throughout their child's development (Cameron et al., 1992). Some have even described their emotions surrounding their child's diagnosis as a feeling similar to experiencing a child's death, as they felt as though they had lost a 'normal' child. As cited by Cameron et al. (1992), one mother explained that, "It's worse than a death. A death you grieve, you get over... Grieving the loss of the 'normal' child seemed to be superimposed on the stress and emotions associated with caring for a child with a disability" (p. 98). Another mother also explained that although she felt she needed time to grieve this loss, this was not given to her,

and instead, she was faced with the difficult task of not only being a new mother, but also caring for a child with a disability (Cameron et al., 1992).

Mothers of children with disabilities have also described feelings of isolation, believing that they are the only ones experiencing the challenges of caring for a child with a developmental disability (Cameron et al., 1992). Another theme presented by these authors was the lack of understanding from non-family members and the general public, which often led the mothers to feel that those around them were criticizing them or their child.

Others have also explored the relationships between mothers and their children who have disabilities. For example, Charles and Berman (2009) explore the relationship between mothers and children who have autism, in particular. The authors note that this is a subject that has not been explored through the use of maternal narratives and argue that:

Given the predominance of the good mother ideology and the stronghold attachment theory has...mothers of children with ASD have been silenced within much of the scholarly literature, specifically in regard to discussing their mother-child relationship positively or otherwise. (p. 183)

The authors conclude that indeed mothers of children who have ASD experience their relationship with their child in positive ways, such as having the opportunity for self growth, building compassion, accepting different situations, and learning to voice their concerns and stand up for their child with a disability. Although the authors of this study certainly recognize that having a child with autism presents challenges, it also highlights the positive aspects mothers encounter with their child as well.

While the articles discussed above may highlight different experiences of mothers of children with developmental disabilities, one of the key findings discussed in many of them is

the fact that although raising a child with a developmental disability can present challenges to mothers' physical and psychological wellbeing, there are also a number of positive aspects that come from raising a child with a disability.

The Health of Mothers of Children with Disabilities

While mothering can be an experience of joy and fulfillment, it can also present many challenges, including depression, stress and anxiety (Arendell, 2000). Although mothers have been found to be more satisfied with their parenting role than fathers, they have also been noted to experience more parental strain than their male partners (Arendell, 2000).

In their study, Meirsschaut et al. (2010) explored how mothers of children with ASD perceive the impact that children with ASD have on their families. The authors noted that mothers who have children with a diagnosis of ASD have higher stress levels than mothers with children without a developmental disability.

Other researchers have explored the emotional and physical reactions that mothers of children with developmental disabilities experience (Cameron et al., 1992; Eisenhower et al., 2009). Eisenhower et al. (2009) compared the physical health of mothers who have young children (3-5 years of age) with a developmental delay to mothers who have young children without any delays. Not surprisingly, mothers of children with delays reported poorer physical health than the mothers of children without delays. As discussed by the authors, mothers' perception of poorer health is often related to the behavioural challenges present with the children with disabilities, more so than any specific disability itself. In other words, a certain disability does not necessarily affect a mothers' health, but instead also depends on how hard the child is to manage due to his or her behaviour.

Mothering and Mother Blame

Given that the current study focuses on the experiences of mothers, it is appropriate (and necessary) to briefly discuss the culture of mothering and how it is presented in North America. The viewpoint for what being a mother means is something that is fluid and can be ever-changing (Medina & Magnuson, 2009). Indeed there is a culture of mothering in North America - women must be nurturing, self-sacrificing, and always be considered a mother first (Arendell, 2000; Jackson & Mannix, 2004; Kruger, 2003; Medina & Magnuson, 2009). To be a mother is to be feminine and womanly (Medina & Magnuson, 2009), while being put in an ever-changing and evolving role (Arendell, 2000). Tong (2001) also discusses the expectations that are put on women as mothers, and notes that women are judged if they are unable to provide care to their child that others consider as acceptable. For instance, Tong discusses how a mother who misses her pre-natal appointments may be considered selfish.

While the culture of mothering has been present throughout the past, the 1950s era seemed to bring with it a new image of what the “good” mother should look like (Dillaway & Paré, 2008). Although there are many different realities for parents, this time period seemed to portray mothers as women who stayed at home, baked, and took care of the family. Dillaway and Paré (2008) note that, “we can see that this ideology represents only one experience of mothering: that of White, middle-class, married women who did not work for pay and lived in new single-family units some distance from workplaces” (p. 440). Presently, in order to be a good mother, a woman must always be present, and forego all other commitments in order to spend time with her children (Dillaway & Paré, 2008). Dillaway and Paré (2008) argue that these responsibilities have likely intensified as women are not only expected to be present for their children, but are expected to offer them stimulation and attention throughout the day to assure they are receiving the resources they need to develop in a healthy manner. In order to be a good mother a woman

must not work, must spend quality time with the children, provide them with age appropriate toys and stimulating games, while always being on the watch for any signs that their child is not developing normally (Dillaway & Paré, 2008).

Kruger (2003) discusses the power of society's expectations that women become mothers, citing the fact that almost all women hold the ultimate goal of becoming mothers. Indeed, this expectation is so powerful that any woman who has not fulfilled the expectation is held accountable for her deviance from the norm (Arendell, 2000). This includes women who voluntarily have not become mothers, as well as those who are unable to bear children. In effect, a woman who is not a mother is not a complete woman.

Yet when a woman becomes a mother to a child with a disability, she often receives little recognition for the care she provides her child (Home, 2008). As described by Home (2008), there is often little understanding surrounding the challenges that mothers with children with disabilities face. Even these mothers may themselves adapt to their often-demanding roles, without recognizing the sacrifices they make because of the stress they are dealing with each day. Part of this lack of acknowledgment could be due to the high standards that mothers are expected to attain while parenting their child. One normative standard to which women and mothers are compared is that of the *intensive mothering* ideology (Arendell, 2000), which considers mothers as the ideal and preferred caregivers of children (Medina & Magnuson, 2009). When discussing the norm of marrying and having children, Hays (1996) (as cited by Wrigley, 1997) contends that mothers have accepted an ideology of intensive mothering, which is not only child-centred, but also labour-intensive. This ideology views children to be sacred, and in need of time and energy which only some women have to offer (Medina & Magnuson, 2009). This

ideology also implies that if a woman cannot offer the energy and resources to her children, then she should not be a mother (Medina & Magnuson, 2009).

In her review of Sharon Hays' book "The Cultural Contradictions of Motherhood" (1996), Wrigley (1997) cites Hays as explaining that the effects of intensive mothering can be quite difficult on women who are mothers, as they seem to be caught between the ideal mother who gives their children all that they have, without expecting anything in return, while also being placed in a society that values results and efficiency from its members. Hays asserts that women strive hard to be the ever-sacrificing mother to their children. When women do not live up to the good mother ideal, they are often blamed and ostracized. As Jackson and Mannix (2004) explain, mother blame can complicate the already difficult responsibilities that encompass mothering.

The authors define mother blaming as:

A term that describes mothers being held responsible for the actions, behaviour, health and wellbeing of their (even adult) children. It also describes situations where women are blamed for their own predicaments, such as being abandoned or living in poverty. (p. 150)

As noted by Jackson and Mannix (2004), people use theories that can create sexist bias, for example by using learning theory, Freudian theory, or attachment theory, which tend to put the responsibility onto the mothers, while failing to do so for the fathers. Furthermore, Jackson and Mannix (2004) discuss the societal burden these women must face if they fail to fit the idealized view that society holds of mothers, or if they act in a way that is not deemed appropriate for mothers. They argue that this blame begins as soon as a child is conceived, and continues during pregnancy, after birth, and throughout the child's life. In explaining where and why some of this blame may be present, the authors note that, "it is easier to blame individual parturient women for causing harm to their unborn children than to consider the role played by societies

and governments for policies that are not friendly or supportive to women and, especially, women as mothers" (p. 151).

Considering the mother blame of mothers with children with disabilities, Bennett (2007) notes that mothers with children with ADHD face accusations of blame from those around them. Bennett's (2007) article looks at mothering children with ADHD, and discusses how mothers view not only their child, but their mothering roles as well. When discussing the specific diagnosis of ADHD, Bennett (2007) notes:

Although the data suggest the diagnosis can free women from blame, mothers appear unable to easily resist the blame associated with having to know everything, having to get it right, and the taking on of the child as their absolute responsibility. (p. 108)

Blum (2007) also looks at mothering children with invisible disabilities, although her study focuses much attention on children with ADD or ADHD (31 of the 45 mothers had children with said delays, while the others had different disabilities including Asperger Syndrome). Blum (2007) discusses her observation that the experience of mother blame was something present for many of the mothers, as was a perception that people did not want to be their friend, due to their child's difficult behaviour. Blum (2007) also discusses the mothers' need to internalize that they are doing everything they can, including getting their child assessed, possibly looking at medication options, and ensuring they are getting the attention they need. However, as these goals may be unattainable, there may also come a sense of guilt and blame when the child is still demonstrating concerns. In her study, Blum (2007) is also able to share the mothers' perspectives of being blamed for their children's disabilities. Not only did every

mother in the study talk about receiving mother blaming remarks, some mothers reported that their doctors blatantly blamed them for their child's behaviour.

Whereas Blum (2007) and Bennett (2007) focused more so on children with ADHD or ADD, Gill and Liamputtong (2013) explored the experiences of mothers of children with Asperger Syndrome. Fifteen mothers were interviewed and six provided the authors with diaries that chronicled their lives. The authors discuss how mothers of children with an autism spectrum disorder (which Asperger Syndrome falls under) experience hostility from the public due to their child's inappropriate behaviour. The authors note that Asperger Syndrome may be even less evident and obvious to the public than some forms of autism, which might further increase a negative response from the public. Gill and Liamputtong (2013) discuss different ways that mothers who have children with Asperger Syndrome are blamed by others for their child's behaviour. For example, the authors note that when a child misbehaves in public, if the mother is unable to control her child, society may believe she is not fulfilling her mother role, as a good mother who should be able to stop her child's undesirable behaviour. However, the authors did find in their study that mothers found some relief when their children were diagnosed with Asperger Syndrome, as they felt this highlighted that their child's behaviour was due to their disability, and not because of their supposed poor parenting practices.

Although some articles have been found that discuss the relationship between mothers who have children with disabilities, and mother blame, there nonetheless seems to be a significant gap in the literature in this area. As noted above, much of the information found for this literature review related to ADD and ADHD; however, little information could be found on studies examining mother blame and mothers of children with ASD, or similar developmental disabilities.

Chapter Four: Methodology

Research Question and Goals

The overall research question that guides this study is: What are the experiences of mothers of children with developmental disabilities? As I noted in Chapter One, I would like to understand what it is like to be a mother of a child with a disability. I hoped to identify the successes these mothers experience, while acknowledging the challenges they encounter. Furthermore, I wanted to explore how mothers feel about their mothering experience. Simply, it was my hope to look at the mothering experience overall, whether it be positive aspects like pride, joy, and love for the child, or negative aspects such as stress, loss and sadness, and ultimately to gain a better understanding of what this experience is like for mothers, something that at this point I believe is lacking in the literature. By examining the experiences of mothers in greater depth, I sought to also identify the various supports and services that are most useful for meeting the needs of mothers of children with developmental disabilities. Ultimately, it was my hope that this research will lead to better programming for mothers of children with disabilities, and of course for their children.

Theoretical Framework

Since the purpose of this study was to learn from mothers who have children with developmental disabilities, it was appropriate to use a feminist-informed theoretical framework to guide or inform my research. This feminist-informed framework is based on the fundamental principles that cross-cut all feminist theories, including the notion that women's voices matter, and that ultimately, it is not only necessary to give women an opportunity to voice their concerns and tell their stories, but to consider them as experts of their own situations (Reinharz, 1993).

In my own personal experience as a social worker with St. Amant, a not-for-profit agency that provides both community and residential support to individuals with disabilities and their families, it has become apparent that mothers are often given not only the responsibility of caring for their children, but are also frequently held accountable for their children's challenging behaviour. As this research centers on the lives and experiences of mothers, it is important to use a standpoint that encourages women to share their stories in a manner that keeps them at the center of the work being done, and also considers these women as the experts of their own situation. Therefore, this study adopts a feminist-informed theoretical approach which is outlined in greater detail later in the thesis.

The literature reveals that women are generally the primary caregivers of children, including children with disabilities (Arendell, 2000; Jackson & Mannix, 2004; Tong, 2001). As discussed previously, the culture of mothering is one that can place many expectations on women (Arendell, 2000; Jackson & Mannix, 2004; Kruger, 2003; Medina & Magnuson, 2009) and often blames them when they do not meet these expectations (Jackson & Mannix, 2004). Because this study examines a topic where women are the focus and the main source of information, it is important to ensure that the theoretical framework used recognizes the importance of gender and how women's social location (i.e., primary caregivers of children) affects their wellbeing. A feminist theoretical framework recognizes that women are sources of knowledge and experts of their own experience and should be respected for the information they share. As I sought answers that portray the life and the experiences of a certain group, that is, women who are mothers, I believe it is critical to ensure that the information and knowledge that is gathered stem from these women's own stories. Research has traditionally ignored the experiences and voices of women (Beetham & Demetriades, 2007). Beetham and Demetriades

(2007) contend that “from a gender perspective, researchers have noted that ‘traditional’ methodologies, epistemologies, and methods are not scientifically ‘objective’ but the opposite: they generally ignore women’s knowledge by showing bias towards the male perspective” (p. 199). According to Beetham and Demetriades (2007), it is the framework, or research approach, that is critical in conducting research, which highlights a gender perspective. When looking at different characteristics of research that uses a gender perspective, the authors note that it is important to consider how hierarchical power relations between women and men can disadvantage women during the research process. Furthermore, feminist research methods (like qualitative research methodology more broadly) can challenge the status quo, providing the opportunity for the voices of women to be heard (Reinharz, 1993). Feminist research methods, as a type of qualitative methodology, will be discussed later.

Lastly, how the results of this research are shared with the study participants is another way that reflects or is consistent with a feminist-informed theoretical framework. The results will be shared with the mothers who took part in this research, and provided me with the information found in this research study. It is my intent to share the findings with the mothers/participants once my thesis has been defended. By sharing these results with the mothers who took part in this study, I will inform them about the important role they have played in this research and its findings, while also encouraging them to continue to share their stories and consider themselves as experts of their situation. Harding (2005) contends that researchers have the opportunity to use their power to assist those people they consider disadvantaged. To be clear, I am not stating that the women with whom I met are disadvantaged, or should be considered as such. Rather, I am stating that through hearing some of these women’s perspectives, I will attempt to use my own personal power as a researcher to look at how this

research could be used in a way to inform others (such as social work practitioners) of the experiences these women have faced, while also using these findings to help determine what the most beneficial supports are to these women.

Research Design

This study incorporated a qualitative, exploratory methodology. The reason for this choice was, quite simply, to explore in-depth the perspectives of the mothers of children with developmental disabilities. It was also my intent to gather the stories that have possibly remained unheard by others. While there have been studies done examining the effects and/or experiences of parenting a child with a developmental disability (Boström et al., 2011; Bristol, 1987; Cameron et al., 1992; Charles & Berman, 2009; Eisenhower et al., 2009; Feldman et al., 2002; Hastings et al., 2005; Heiman, 2002; Kayfitz et al., 2010; Nankervis et al., 2011; Stainton & Besser, 1998; Stuart & McGrew, 2009; Trute et al., 2010; Trute et al., 2007), there has not been sufficient research conducted on the overall experiences of mothers with children with disabilities. For this reason, exploratory research was appropriate and useful, as it helped to more fully investigate and learn about this topic, and add to the existing body of literature. It was my goal to provide an opportunity for women to share their own perspectives and to have their voices heard. I, therefore, made the decision to use a research method that would enable this (i.e., feminist research), while promoting the gathering of thick, rich data. As mentioned earlier, qualitative methods align well with the values of feminist research, which is the guiding theoretical framework for this study.

This research study was designed to learn more about those considered the experts of this topic – that is, women who have a child with a developmental disability. In order to gain the understanding of what it is like to be a mother of a child with a developmental disability, I

required a research style that enabled these women to openly share their own stories, ideas, and perspectives. By using a qualitative research approach, the mothers were able to share their stories in a relatively open manner, without being obstructed with closed-ended questions that only required yes or no responses. As the primary aim of the study was to gain in-depth knowledge of mothers' experiences, a qualitative exploratory methodology was an appropriate choice.

Eligibility Criteria

Biological mothers of children (i.e., under the age of 18) with developmental disabilities who have been professionally diagnosed no less than two years ago were selected to participate in the study. This study looked at biological mothers only because one aspect of this research was to explore how mothers may blame themselves for their child's disability, and whether or not this blame was connected to previous events, including the pregnancy of the mother. By including only biological mothers for this study, I would remain open to exploring these particular experiences of guilt, should they come up.

My choice to interview only mothers of children who had been diagnosed by a professional was based on my concern that children can often be incorrectly labeled as having a particular disorder (e.g., attention deficit disorder, attention deficit hyperactivity disorder, oppositional defiance disorder, etc.) without there being any official diagnosis present. Due to these inaccurate assumptions or labels being placed on children by individuals without the skills and expertise to provide an appropriate diagnosis, I believed it would be best to ensure a child has an actual professional or medical diagnosis, as opposed to a child who is suspected of having a developmental disability. Further, a professional diagnosis may have a unique impact on

mothers, including stronger feelings of guilt and shame, or perhaps, feelings of relief and affirmation (i.e., that indeed something was not typical with their child's development).

The reason for the two years since diagnosis criteria was related to my desire to know not only how a mother feels upon initial diagnosis of her child, but also what kinds of emotions surface following this diagnosis. Because I was looking at various issues relating to caregiving, including the positive emotions that may have grown over time, their feelings of guilt and loss as the child gets older, as well as perception of supports by these mothers, I believed it was appropriate to interview mothers who had lived with this diagnosis for a long enough period of time to really be able to speak to and reflect on what it has been like raising a child with a known disability.

Participant Recruitment

Prior to recruiting participants for this study, this research was approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. Research participants were recruited by posting flyers at St.Amant, a facility in Winnipeg that supports individuals with different disabilities and their families, and Access Centres that offer a range of services, including Children's disABILITY Services, throughout Winnipeg. Flyers were also given to the various St.Amant staff (e.g., social workers, behaviour analysts, and occupational therapists) who then distributed the flyers to clients. The flyers informed potential participants about the major objectives of the study and study eligibility requirements (see Appendix A).

Participants were asked to call me at my cell phone number, which was a private and confidential phone line to which only I had access. I also had a voice messaging system set up in case I was unable to answer the call at the time. Upon receiving interest from a potential participant, I first spoke with her over the phone, in order to ensure that she met the criteria.

If the potential participant met all of the eligibility requirements of the research study, I explained that I was a social work graduate student, the purpose and objectives of the research, as well as details regarding where the study would/could be held, and how long the interview was expected to last. Following this phone call, if the caller was still interested in participating in the study, I scheduled an interview time that was convenient for her. Although the mothers were given the option of either meeting in their homes, or meeting at a different location, such as St. Amant or an Access Centre, five participants asked to hold the interview in their own homes, while one asked to meet at her workplace in a private meeting room. In recognition of the time the mothers gave for this research, they were each given a \$25.00 honorarium.

Data Collection

In terms of specific research methods, semi-structured qualitative interviews with mothers of children with disabilities were conducted. According to Tutty, Rothery, and Grinnell (1996):

Interviews provide you with an opportunity to learn about that which you are unable to directly observe in a person's natural environment. This is particularly true when you are interested in learning about a person's experiences, behaviors, thoughts, and feelings. (p. 52)

A semi-structured, open-ended interview guide consisting of six main questions was used in the interviews (see Appendix B). The interview guide allowed me to examine specific areas of interest regarding my participants' experiences but was not so structured that it prohibited unanticipated responses (Tutty et al., 1996). Given the exploratory nature of the study, questions were not framed to only yield closed-ended (i.e., yes or no answer) responses. Rather, questions were worded in a manner that did not influence the participants' responses, or lead them to believe there was a "right" or "wrong" answer to the question. Before each of the interviews

commenced, mothers were asked demographic questions, such as their age, marital status, annual income, and employment status, which were noted on a demographic face sheet (see Appendix C and D). This demographic information was gathered to draw comparisons among and between participants, as well as to provide additional information that would contextualize their responses and experiences.

Data Analysis and Interpretation

The interviews lasted between 30 minutes to just under two hours. All of the interviews were digitally-recorded and transcribed verbatim by me, enabling me to immerse myself in the data and become familiar with the interviews. During the interviews, I took only a few notes when I felt it was necessary, which related to something the mother told me, or something I wanted to follow up on with the mother during the interview.

I adopted a mainstream social work approach to qualitative data analysis (Tutty et al., 1996). The first step of the data analysis included the verbatim transcription of the interviews. As the interviews occurred within a six-month timeframe, following each interview I was able to transcribe the interview, and then go through each of the transcripts line-by-line to sort the data into the initial categories (first-level coding) (Tutty et al., 1996). This was done by creating a word file and categorizing different topics as they were brought up in interviews. The initial codes and categories were revised a number of times, due to my own understanding of the evolving information. After completing the first-level coding, I began second level coding, which involved determining what each category meant, or signified, and then examining the similarities and differences between the categories (Tutty et al., 1996). Furthermore, I used techniques from grounded theory while conducting my research (Strauss & Corbin, 1998). For example, I utilized constant comparison, which is the process of continuously comparing and re-

assessing new-found data with the initial information that had already been retrieved and analyzed; and memoing, which included my handwritten notes used as records of analysis for the data. Following my initial second level coding, I met with my thesis committee, and was given a number of recommendations regarding how I might refine/develop the coding that I had started. Following this meeting, I re-listened to the interviews a number of times in order to gain a better (and more nuanced) sense of what the mothers were trying to say through their stories. This last piece was especially helpful in being able to identify certain themes that were related to the mothers' experiences when raising a child with a disability.

Through the coding process, I hoped to draw meaning from my research, and discuss the different themes being introduced. Throughout this process I continued to reflect on my own thoughts and feelings about the information I was given, in order to ensure I was looking at the information from a viewpoint that made me aware of my own biases and assumptions, and consequently limited these biases. This process was further assisted through meeting with my advisor, as well as having her review my findings in order to reflect on the themes I had found, and how they could be interpreted or shared in a different way than I had initially chosen. Also, as noted above, throughout my data collection and data analysis I used memoing in order to record my initial thoughts surrounding my analysis, and in order to maintain my own reflexivity.

Through these different coding practices, as well as from looking over my own personal notes, I was able to start developing the data into several themes. In total, six major themes were identified as relating to the mothering experience: 1. positive experiences and emotions; 2. mothering a child with a developmental disability as difficult, stressful, and overwhelming work; 3). mothers' fears for their children; 4). mothers' sense of loss; 5). mothers' relationships with

their non-disabled children; and 6) mothers' perceptions of the helpfulness of formal and informal supports. These themes are discussed in Chapter Five.

Quality and Verification of Results

This research ensured reliability and trustworthiness in a number of ways. First, the methods I used in this study were methodically and theoretically congruent with my research objectives. As mentioned earlier, I adopted a feminist-informed theoretical framework, which coincided with one of the overall purposes of this study - to gain an understanding of the different experiences mothers face when having their biological child diagnosed with a developmental disability. By understanding that this type of research needed to be sensitive and respectful to women specifically, and due to my attempts to ensure their voices were not only heard, but understood to be the experts of their own experiences, the decision to use a feminist perspective was appropriate for this task. Also, I used open-ended interview questions that assisted with my use of qualitative, exploratory research, and also helped to fill some of the research gaps that are present with regard to mothers of children with disabilities.

As discussed by Lincoln and Guba (1985), trustworthiness requires dependability, transferability, credibility, and confirmability. The results from this research underwent many techniques that ultimately lead to its trustworthiness. In terms of dependability, the first technique was the interview process itself. While there were multiple questions that enabled the mothers to speak openly and honestly about their experiences, there was also time given for them to talk about experiences that might not have been anticipated. All of the participants were asked the same interview questions, although different themes arose from different participants, and some participants wanted to talk more about a particular aspect of their parenting. If an

additional topic was introduced by a participant, I would follow up with any questions I had in order to confirm I understood the meaning of the comment.

A second technique included debriefing with my thesis advisor and thesis committee in order to ensure that my analytic process was both sound and appropriate. One meeting was held as a group where I shared my coding process so far, discussed some of the observations I had made, and received feedback and recommendations for the committee members. One of the recommendations made at this time was to ensure that my findings focused on the mothering experience, and did not focus solely on the child with a disability. This recommendation was one I kept in mind throughout the analysis of my data.

Lastly, I held interviews with a number of women, in order to obtain my data from multiple sources, thus making it richer, and being able to draw conclusions from more than one source of information. As was shared during my thesis committee meeting, as I continued interviewing the mothers, it became clear that no new themes were emerging (i.e., theoretical saturation was reached). It was due to this observation that it was decided that six participants was adequate for this particular research study.

For transferability, Lincoln and Guba (1985) explain that the researcher must provide a thick description of the data, in order to allow for someone else doing research to make a judgment on whether or not a transfer or generalization of the data to a different setting or situation is possible. Through the interview process itself as well as the methods that I used to analyze the data, as described above, it was my intent to create research data that is thick with description and offers others the opportunity to understand how it was that I collected the information shared. By listing the questions posed to the mothers, by giving a description of each mother I interviewed (as was provided on the demographic face sheet) and by discussing

the limitations of my study, I believe that I have provided researchers with an understanding of how I gathered my information, from whom I gathered the information, and how I coded the information, and ultimately how I came to the conclusions shared in this thesis report. This could also allow for others to make an informed decision on whether or not my data could be transferred to a different situation or environment.

For dependability and confirmability, Lincoln and Guba (1985) discuss the option of having an auditor examine the data, as well as the findings and recommendations. It is consequently important to note that throughout my research I discussed my preliminary findings with my thesis advisor and thesis committee, in order to ensure that I was analyzing the data consistently and accurately (i.e., based on theoretical framework and adhering to proper qualitative data analysis research methods). By having these members review my research and ensure that its findings were congruent with the collected data, I allowed my work to establish both dependability, as well as confirmability. I also used rigorous methods to analyze my data, including first and second level coding (Tutty et al, 1996), memoing (Strauss & Corbin, 1998), and constant comparison (Strauss & Corbin, 1998). The methods that I used in this study go well together with those commonly found within social work research. As discussed by Tutty et al. (1996) the use of a qualitative research approach is a beneficial tool to use when attempting to accomplish the goal of understanding the participants' perceptions of the chosen topic.

Furthermore, throughout my research, I remained aware of my own possible biases and preconceptions. I did this by first noting what some biases might be that I possess, and later on checking and rechecking my conclusions to determine whether they had been formulated by the data, or by my own beliefs. Memoing (as discussed in the analysis section) also assisted me with this (Straus & Corbin, 1998), as did debriefing with my thesis advisor.

One challenge I experienced while coding the data was my initial reaction to focus on how the mothers' answers described their children, as opposed to themselves. Part of this was likely related to the mothers' automatic tendency to speak about their child, as this study was, after all, about them being the mothers of a child with a developmental disability. While this presented some concerns initially, after re-listening to the interviews, reviewing the coding again, and looking at my own personal notes, I was able to take a broader look at the answers, and see that in fact, they had much more to do with the mothering experience than I had initially thought.

Study Limitations

As is the case with any research, this study was not free of limitations. One such limitation was the fact that I only met with the participants on one occasion. While I believe that this provided an ample amount of data and knowledge from the participants, it might have also kept the women from sharing everything, as they may not have been as comfortable with the interview process as they might have been over a number of meetings.

Also, since the posters for participants were posted in different locations around the city, this might have put a limit on who was able to access this opportunity. More specifically, the population who came into contact with these flyers was likely women who are able to travel around the city, were literate, and who have the confidence and knowledge to call and set up a time to speak with me. While I was appreciative for all the calls I got from potential participants, I must also be aware that my research might have missed some important voices in the community, namely women who are less mobile, are not able to read, and/or who may not have had the confidence to take down my number and call me for more details, or who may have been too overwhelmed and busy with providing care for their disabled child to participate in a

research study. Although some of the participants were found by having other professionals distribute my flyers, this too posed a limitation, as only mothers receiving services from St. Amant were provided with these flyers. While St Amant services are provided free-of-charge to all families, and therefore serves families in any income bracket, only a small percentage of families who have children with disabilities are given services at any one time through St Amant, and, therefore, only a small sample of mothers throughout Winnipeg and Manitoba were given these flyers.

It is also important to note that five out of six participants in this study self-identified as Caucasian, and only one as Aboriginal. This study, therefore, lacked the voices of Aboriginal mothers and mothers from other cultures. It may be that these women's experiences differ because of cultural beliefs and practices and also because they tend to be more marginalized and experience greater barriers (e.g., poverty and racism). Also, although my sample of women had a range of income levels, it is important to mention that of the six women interviewed, only two were in the low-income brackets, which limited me from hearing the voices of women in these lower income levels. This may also have impacted the findings, as a mother living in poverty may have a very different experience than a mother with secure housing, and (as was the case for three of these mothers) little worry surrounding feeding the family, getting them clothing, or ensuring they have lunches to take to school everyday.

Also, all of these mothers either are, or had been, in a relationship with a male partner. Findings may have been different if mothers were involved in same-sex relationships, as this might have impacted the roles and responsibilities within the home. Lastly, all of these women had sons, which was simply a coincidence; however, it may have affected the results, as the findings were only based on sons. However, experiences may have been different had the

mothers been raising daughters. Given the limitations inherent in the study one must consider these findings cautiously, as they do not reflect the experiences of all mothers of children with developmental disabilities. Nevertheless, the study is significant because it explores the overall experiences these mothers face everyday as they mother their child with a developmental disability. These women were able to share a holistic perspective on the mothering experience. The reader has been given insight into how this experience creates opportunities for growth for the family, while also understanding the unique challenges that are encompassed in this experience. It is my hope that through this research, others will be able to gain a better understanding of what it means to be a mother of a child with a disability, as well as how service professionals can further assist these mothers with this experience in order to make it a positive one.

Chapter Five: Study Results

Study Participants

As stated above, all of the participants in this study were biological mothers of children with developmental disabilities. In total, I received 11 phone calls from women who were interested in my study; however, four were deemed ineligible, as they did not meet all of the required criteria. I also received a phone message from one mother who requested a call back; however, her phone line was disconnected when I attempted to return her call. In total, six women were interviewed for my research study. To maintain participant anonymity, women were asked to identify pseudonyms for themselves, however, if they were unable to think of a pseudonym, one was offered.

Five of the participants self-identified as Caucasian and one mother self-identified as Aboriginal (see Appendix C and D). At the time of interview, three were married and three were separated. Of the three women who were no longer with their partners, none were currently employed (one was on disability leave). However, of the three mothers who were married, two were working part-time, and one full-time. All six mothers had at least some university or college, with two having completed university, two having completed college, and two who had taken some university or college courses. The annual family income for these women varied greatly, and ranged from \$12,000 to \$100,000, with the mean salary being just over \$51,000.00, with two mothers earning 0 - \$20,000 per year; one participant earning between \$20,001 - \$40,000 per year, one mother earning \$61,001 - \$80,000, and two participants earning over \$80,001 per year.

In terms of their children, all of the participants had male children between 7-16 years old, with a mean age of 10 years, who were developmentally disabled. The fact that all of their children with disabilities were boys was an unexpected finding, and can be considered

coincidental. Mothers reported that their boys were diagnosed a significant time ago. Three mothers reported their children were diagnosed three to four years ago, two mothers reported the diagnosis occurred five years ago, and one mother stated her son was diagnosed eight years ago. Also important is the fact that all of these mothers had at least one other child who did not have a disability.

The six mothers in this study all presented as high functioning (i.e. participated well in the interviews, understood the questions posed, and offered insightful answers). All women spoke English, and no language barriers were noted. While the researcher did not gather in-depth information regarding their sons' functioning, all of the mothers spoke of their sons participating in school, although it was not clarified whether they were in specialized programming. The boys' functioning seemed to vary, with some boys being described as having excellent reading skills or memorization skills, while other boys in the study were reported as having lower cognitive abilities.

Participant #1: Samantha

Samantha is a 35-year-old mother of two boys. One of Samantha's sons was diagnosed with autism approximately three years ago, and at the time of the interview was 8.5 years old¹. Although Samantha has completed university, she explained she is a single mother who chose to leave her job, in order to be able to give more care and attention to both of her boys; however, she especially felt that her son with a disability needed her at home. Samantha self-identified as Aboriginal, and stated that at the time of interview she had few informal supports, and was trying to seek healthier relationships, away from family and friends from the past who might be negative influences on her and her sons. Samantha was in receipt of social assistance (EIA) and

¹ Due to anonymity issues, the age of sibling is not shared.

her annual income at the time of interview was \$12,000. Samantha and her two sons live in a Manitoba Housing complex, and Samantha noted that she would like to become employed in the future, but also made it clear that she was willing to live with less money if it meant that staying home to look after her boys was in their best interest.

Participant #2: Heather

Heather is a 39-year-old married woman, who self-identified as Caucasian, with two children, a daughter who is five years old, and a son who is seven. Heather's son was diagnosed with PDD two years ago, and prior to that he had been diagnosed with PDD-Not Otherwise Specified (which is a disorder that falls under the category of PDD) in 2008. Heather's son was also diagnosed with Marfan Syndrome², which Heather stated caused her son to have low tone in his body, and noted that her husband was also diagnosed with this genetic disorder. Heather has completed college and, at the time of interview, was taking university courses and working part-time. Heather reported the family's annual income to be approximately \$100,000. While Heather works outside of the home on a part-time basis, she also explained that she takes the lead on her son's programming, including arranging his therapy appointments, hiring his respite workers, and coordinating her own schedule to match with her son's multiple appointments with professionals. Heather also admitted that her husband holds a more traditional view of family life, and was unhappy when she initially found employment outside of the home, as he would have liked her at home with the children. Despite this, Heather has now been employed for two years, and did not express a desire to leave her current place of employment.

Participant #3: Diane

² Marfan Syndrome affects the body's connective tissue, which holds a body's organs, cells, and tissue together. Marfan Syndrome is genetic (The Marfan Foundation, 2013).

Diane is a 40-year-old single (separated) mother of two children, a 16-year-old daughter and a 10-year-old son, who was diagnosed with autism in 2005. Diane self-identified as Caucasian. Diane reported being the main caregiver for both her children, and stated she always was, even while she was married. Although Diane is the primary caregiver of her children, she contended that her 16-year-old daughter frequently assists her in the day-to-day care of her son with autism. Diane has attended university; however, she is currently not employed. Diane explained that while she was employed in the past, she had been unable to maintain employment, because of receiving frequent phone calls from the school requesting that she pick up her son. Due to the difficulty she had with working consistently, Diane was fired, and at the time of the interview was on EIA, earning \$12,000 a year.

Participant #4: Lesley

Lesley is a 34-year-old Caucasian woman and a mother of three children. Lesley has completed college; however, she was not working at the time of the interview. Lesley was on a disability leave, earning approximately \$23,000 annually. Although Lesley has three children, only two live with her: a 14-year-old daughter and a seven-year-old son, who was diagnosed with autism approximately four years ago. Lesley stated she is now separated, and during the interview insisted that she “does everything” for her son with autism and does not receive assistance from her ex-partner. Lesley also talked about her frustration with services in Manitoba, and stated that there is a waitlist for all the programs that would be beneficial to her son. Due to these waitlists, and the difficulty of accessing programs, Lesley indicated that she would be moving to a different province, where she believes she will be able to get her son into appropriate services right away.

Participant #5: Elizabeth

Elizabeth is a 41-year-old, married Caucasian woman. Elizabeth has three children, ages 18, 16, and 12. Elizabeth's 16-year-old son was diagnosed with fragile X syndrome³ when he was five years old. Elizabeth has completed a university degree, and is currently working full time. The family's annual income is approximately \$90,000. Elizabeth noted during the interview that she believes both she and her husband share in the childcare responsibilities; however, she noted she is often the one in charge of scheduling and setting up services for her son with a disability. Elizabeth's son is nearing adulthood and, as such, some of the topics Elizabeth raised related to her son's future adulthood and independence (i.e., graduating from high school and moving out of the family home).

Participant #6: Melanie

Melanie is a 31-year-old, Caucasian woman. Melanie is married, and has two-step sons (from her husband's previous marriage), and two biological sons, ages six and 10. Melanie's 10-year-old son was diagnosed with autism approximately five years ago; however, Melanie explained that she always knew her son had some kind of delay. Although Melanie stated that her husband is an "excellent father", she also explained that he has difficulty handling their son's challenging behaviour, which has therefore put her in the position of handling the difficult situations. While Melanie acknowledged that some people may consider this unfair, she also stated that she would prefer this, as opposed to her husband trying to deal with a difficult situation, and instead making matters worse. Melanie has taken some post secondary courses, and is currently working part-time. The family's annual income is approximately \$71,000.

In total, six over-arching themes emerged through the analysis. They are: 1. positive experiences and emotions; 2. mothering a child with a developmental disability as difficult,

³ Fragile X syndrome refers to a genetic condition, which causes learning and behavioural challenges as well as intellectual disability (National Fragile X Foundation, 2014).

stressful, and overwhelming work; 3). mothers' fears for their children; 4). mothers' sense of loss; 5). mothers' relationships with their non-disabled children; and 6) mothers' perceptions of the helpfulness of formal and informal supports. Smaller categories or sub-themes emerged within many of these larger themes and are discussed below.

Theme One: Positive Experiences and Emotions

A major theme that emerged during the interviews with mothers was the overwhelming message that the experience of mothering a child with a disability is a positive experience that creates occasions of happiness and joy, feelings of pride, and opportunities for growth as individuals and as mothers. Although the mothers did recount times of stress and challenging situations (as will be discussed in Theme 2), they expressed that having a child with a developmental disability was overall, a positive and pleasurable experience. The mothers discussed that parenting a child with a developmental disability was gratifying, offering the opportunity for learning and growth, and giving the mothers a sense of pride for their children's accomplishments, as well as recognition for their own accomplishments. For one mother, getting to meet people in similar situations who she might not have otherwise met was also a positive experience for her.

Five of the six participants insisted that they did not want people to assume that having a child with a developmental disability was a primarily negative experience. For instance, while discussing what she would like others to know about what it means to have a child with a disability, Samantha explains that she does not want to be pitied, but rather, wants people to act as "cheerleaders" for her family:

I just appreciate when people are open-minded, and I really appreciate it when people are more of a cheerleader to us as a family than – "Oh, your child has autism. That must be

hard"... it just has such a negative, pity kind of connotation to it and even just the tone you know, it puts a sad twist on it... I'm just really happy for the experience... So far so good, you know, things are going good and [we're] just thankful for all of the positives that we do have.

Samantha speaks from a perspective that is shared by other mothers in the study as well.

Melanie spoke about the assumptions some people hold about raising a child with a developmental disability, and notes that the negative beliefs people have are not how she considers her situation. Melanie sums up the positive experience of mothering a child with autism with the following explanation:

From the perspective of just being a mom, it's been fantastic... [Being the mother of a child with a developmental disability] does not end your life...which is an attitude many people have... I think that a lot of people say, or feel like, "So I have a special needs kid and all I'm gonna do is run to appointments and it's gonna become this and it's gonna become that". But they're still just kids. They still do all the things that kids do they just do it to some different music. And some things happen really quick and some things happen really slow. It's not so bad. It's actually pretty great! And you meet a lot of people who you otherwise would never interact with...So what I would say to [others about raising a child with a developmental disability] is be prepared to learn a lot, to settle for less, to fight for more, all those things.

Heather also presented a similar viewpoint as she discussed people's misconceptions about children with autism, stating, "Just because [my son] has autism doesn't mean he's not a pleasant child... I think people see kids with autism, but there's still some misconceptions out there, like about you know what it is and what it isn't". The idea of not wanting others to see her

situation as negative was also reflected by Lesley, whose son has autism: “I couldn’t imagine my life without [my son]. As difficult as it is, you know, he’s great, I love him”.

Lesley also speaks to the amazing experience of watching her son grow and how this may be different for those raising a child who is developing typically:

It’s beautiful. It’s watching your newborn only he’s always like that...knowing that when he turns 18 he still will be with me. You know, but that’s something you know that God gave to me, that’s my gift.

Lesley expresses gratitude for the experience she has had as her son’s mother. This experience may be one with exceptional challenges, yet Lesley is able to view it positively.

Along with the overall positive feelings that are experienced by the mothers, this research also showed specific areas of positivity that these mothers encountered when raising a child with a developmental disability. These include: learning and opportunities for growth; feelings of pride; and mothers’ own sense of accomplishment.

a.) Learning and Opportunities for Growth

As expressed above, the mothers did not want sympathy from others simply because their children have a developmental disability. Rather, the mothers noted that parenting a child with a disability led to opportunities of increased learning and understanding for them as mothers. All of the mothers interviewed talked about their own learning that occurred from their experience of mothering a child with a disability. Four of the mothers noted the importance of reading up on their child’s diagnosis. These mothers talked about their reactions to finding out about the diagnosis, and also discussed their determination to research what it meant for their child. This was especially important for some of the mothers who admitted to knowing very little about the

disability prior to their child's diagnosis. This was highlighted in the interview with Heather, who began researching autism following an appointment with a specialist:

The only image I had of someone with autism was like sitting in a corner banging their head against the wall, this sort of typical image that everybody has... so they got all these appointments made and we started getting books out of the library and we read them and we're like, "oh, okay he does have autism... that sounds like him, he does that and this". That was November so when we were actually diagnosed in March, it didn't come as a huge shock to us because we'd sort of anticipated it.

While Heather was able to research her child's disability prior to the actual diagnosis, Elizabeth did so following her son's fragile X diagnosis. As Elizabeth explains, while she did read books on this syndrome, she also found it helpful to join an internet list serve, enabling her to read other people's questions, concerns, and/or comments about disabilities:

The list serve was also very important because it just gave me this bigger picture of what to expect with [my son] as he grew up... I also read a number of books, so I read a textbook on fragile X syndrome that really laid out all the genetics of ... the condition.

For Samantha, although she has done reading on her son's autism, it is the direct experience of mothering a child with a disability that has enabled her to really understand what it means for her son to have a disability:

I've done a lot of reading on it but unless you can really experience it in real life it's just... I know it's not anything about his intelligence you know, he's very intelligent, he just experiences life in a different way.

Lesley describes how having her son with a disability has been a positive experience for her, how she has grown as a mother and how her son has helped her to become more

understanding about others, stating “I wasn’t so patient and ... understanding and so open-minded ...so I mean he’s helped me grow”.

As an aside, three of the mothers in this study talked about ways they believe their child without a disability may have grown or been affected positively by his or her sibling. Heather was able to discuss some of the positives she feels are relevant for her daughter without a disability. Heather discussed her belief that her daughter is further ahead due to the services her brother receives:

I think [daughter is] almost like advanced in a way because [the workers] started working with [son]... the day after he turned three, like the day after his third birthday, so my daughter was... like one and a half, 18 months 20 months old, so I think she’s really advanced because she’s used to seeing people in the house and working with [son] and she wants to work too.

Samantha also talked about how her son without a disability has learned helpful skills: “[Son without a disability has] to be more patient... they have to be a little more helpful”. This extra responsibility was also cited by Diane, who explained that her non-disabled daughter will often help her with her son, and will even care for him so that Diane can take a break.

b.) Feelings of Pride

Another sub-theme that emerged was mothers’ pride that they have in their children with disabilities. Five of the six mothers interviewed discussed ways in which they feel pride for their child. During Samantha’s interview, she stated, “I guess I’m proud that [son is] doing really well. Yeah, and I just was really worried when he was younger I guess, and now I just feel really hopeful - yeah that he’s doing really well”.

Heather also explains that:

One of the strengths [my son] has, he's very good at math, excellent at math and he's also very good at spelling. Like, crazy good at spelling... he sees a word and then just will spell it like almost immediately...but then you read him a sentence, "Marcus went to the bank yesterday. He got ten dollars and put it in his wallet". And you'll say, "Who went to the bank?" ... "I don't know."... So it's like he has like super huge like... spelling, but then he can't comprehend, he's probably quite like grade one level of comprehension.

Heather is able to identify both strengths and challenges that her son has in school.

While she can illustrate these skills, there is a sense that Heather is proud of her son for his abilities, and is comfortable discussing them without needing to change them. This sense of pride is also shared by Lesley. While Lesley is able to identify her son's challenging behaviours, she later comments that "[Son's] improving... I mean we have our moments, but you know like just, just to see him flourish, and you know, see what comes out of his mouth that day, 'cause it's always something quirky".

c.) Mothers' Own Sense of Accomplishment

Two of the mothers in this study also talked about their own sense of accomplishment in their mothering a child with a disability. Diane noted that although it can be harder to teach her child with autism, when she is able to do so, she feels a great sense of accomplishment:

[Son] ...gets a bit overwhelming with the stuff that you need to teach him...it's the stuff that you are able to teach somebody ... This is not teaching him to get dressed or just to eat. Whatever you do you're actually teaching him how to live his life. It feels so rewarding... You're paying more attention I guess to the child than their needs. You feel when at the end of the day even you see they've accomplished something you feel so good. It's like you created something. I don't even know how to explain it. It's just – I

would not change that ever. And like they said, “God doesn’t give you what you can’t handle”.

Melanie also discussed the fact that she knows her son best and is, therefore, able to offer assistance to the school when they need it. While Melanie explained this, she indicated a sense of accomplishment in knowing how to improve a situation for her son quickly:

[The school] can email us with a really small problem saying like “we don’t understand why this is happening”. [I say], “We see it here all the time we know the solution - give this a shot you’ll probably see how well it works”... We would send [son] to school in a T-shirt, he would come home and he’d eaten the entire seam off of his shirt... so we said to [the school] “every time you start a new thing hand him a piece of gum so that he’s constantly changing the piece of gum, the smell of the gum, the taste of the gum” ... and magically it stopped.

The experiences noted above illustrate the pleasure that the participants experience from having a child with a developmental disability. The mothers were able to identify a number of positive experiences of mothering a child with a disability. However, mothers also discussed the challenges associated with mothering a child with a developmental disability. These concerns will be discussed below.

Theme Two: Mothering a Child with a Developmental Disability As Difficult, Stressful, and Overwhelming Work

Although the mothers in the study identified numerous positive aspects of having a child with a developmental disability, they also (not surprisingly) identified many negative or challenging experiences. Subthemes in this discussion include: exhaustion, stress, and feeling

overwhelmed; dealing with difficult behaviour; managing alone; and feeling blamed and judged by others.

a.) Exhaustion, Stress, and Feeling Overwhelmed

Five of the six mothers reported that caring for a child with a developmental disability often left them feeling physically and emotionally exhausted, stressed, and overwhelmed with their caregiving responsibilities. Others talked about having to attend to numerous appointments, which they found to be both physically and emotionally demanding.

Diane poignantly articulates the stress of mothering a child with a developmental disability: “[Raising a child with autism] gets to the point that you are so stressed out that you could wake up at 7:00 a.m. and by 7:10 a.m. you could start crying”. Lesley also notes:

It’s tiring. It’s very tiring. I, I am very worn out. I’m very exhausted. There’s only one of me now. So, it’s definitely a lot more challenging. Doctor’s appointments, psychiatric [appointments], meetings at the school - you know, there’s always something.

Lesley also talked about feeling overwhelmed:

I mean there’s pros, and you know there’s cons. But I mean there’s always an end to the day. You know? Like, some days I just...I just feel like I’m not gonna make it - I just want to walk out of the house turn around and never come back.

For Heather, the process of having her son diagnosed with autism was quite challenging and involved attending numerous appointments with professionals, being asked a multitude of questions, or receiving recommendations (prior to the actual diagnosis being made) surrounding how she could assist her son in developing more skills:

Initially it was pretty stressful... [My son] was 23 months before walking. We had contacted his pediatrician... [and] he wanted him to see a physiotherapist and an

occupational therapist...and so they were asking us all of these questions, about this that and the other thing and, and they just made me feel really awful. [The specialists] were like, “You have to get that kid socialized, you have to take him out”. ... And there was a registration for a playgroup running in my community... and so I’m dragging this kid who can’t walk, and a two, three, four week old to this play group because it started pretty much right after, and Oh my God, he was so out of control... He was okay during the playtime, but when it was time to transition to the snack, or the craft, he would just scream and cry and he would knee-walk me over to the stroller and want to go home... so it was very challenging. I would come home from there, and I would like make sure everybody was safe and I would go lie in bed for a few minutes just to like gather myself because it was just like, ugh it was so awful.

Diane also talked about times where she will start to cry due to the challenge of raising her son, and consequently need time to herself in order to calm down, prior to getting back to her responsibilities, noting “Like you get so stressed out so overwhelmed, that it takes you five minutes ... Get going again and that’s it. Like yes, that gets very overwhelming – it does”.

Melanie articulated the following regarding her mothering a child with autism: “Mothering, parenting is a full time job. When you have a child with special needs, it is an eighty-hour a week job”. Melanie was also able to present the differences between raising a child with autism, versus a child who is developing typically:

For my six year old [who does not have a disability], I can say to him, “Go get on your shoes, pick up your backpack, wait outside for me, we’re gonna walk to school”. My [son with autism] needs three different ten-minute warnings. Three different – “Those are

the shoes you're wearing". Three different – "Grab your backpacks". So the process of raising them has been the same [but] the level of work has been different.

b.) Dealing with Difficult Behaviour

Many of the mothers reported that their children often present with difficult behaviour because of their disability. Contributing to this difficulty is the violent and aggressive behaviour of some the participants' children. Of the six mothers, four talked about their sons being aggressive or threatening. Lesley described how her son with autism at one point threatened to harm both her and her daughter, and even had a plan laid out for how to do so, stating, "At one point [son] was threatening to kill us and he had a plan... just the other day he said to me, he was mad at me, and he says to me, "I'm gonna kill you when you're sleeping".

Diane also talked about her son's aggressive behaviour towards her teenage daughter, stating "[Son] gets overwhelming for [daughter without disability] but he's so stressed out so... [daughter] gets upset because she can't help him so she trying to, so he would hit her".

Elizabeth also noted that her son can be aggressive to both her and her other son, stating "[Son] will get really close to me and I feel like he's gonna hit me".

While Melanie did not talk about her son being aggressive or violent to people, she did discuss how he at one point would come home from school and act aggressively towards the home:

[Son] was extremely aggressive. ... he would come home from school and rage. Like literally drop his backpack at the door, take off his clothes and come in and start punching walls. At 7 [years old] he ripped that [bedroom] door off the hinges.

c.) Managing Alone

All three of the mothers who were single at the time of interview believed that the fathers of their children with disabilities assumed very little (or no) caregiving responsibilities, leaving them with the overall responsibility of caring for their child. For the women who were married, all of them were also able to discuss in what ways they do more for their developmentally disabled child. Melanie's story, which expresses how she is responsible not only for her child, but also with helping her husband to cope, is an especially compelling account of the gendered differences in caregiving a child with a disability. For Melanie, not only does she take primary responsibility for her son when he acts out or presents with difficult behaviour, she also has to look after her husband who does not cope well with having a disruptive child:

My husband is a fantastic father and a fantastic partner, he doesn't do... we call it - he just doesn't "do [son]"... So, when [son] is having a tough day, he can't... cope with it because he can't see outside of the behaviour either. So when [son] is super-aggressive or super angry... [father] cannot do that. Even though I've just worked maybe a 12 hour shift and have grocery shopped and cleaned and whatever, I still have to come home and deal with that... but I would rather that [father] said to me, "I can't deal with this", then try and then create bigger problems. Which frankly is what has happened in the past... I was out of town one day, [son] had a problem at school, the school called and said "we need him out of the building it's escalated to the point we can't deal with it". [My husband] went down there and it just, it was explosive. I ended up driving into town to get both of them out of the school.

Melanie's story describes and highlights well the amount of work that is required of mothers who have children with disabilities, whether they are single parents, or have partners. Although the mothers who were married did discuss having extra responsibility for their child

with a disability, Melanie was the only mother to note that she must attend to her son's challenging behaviour on her own, as her husband is unable to cope with this difficult behaviour. Aside from Melanie, however, the mothers who were single in this study did talk about how much more they do for their child with a disability than their ex-partners.

Diane also talked about doing more for her children than her ex husband:

I was way more involved, so I do understand [son's autism] way more than [father] does. [Father] was never involved and I don't think he fully understands what's autism – why is [son] that way... I was the only one always taking care of [my children]. Even when we were married, that was a long time ago...[ex-husband] never did anything when we were married and not when we were separated.

While Elizabeth initially explained during the interview that she and her husband share equal parenting responsibility in general (when parenting all of their children), she later stated that she does take on more responsibility for the care of their child diagnosed with fragile X syndrome:

I do probably take on a lot of responsibility with organizing things around the house... and for the kids. So although my husband is very supportive and involved in the children's lives - he's not, like calendar guy... So all the respite and all those pieces, I do most of that.

Interestingly, Elizabeth, whose son is nearing adulthood, talked about the fact that although she and her husband share parenting responsibilities, it is her son who often puts the responsibility of caring for him onto her. For example, her son will come to her (not his father) whenever he has a concern (even if it is very minor):

It seems that [son] always chooses to save up his problems for me...For example, if he doesn't like his socks, he'll go on about socks with me for 15 minutes and then my husband will walk into the room and he will stop talking. I'm like, "[son], don't you want to keep telling dad about your socks?" And he walks away and then I'll say to my husband, "Okay you need to take him out shopping and go buy him socks because he needs new socks". But I don't know why he has to save up all of his angst and lay it out on me. But anyways that's part of my job with [son] - I am his "depository of complaints" and his release of frustration because I know he doesn't act like that with anybody else.

Although Elizabeth and Melanie both talked about ways their husbands are supportive within the family, all of the mothers acknowledged that they were the ones primarily responsible for the care of their disabled children. However, it should be noted that as explained by Elizabeth in her interview, this responsibility is something she prefers to take on, as she believes she can organize her and her child's days well. According to Elizabeth, "[respite] is all self-administered, which I wouldn't want it any other way... I wouldn't want anybody else to sort of decide who would hang out with [my son]".

Melanie was the only mother in this study who vocalized her belief that it is her responsibility to ensure her son thrives, and reaches his goals for the future:

So now I'm at a place of – [son] is my responsibility, he is my son, I am going to keep him on track - he is going to get married he is going to have a job, he is going to do whatever he wants to do.

d.) Feeling Blamed and Judged by Others

Another difficult aspect of this mothering work is feeling blamed and judged by others, or feeling anxious that their child is being judged by others, as was described by five of the six mothers in this study. According to Diane:

I had the police following me because [a bystander] called the police on me because [son] was having a big huge tantrum outside. [One of] the things that helps him is [me] blowing through his fingers - so he stops. So I was doing that... The [bystander] from the other side was yelling at me and she called the police... she was telling them that I was biting him. So it's a part when you are in public... Way too big judgment. And looking at him like, "What's wrong with him?" Nothing's wrong with him!

Diane presented her concerns that others do not understand her son, and that the public (as well as professionals) needs to further educate themselves on people with disabilities in order to understand them:

People don't want to understand [disabilities], or don't care... I did run into couple people that...were really understanding... But it's not nearly enough for the kids to be able to function. Not nearly enough people understand [disabilities]... if the people [did] understand more, [kids with disabilities] would be better off.

Samantha also expressed feeling blamed and judged by others: "When I was younger I did feel like, did I do something? Do people look at me different because my son is disabled (autism)? Not only do they look at him different, do they look at me different?" Elizabeth also recounted experiences of her son being judged by others but explained that it does not bother her. "I don't even realize how different [son] acts but then I do recognize that other people are looking and thinking, 'Why is that kid acting so weird?' But I don't even notice and I'm not very insecure about anything".

The mothers also expressed anxiety because they saw their children being judged by others or were fearful that others would judge their children. As Samantha explains:

Sometimes if [son] was having an off day or maybe even if he was being babysat in an unfamiliar environment and...having his kind of little personal meltdown, that somebody might misconstrue that, you know, as him not listening or being disrespectful with the no eye contact and stuff like that. But really it's not, it's just that's his own... when he's just kind of shutting down and he doesn't really want any types of confrontation.

Melanie also shares her experiences/fears of her child being judged by others because of his developmental disability.

One of the things that we have struggled with... is that schools see labels. So it's like looking at boxes of cereal. You see Cheerios, Cornflakes, and ... wheat bran. [My son] has the label of Cheerios right? Autism. So, when he presents with typical autism things they can deal with that. But when he presents with something that's a little bit Cornflakes, and a little bit wheat bran, they can't see past just this one label. And the other trouble for us is that [son] presents to people as a behavioural problem. So he's upset, he's crying, then he becomes aggressive, then he's name-calling and swearing – they just see this angry, frustrated kid who's lashing out at anybody within spitting distance.

Heather also talked in the interview about feeling the need to tell people her son has autism, as she does not want them to think he is being a “brat” due to his behaviour.

As demonstrated above, these mothers face daily challenges in mothering their child with a disability. While some of these mothers discussed the stress they felt when they first received their child's diagnosis, others focused more so on the stress they are experiencing currently, such

as dealing with their child's difficult behaviour. These mothers' stories also exemplify how they have had to take on more responsibility than their husbands (or ex husbands) and the additional stress that this can sometimes cause. Lastly, these mothers noted how their mothering experience has also included feeling blamed by others, and worrying that they (or their children) are being judged by others.

Theme Three: Mothers' Fears for their Children

Five of the six participants expressed fear and anxiety when discussing what it is like for them to be mothers of children with developmental disabilities. Fears and anxieties included fear of their child becoming isolated from peers; fear of child being victimized by others; and fear of uncertain futures.

a.) Fear of Their Children Becoming Isolated from Peers

When discussing how their children interact with others, three participants spoke about their children's lack of friendships. Mothers talked specifically about how hard it is to watch their children miss out on the friendships that typical (i.e., non-disabled) children get to enjoy throughout their childhood. For Heather, she described how she tries to cope with knowing her son does not have many friends:

[Son] is not invited to birthday parties and does not get invited to play dates, I mean, so I mean we have friends that have kids and we socialize with them a bit but for the most part we spend a lot of time like just hanging out like as a family.

Melanie also spoke about her son not having friends, again using the example of the children's birthday parties:

My son struggles – his biggest struggle is social. He [is] in grade five now, [and] still has no friends... For [son], it's heart- breaking. Our son [is] in grade five, and has been

invited to [only] two birthday parties since daycare. Other people, other adults, we feel are fearful of things they don't know. So they don't want to invite this kid with autism who has an [educational assistant] with him at school all day to a birthday party where they're gonna have to deal with him. We know if he went he would be fine. He would keep it together for those two hours. But the moment that people find out about it, they become petrified.

When discussing her son with a disability not being invited to birthday parties, Melanie explains:

So, for [my son with autism] it's a struggle because he's saying, "I'm a good person, I'm a good kid. Mom and Dad tell me I am. But nobody wants to spend time with me, nobody wants to play with me". It's crushing. It's the worst. We know that it's lack of education.

As noted earlier, Lesley also expressed sadness about her son's isolation from peers: "We don't do birthday parties, we can't go to birthday parties we can't go to people's houses because of his fears, and his anxiety to hair, and bugs".

b.) Fear of Child being Victimized by Others

Another fear that four of the participants expressed was about their child being victimized by others. Heather noted concerns that her son has been bullied, which she only became aware of after her daughter disclosed this to her (not her son with a disability):

I don't know what's gonna happen with him so it's like the uncertainty thing that's definitely different and its like you know, he's getting bullied a bit at school and it's like grade two and it's like okay what's gonna happen, and it's really hard for him to tell [that he is getting bullied].

Samantha also discussed her concerns surrounding how her son may be mistreated by others:

Just socially you know, growing up, and we knew that there was special kids at the school you know. We know that there's people that are different. And just observing how sometimes those people get treated differently or how their experiences are different it just hurts my feelings.

Although Diane's son has not yet been bullied by peers (to her knowledge), she did express a fear that this might occur in the future, or could even be happening now. Diane explains, "People [are] always gonna look at [son with autism] weird ...you know how the kids are, the teenagers and the staff they...they are probably mean and stuff". Lesley also discussed her fear of bullying and its inevitability:

I'm terrified of the bullying and you know I don't want [my son with autism] to think that he's any less... you know but I mean, I mean kids are mean. You know? I mean kids are cruel. You know? And it's yeah, that's one of the challenges that we're going to have to face like soon, sooner or later.

While four of the mothers in this study focused on their child's treatment from other children or adolescents, Diane also voiced her fear that others, including staff at the school, may mistreat her son.

c.) Fear of Uncertain Futures

While five out of the six mothers discussed specific concerns and fears surrounding bullying, another topic that was introduced by three of the mothers was the fear of the unknown or uncertainty with regard to the child's future. As explained by Melanie:

There's just the sheer terror. When you have a baby, you plan for that. Right? So they're going to walk and they're going to talk and they're going to have friends. They're gonna get a driver's license and a job and they're going to meet a girl, or a boy, whatever and they're going to get married and have kids and you're going to go to their wedding and all those things. And then you get that... that formal diagnosis [autism] and your world comes crashing down. Will he live with me till he's 40? Will he ever hold a job?

Elizabeth also expressed uncertainty about her son's future (with fragile X syndrome):

I just keep thinking what is his future going to look like... and at this stage I think I've gotten so used to parenting him that the demands I think are going to hit me more when he's 30 and still living at home potentially... Or when he's 22, we're trying to figure out how to maintain like a really high quality of life for him when he's out of school.

Heather also talked about the fear of uncertainty for her son:

I don't know what's going to happen with [son] so it's like the uncertainty thing that's definitely different and its like you know, he's getting bullied a bit at school and it's like grade two and its like okay what's going to happen?

The discussions above note the general fear and anxiety that these mothers face regarding their child with a disability. These mothers are concerned for their child's wellbeing (especially surrounding relationships with peers), and worry that they are vulnerable to others. As noted above, these mothers hold a fear of the unknown, and what their children's futures will ultimately look like.

Theme Four: Mothers' Sense of Loss

In the present study, mothers noted many instances of loss. Some mothers talked about the loss of a "typical child" and future milestones (e.g., weddings, grandchildren, etc.), loss of

their own social life, and loss of career or job opportunities. As will be noted below, these feelings of loss were presented in some way for four of the mothers in this study.

a.) Loss of a “Typically Developing” Child and Future Milestones

Three of the mothers in this study talked about the loss of a “typically developing” child, and future milestones they would have expected their child to achieve.

Lesley reported feeling a sense of loss for her child with autism: “We don’t do birthday parties, we can’t go to birthday parties... we can’t go to people’s houses because of his fears, and his anxiety to hair, and bugs”. Melanie also described during her interview not knowing what to expect for her son’s future, and asking herself “Will [son] live with me till he’s 40? Will [son] ever hold a job? Will [son] ever have friends?” When talking about working with the school to get her son the services he needs, Elizabeth spoke about the school staff and their significant effort to try to get her son an educational assistant. While Elizabeth was appreciative that the school staff assisted her with completing the necessary documentation to obtain an EA, she noted how difficult it was to hear all of the things her child is not able to do:

[School staff] were able to get [son] an EA because he had a low IQ right? ... But oh, it was devastating for me... I was listening to them... the more bad things they put on those reports, the better it is for [the child]... and then, also because he once wet his pants at school they were able to put toileting on his... request form... which I kept saying he doesn’t have any problem toileting, I’m like he can go to the bathroom, but then [the school staff] were like, “No [Elizabeth] just like let it sit”... I’m like, “Okay, just don’t even show me what that piece of paper says because I don’t want you to – I want you to make a case for him, I want you to get us as many supports as you possibly can but I really don’t want to know all the things you’ve brought up right now.”

Elizabeth, whose son has fragile X syndrome, also discussed her son being initially diagnosed and described how hard it can be as a mother to hear a doctor tell you all the things that your child will not be able to do:

I just have to say that I'm sure that [doctor] didn't intend to be so depressing but she was completely not helpful... I mean like, [my son] was five years old, right? But she just basically said he'll never get married, he'll never have a serious relationship, he'll never live on his own, she just listed all these things he'll never do... But just the, the emphasis on all the impossibilities for his life just totally made me frustrated at her and perhaps I received it in a negative light because it was so shocking to me.

b.) Loss of Their Own Social Life

Two of the participants reported feelings of loss for their own social lives, either due to the mother not being able to find respite, or due to the mother needing to remain with the child while he is receiving services. The topic of losing one's own social life was not directly asked during the interviews, but rather, arose while these mothers were discussing their stories. However, I suspect that had this question been brought up directly during the interviews, more mothers would have noted a loss of their own social life. According to Lesley:

[Son] is like a two or a three-year-old. I've had a two or a three-year-old for five years now. I don't get to go out. I don't have a social life... my daughter babysits for little bits at a time when she can. But you know even that sometimes it's just, it's too much for her depending on his mood... The only place that we do go is to my best friend's, but she lives [outside of the city]... so she took [my son] there a couple weeks ago for two days and that was the first break I'd had since September, and before September was five years.

When discussing in-home services that were being offered to her son with PDD, Heather talked about the difficulty of having to stay in the home all the time due to her son's programming, which required that at least one caregiver was at home during the day while programming was occurring. Heather's son was receiving Applied Behavioural Analysis (ABA) through St. Amant, and although she was not with her son during these sessions, she was obligated to be in the home (or on her property) while her son was receiving them. According to Heather:

When I had a three-year-old child and then a one-year-old baby I had to be home in my house all day [due to son receiving disability services in their home every weekday]. And I mean which is fine in January... Where am I going to go? But like [me and my daughter] couldn't walk around the block. I would take [daughter] around the block but we weren't supposed to leave the property line... so it was definitely like more isolating in that way like people would have to come over to our house or you know we couldn't just go out and do stuff.

c.) Loss of Career and Job Opportunities

Three mothers talked about the loss of career or job opportunities because they had to care for their child with a disability. For example, Heather noted that because of her son's intense in-home programming, she was unable to return to work until her son was almost five years old, explaining "I couldn't go back to work until [son] was almost five because I have people working in my home all the time". However, Heather still noted that since she got her job prior to her son starting school, she still needed to hire a nanny for the last few months of spring, as well as over the summer:

So I ended up starting [work] in April so we just had a nanny working here for a few months in between [son] like finishing... in the preschool [ABA] program in August, so, it's from April to August we had someone working in here, nannying, but she just basically came and hung out and cooked because when [son] was working in the basement [with ABA]... he just needed someone to feed him.

Samantha also talked about not being able to work due to needing to care for her son with autism and the effect that it has on their family income. Samantha states:

It was always a goal of mine to be a working parent... but I find that [my son with autism] needs a lot more care and attention right now... I'm willing to give up, I guess the comfort of having more income than just giving him a good basis for his future.

Diane described her challenges of maintaining employment while being a single mother for her son with autism. As Diane explains, she was unable to maintain employment due to the time she needed to take off in order to care for her son:

I just had issues because I was losing so much time from work because [my son] gets upset so I have to go pick him up so I lost the job, so I had to claim bankruptcy because I did not have the money to live on, right, so I lost the apartment...I didn't have a place to go, and I couldn't take my son to the shelter, because he can't handle the changes.

As Diane exemplifies, the loss of her employment triggered a tragic chain of events that resulted in bankruptcy and the loss of her home. Further, because of the nature of her son's disability she was not able to access supports to assist her in dealing with her financial loss.

The mothers in this study noted some kind of loss they have experienced that is related to having a child with a developmental disability. For some, this feeling of loss came from the understanding that their child's future may not hold the same milestones as they might have

otherwise expected (e.g., child birthday parties, employment, marriage, parenthood, etc.). For other mothers, they focused on their own losses, including loss of their social life and peer relationships, and a loss of employment and career opportunities outside of the home.

Theme Five: Mothers' Relationships with Their Non-Disabled Children

As a reminder, all of the mothers were asked about how parenting a child with a disability may be different than parenting a child without a disability. All of the mothers in the study had at least one other child who did not have a disability. Five of the six participants discussed the impact of their child's disability on their relationship with their non-disabled children.

While the mothers were able to list ways their children without a disability have been positively affected (as discussed earlier), four discussed concerns they hold for their non-disabled child. For example, Samantha worries that because of the large amounts of time she devotes to her child with autism, her non-disabled son may feel neglected: "It also causes me anxiety that maybe my son that is...developmentally healthy is maybe feeling neglected...so I try [to give] them like equal time or equal attention". The concern of giving their child with a disability more attention than their other child was also shared by Lesley, who noted:

The attention for [son with autism], like he gets a 180% of my attention and [daughter who does not have a disability] is kind of left in the dust. You know? So, I try and pick up on days like today where she's not in school so we can go shopping and spend time together...I pull her out of school you know every couple weeks to do that. And you know, the school doesn't understand - she's my daughter and she needs my attention too.

Heather also talked about trying to find balance for her non-disabled daughter, referring to the numerous appointments required for her disabled son and how it can be a challenge to

balance the interests of her children: “That’s the other thing - trying to balance [the schedule]... I have to take [my daughter] to [my son’s appointment] tonight, drag her there - she gets dragged a lot to different places”.

In her interview, Diane also discusses how much her daughter cares for her son: “[My daughter] was a really good help to me - she would see that I’m upset - or crying. She would say I think you need to go to your room. I’ll take [care of brother]. However, Diane later talks about her concern that her daughter has too much responsibility, as a sibling, for her brother:

I think it’s worse, harder for siblings than a parent. Parents – you have children and you have to take care of them, it’s your job. This is what I got, this is who I have to take care of. But the kids don’t understand. It’s really- more hard on the siblings than the parents.

As expressed above, these mothers speak to the difficulty of trying to balance the interests of both their children with a disability, as well as their children without a disability. This difficulty puts further responsibility on these mothers, as they are put in a position where not only must they care for their child with a disability, but also try to ensure that they are giving their other child equal attention, thus making their mothering responsibilities even more intense.

As demonstrated above, the mothers in this study were able to identify positive outcomes of having a disabled sibling for their non-disabled children, but also acknowledged that their non-disabled children may be negatively impacted. One of the main concerns appeared to be the worry that the non-disabled child might develop feelings of resentment due to their sibling receiving more time and attention from their mothers. It was also due to this concern that Lesley and Samantha noted they try to ensure their child without a disability still receives some one-on-one time and attention from them.

Theme Six: Mothers’ Perceptions of the Helpfulness of Formal and Informal Supports

Another theme that emerged in this study relates to how mothers viewed their interactions with others, including formal and informal supports. Formal supports include professionals working in the area of disability (e.g., doctors, social workers, occupational therapists, physiotherapists) and also other professionals, namely school staff and/or daycare staff. Informal supports include friends and family members.

a.) Support from Professionals

Below is a discussion of what mothers considered positive in their working relationship with professionals, as well as how they felt their relationships were strengthened. While many of the mothers discussed positive interactions with their formal supports, there were some concerns identified as well, which will also be considered in these subthemes.

The mothers spoke of the following forms of interaction as positive and essential from professionals: 1.) Compassionate and non-judgmental support; 2.) Being recognized by the professionals as experts of their own situation; 3.) Having a united front with professionals; and 4.) Receiving accessible services from professionals.

1.) Compassionate and Non-Judgmental Support

An important aspect of these services was working with professionals who are compassionate and non-judgmental, which three mothers discussed in their interview. Melanie spoke about appreciating the non-judgmental attitude of her CDS worker: “she’s non-judgmental, like I never call her and feel like I’m being judged”. Elizabeth also noted that she appreciated supports that were accessible and compassionate:

[Occupational therapists] the [physiotherapists] and the speech therapist and all of these people who came to our house and did all of those things with us – those were amazing

people...they were just... so compassionate...they always came over... they gave really great little tools of how to help [my son].

Samantha also alluded to the importance of compassionate and non-judgmental care when working with professionals: “[Professionals] always checking in on us, and always making sure that, that we’re comfortable you know in this journey because you know, it’s always evolving”.

2.) Being Recognized by the Professionals as Experts of their Own Situation

Melanie and Samantha also expressed feeling positively about their interactions with their service providers when they were able to acknowledge them (as mothers) as experts of their own situation. Melanie notes: “When I say to [my CDS worker] I am [son with autism’s] mom and nobody knows him like I know him, she knows that I mean that”. Samantha also shared this viewpoint, noting that she appreciates communicating with the school while feeling like part of the team: “giving me feedback at school and just letting me be part of the solution”.

Melanie talked about how she feels professionals sometimes do not view her as an expert on her situation and noted that she does not like when professionals imply they know more about her own child than she does:

Yeah and it’s crazy to me... “Yes, you’ve had 10 years of education and you’ve paid a lot of money and you have many letters behind your name and I appreciate that, but I live with [my son with autism] every single day”.

Melanie was also able to provide some insight into what she believes professionals could do better when meeting with her family, and preparing to work with them:

The thing that I want for all professionals to know is mostly that... if you meet me and you meet my son [with autism] and you are there to you know “quote unquote” help, then

listen to our story. Listen to what we have to say, take from it what you will, but listen. And hear. Because that is something that we found was lacking... a lot of times we were passed to a new professional... we walk into the meeting and realize they know nothing about us. Which is okay even though you had that big giant file to read, but then when we're saying, "Well, this is what's happening or this is whatever," they start referring to other cases - "While I have this other case" or "I have this other client" or "I have this other" ... but we're not them... just treat us as individuals.

3.) Having a United Front with Professionals

Samantha and Diane discussed the need for professionals and themselves to be "on the same page", or rather, have a "united front". While Diane did not express dissatisfaction regarding her CDS worker, or social worker working with the family, she did talk about how she thought her son's first school counteracted or undermined the work that she was doing at home, ultimately failing to help her son:

I was so stressed out because [the school staff] were wasting [son's] time. They were wasting his life... I train [son] how to get dressed up how to feed himself right now... and I send him [to school], he comes back he doesn't want to put the jacket on. Or doesn't want to put the boots on. Because they were doing [these things]. They were unable to help him to do what he was capable of doing.

Samantha identified the need to feel she and the professionals were working as a team: "Yeah, so I really appreciate the feedback and it helps that we [Samantha and professionals] have a united front".

4.) Receiving Accessible Services from Professionals

A final subtheme discussed by the mothers in this study did not look specifically at their interactions with service providers, however is nonetheless important to discuss as it focuses on how services in general can create positive (or negative) experiences. The mothers in this study discussed the importance of having accessible supports, which can be attained through funding by the government, and which are readily available to the family. Of the six participants, four spoke highly of the current supports they received for their children with disabilities. For example, Heather spoke highly of the ABA Program, a program that runs out of St. Amant, noting, “I am really happy with the program, and the fact that the government’s funding it is awesome”. Although Heather was happy with this assistance, while talking about her relationship with her Children’s disABILITY Services (CDS) worker, she noted that she thought that CDS would be more beneficial if they could meet with her more often and share resources with parents in a more organized manner. For example, Heather noted that she would casually hear about services for her child with a disability from other mothers, as opposed to from her CDS worker. However, this experience was different for others. Melanie spoke very highly of her relationship with her CDS worker and considered her worker to be helpful, not only with assisting her child to receive the services he needs but also with supporting Melanie whenever she needed it:

It comes down to who she is as a person. And who she is as a person is like straight shooter, call it as it is... let’s fix it. My opinion is that a lot of social workers have a band-aid thing – “Okay, you’re having problems with this – let’s do this to fix it”.

Whereas she will take the time even if it takes months to really get to the root of the problem and fix it.

While the comments above speak positively about the accessibility of services, Lesley discussed her concerns with the system in Manitoba, and noted that she was unhappy with the current waitlists for services, so much so that she considered relocating to another province.

My [son with autism] is on waiting lists everywhere. Manitoba is ... horrible for waiting lists. "We'll put you on the waiting list. We'll put you on – okay here's a two [year] waiting list. Here's a three-year waiting list." [Son] is on a waiting list everywhere. Next July, we are relocating. [Researcher - And is that for the services?] Yeah... it's for the services.

Lesley discussed what she believes must change in order for better services to be offered in Manitoba, noting that "Manitoba definitely needs to step up on their, their actions for... special needs children. Because the waitlists are ridiculous and I mean there's children worse than [son] you know and they're waiting just as long as [son]". Lesley talks further about how she believes Manitoba should be offering more assistance to her son, and notes:

Just the other day [son] said to me he was mad at me and he says to me, "I'm gonna kill you when you're sleeping"... I don't know it's just frustrating because you know like if he was getting the therapy that he needed you know I would almost guarantee that he wouldn't be saying stuff like that you know because he'd be learning ways to cope with his anger in more positive ways.

These mothers were able to speak about their unique experiences with formal supports, and how their different interactions could be viewed as negative or positive, depending how the services were being provided. These mothers noted that they and their children benefit from having services that are easy to access, and are provided by professionals who are compassionate and non-judgmental. The mothers also expressed the need to be recognized as experts of their

own situation, and would like to feel a part of the team, and have a united front with the professionals they are working with. Due to the understanding these mothers hold for their sons, there is also a general consensus that the professionals (no matter how much experience they might have) need to respect the knowledge coming from these women, and understand that in order to assist the child in the best way possible, they must listen to what these mothers have to say.

b.) Use of Informal Supports

Although many of the mothers were more inclined to discuss formal or professional supports, five of the six participants did discuss the assistance they received from informal supports, namely family and friends. Samantha explained during her interview that she is trying to distance herself from previous unhealthy relationships, and as such did not have many relationships to speak of that offered her much support. However, she briefly mentioned a friend she had in her apartment building: “I have a friend in the building who has children and they’re a working family and we kind of babysit, share, and what not and so that helps me socially”.

Both Heather and Elizabeth talked about having family who sometimes care for their children. Heather noted, “both my mom and my mother-in-law don’t live in the city...but, they’re helpful. They do come in and babysit”. Heather also explained that her nephew has occasionally cared for both her children. While discussing her informal supports Elizabeth notes the importance of having supports that genuinely love and care about their children:

I have a sister, and my sister and brother-in-law, they are very understanding of [son] and so actually for a little while they kind of did a bit of respite for me. Before they were married my brother-in-law did a lot of respite with [son]... and that was really helpful... they’re very like calm and they know how to redirect him, and he loves to spend time

with them. So anytime that someone loves to spend time with your kid then you should appreciate it.

Lesley also noted the importance of having supportive people who truly understand her children, but explained she does not feel she has family from whom she can ask (or expect) assistance:

I have a lot of family but like, I think that they're all kind of scared to [help with son] because of [son's] outbursts... and how he can be. I think they're afraid to offer support, or to offer help. They'll bring it up but then I never hear it again.

Although Lesley noted in her interview that she does not have family who can assist her with her son with autism, she has a best friend to help her and her child so that she can take time for herself (i.e., respite):

The only place that we do go is to my best friend's, but she lives [out of town] and she has five kids and a newborn, so she took [son] a couple weeks ago for two days and that was the first break I'd had since September, and before September was five years.

For Melanie, she explained that although her friends do not babysit her son, they are able to offer her support by being emotionally available to her: "I have a couple close girlfriends who, while they couldn't step in and watch [son] for me, will kind of say to me "you need a cup of coffee... let's go".

So for some of the mothers, informal supports are an important way for them to cope with the daily tasks of mothering a child with a developmental disability. For Melanie, having friends who would take her out for coffee (giving her a break from the situation) was important. Interestingly, only one of the six mothers could not name any informal supports when asked.

Diane stated, “Family members...everybody has their own stuff to do, right, so they never have enough time. As a parent you need to go for the seminars - not the other family members”.

As is demonstrated above, when asked about supports, these mothers spoke about the importance of both formal supports involved with the family as well as their informal supports - that is, family and friends. Through the conversations surrounding formal supports, however, it should be questioned whether we as professionals acknowledge the importance of informal supports, or do we generally consider formal supports as more pertinent to a family’s situation? This will be explored further in the discussion section.

Summary of Study Findings

The mothers in this study offer a number of perspectives on the experience of mothering a child with a developmental disability. The mothers talked about wanting others to know that having a child with a disability should not be considered a primarily negative experience, as it includes a number of positive and pleasurable experiences, including feelings of happiness and joy, pride, a sense of accomplishment for the mothers, and learning and opportunities for growth for the mothers. On the other hand, the mothers also discussed feeling stressed, exhausted, and overwhelmed by their mothering roles. The mothers shared their perspectives on their roles as mothers of children with disabilities, dealing with difficult behaviour, managing their children alone, and feeling blamed and judged by others.

The mothers in this study were able to acknowledge that, although they do not consider their situations as entirely negative, they are fearful for their children with disabilities, and worry that they may become isolated from peers, possibly victimized by others, and also have anxiety surrounding the uncertainty of their children’s futures. Along with this fear and anxiety was a sense of loss through having a child diagnosed with a developmental disability, whether it is

related to the idea of raising a “typically developing” child, loss of their own social life, or loss of career and job opportunities. The mothers also noted the effect that having a child with a disability may have on their other children, and were able to acknowledge once again that this experience can present both positive aspects, as well as challenges. Lastly, the mothers talked about how they view their interactions with professionals, and the importance of support from family and friends. These mothers discussed what they appreciate about the professionals they work with, and how they feel supported by these workers. For informal supports, the mothers explain the different ways their family and friends are able to assist them and their families.

Chapter Six: Discussion

Mothering a child with a disability is a broad subject that can yield a number of perspectives, explanations, and stories from mothers. The goal of this research was to gain a fuller sense of what being a mother of a child with a developmental disability looks like. Six major or overarching themes were identified in the research that present a rich, multi-dimensional portrait of the mothering experience: 1.) positive experiences and emotions; 2.) mothering a child with a developmental disability as difficult, stressful, and overwhelming work; 3.) mothers' fears for their children; 4.) mothers' sense of loss; 5.) mothers' relationships with their non-disabled children; and 6) mothers' perceptions of the helpfulness of formal and informal supports. These six themes are discussed below and linkages are made to the existing body of literature. As mentioned earlier, a feminist-informed theoretical framework is used to understand or explain women's accounts of mothering a child with a developmental disability.

Theme One: Positive Experiences and Emotions

Unlike the common perception that raising a child with a developmental disability is a negative life experience, rife with challenges and burdens, the mothers in the present study clearly articulated their mothering experience as a positive one. This is not to say that they do not encounter challenges or do not feel overwhelmed with their caregiving responsibilities. Mothering a child with a developmental disability is clearly difficult and overwhelming work (as will be discussed shortly), however, professionals and the general public should not assume that mothering a child with a disability is a negative experience. These mothers offered freely (and quite easily) many positive and pleasurable aspects of mothering developmentally disabled children. Clearly, these women have no desire to depict their mothering experiences as negative. Rather, they want others to understand how positive this experience can really be.

Throughout the interviews, mothers expressed feelings of pride for their children as they watched them grow and learn. All of the mothers in this study expressed that they themselves experienced tremendous growth – for some it was simply developing new skills (such as being organized); others learned to become more patient and understanding; while others discussed feeling an overall sense of accomplishment.

As mentioned earlier, it is important to note that caring for children with developmental disabilities was not an experience these mothers were seeking pity for. In fact, for many of the women, an important reason for their participation in this study was to educate the public about how raising a child with a developmental disability can be a very positive and rewarding experience.

While this study is meant to highlight the experiences of mothers who have children with developmental disabilities, it is important nonetheless to question how, or if these experiences are different from mothers who have children without disabilities. In reflecting on the positive experiences listed above, it appears that some of these mothers' experiences are likely not different than those of other mothers (i.e., mothers of children without disabilities). For instance, it is probable that all mothers, in general, experience a sense of pride as they watch their children grow and learn new skills. Although the skills being learned might be different for children with disabilities versus children without disabilities, the pride that mothers feel when a skill is learned is likely the same, or very similar. A second example is the opportunity for growth that mothers experience due to mothering their child. Again, while the lessons learned by mothers might look different depending on their child, this growth is something you would likely find in any mother. Most mothers would be able to look at who they were prior to having a baby, and comment on how they grew personally following the birth or adoption of their child. While the mothers in

the present study may offer unique experiences to their mothering situation, ultimately, the positivity they have encountered can be considered similar to mothering work in general. However, it is interesting that during the interviews, participants explicitly noted the growth they experienced due to having a child with a developmental disability. It could be that these mothers want to articulate this growth in order to demonstrate that having a child with a disability is not something debilitating or negative and does mean that their experience of mothering is “less than”, but rather, an experience that is just as legitimate (and worthwhile) as the experience of mothering a child without a disability. These mothers recognize that others may view their situation (mothering a child with a disability) as a pity or burden, or something that makes their lives less pleasurable than others. However, these mothers were able to not only talk about how mothering a child with a disability has been a positive experience, but also what gains they have made due to this unique experience (and learning experiences they might not have otherwise had).

Mothers' reports of positive experiences are consistent with findings from other studies. For example, in the study by Hastings et al. (2005), the authors noted that mothers (often more so than fathers) discussed how having their child with a disability offered them feelings of happiness while also strengthening family closeness. These mothers expressed perceptions that their child with a disability made their family closer, helped the family grow stronger, and also expanded their social networks. The mothers also noted that they felt their children with disabilities created feelings of happiness and fulfillment. Trute et al. (2007) also note in their study that, although parenting a child with a developmental disability can be stressful, it also offers positive feelings surrounding their family and their child. The authors argue that when families are encountering times of stress related to parenting their child with a disability, they are

able to respond to these challenges positively and resiliently. This response is often related to how the parents perceive their situations with a child with a disability. That is, the greater the perceived positive impact of having a child with a disability, and the lower the level of perceived negative family impact, the greater the likelihood of family well-being over the long term.

Some studies have examined the positive experiences of raising a child with a developmental disability, specifically. For example, Kayfitz et al. (2010) discuss positive mothering experiences associated with mothering a child with disability, including mothers believing their families became closer due to their child with a disability, and recognizing that raising a child with a disability includes continuous learning on their part. Similarly, Charles and Berman (2009) note in their study how mothers of autistic children were able to experience many positives, including learning to defend and advocate for their children, becoming more compassionate, and growing as individuals themselves. Melanie and Diane, who both talked about having to defend their children when they felt the schools were not providing them with appropriate services, also spoke of advocating for their child with a disability. Stainton and Besser (1998) wanted to look at positive outcomes related to parenting children with disabilities (although they did not focus specifically on developmentally disabled children), and identified a number of positives shared by both mothers and fathers involved in their study. These positives included increased happiness and joy, increased tolerance and understanding, and increased growth and strength. Similar to the findings in the current study, all of these articles demonstrate that these families did not want others to consider their experience as negative, but rather, named a number of ways that having a child with a disability impacted their lives positively, and helped them to grow as individuals.

Mothering a child (with or without a disability) is rewarding work and one that should be highly regarded and valued. Looking at how professionals work with mothers of children with disabilities, workers must not only understand that these mothers view their situations positively, but they must also explore these positives, just as they might the challenges in their lives. In other words, it is not enough for a professional to acknowledge that families in this situation experience positives. Rather, just as they might ask about stressors in families' lives, they should also be asking what strengths they have and what positives they experience with their disabled children, and incorporate these areas into their work with families.

Theme Two: Mothering a Child with a Developmental Disability As Difficult, Stressful, and Overwhelming Work

Another common theme identified in the interviews with mothers was the ongoing challenges they experienced in their mothering role. As will be discussed below, the mothers in this study spoke of a number of significant challenges related to mothering a child with a disability, including physical and mental exhaustion, feeling stressed and overwhelmed, dealing with difficult behaviour, managing alone, and feeling blamed and judged by others.

In this study, the mothers spoke specifically of their various responsibilities and how much work it can be to care for a child who has been diagnosed with a developmental disability, and the physical and emotional toll that this difficult work has on them. Mothers expressed fatigue and exhaustion with the day-to-day work that comes with parenting a child with a disability. Simple daily tasks that most mothers with non-disabled children would consider easy to accomplish, such as getting their children dressed in the morning, can take an enormous amount of time and emotional energy for mothers of developmentally disabled children.

When looking at feelings of stress and exhaustion, researchers have found that caregivers (both mothers and fathers) report higher levels of anxiety and stress than do caregivers of non-disabled children (Bristol, 1987; Heiman, 2002; Nankervis et al., 2011; Stuart & McGrew, 2009). Heiman (2002) found that both mothers and fathers who have children with delays experience greater stress than parents who have children without disabilities. Stuart and McGrew (2009) looked at parents (not mothers specifically) of children with autism, and determined that the greater the symptoms of autism, the higher the burden for the parents, and the families in general. The researchers noted the intense challenges caregivers of children with autism face, such as dealing with the severity of autistic symptoms in their child, sometimes having little social support from others, and continuing to meet any additional life demands, and conclude that when additional stressors are presented, these can push the parents to a point where they no longer feel they are able to cope or manage with their current situation. Nankervis et al. (2011) examined the experiences of mothers of children with intellectual disabilities and found that they often suffered from exhaustion and stress, and talked about these negative effects likely being due to the fact that the caregiving role generally fell onto them. While Arendell (2000) does not look specifically at mothering children with disabilities, she does note in her research the many challenges that mothering can present, including stress and anxiety. Eisenhower et al. (2009) note in their research that mothers of children with disabilities reported poorer physical health than mothers without children with disabilities, while also explaining that poorer health is often associated with a child's behavioural challenges. Although the mothers in the current study did not identify health problems, this topic was not explicitly asked in the interviews. Finally, Home (2008) also discusses the emotional and physical exhaustion that occurs for

mothers of children with developmentally disabled children given the amount of time and energy simple tasks require (as noted by the participants in my study).

Another subtheme that was introduced in the present study was the challenge of dealing with difficult (and sometimes violent) behaviour. For Lesley, this violence was demonstrated with verbal threats, and she described how her son would threaten to kill her, and even had a plan to do so. Melanie labeled her son's aggressive behaviour as "rage" and talked about her son ripping a door right off its hinges during one of his emotional meltdowns. Diane talked about her son's physical aggression to her daughter, which included hitting and kicking her, while Elizabeth explained during her interview that her son has hit her in the past, and she sometimes worries he is going to hit her when he comes close to her, although she then noted this would often result in her son shoving her, instead of hitting her.

Other mothers in my study noted that their children's odd or strange (but not violent) behaviour posed considerable challenges for them. Heather, for instance, was able to talk about how stressful it was to attend a playgroup due to her son's behaviour, which consisted of him having an emotional meltdown, and attempting to "knee-walk" while pulling her to his stroller so that they could go home. Samantha also talked about her son's behaviour possibly appearing disrespectful (not making eye contact) when in fact he was trying to protect himself from being over stimulated or engaging in a confrontation. While some difficult behaviours, as noted above, might include aggression or threats, others might consist more so around the peculiar manner in which the child behaves. Although these behaviours are not violent in nature, it is important to state that this does not mean that they are easier to deal with. These behaviours can still be hard to manage, and take an emotional toll on the mothers. Not only is it hard to deal directly with

this behaviour, but for these mothers there is also the concern that they and their children will be judged due to their atypical behaviour.

In her article, Home (2008) discusses a number of difficult behaviours that may be present for a mother when raising a child with a hidden disability such as autism and ADHD. Some of these behaviours may include violence, or a threat of violence towards the mother. One mother expresses the emotional challenge of having a potentially violent child, and talks about her fear always being present that violence will reoccur (and thus never feeling confident that their home will not face another violent situation). As this mother explained in Home's article, there was a fear that her son's violence would necessitate a call to the police.

While the mothers in the present study did not use this specific wording, their stories illustrate violence towards them as mothers. While violence towards parents or family members does occur, there appears to be a lack of research on the topic, especially concerning mothers of children with disabilities. Stewart, Burns, and Leonard (2007) (who looked at mother abuse specifically) discuss the different types of abuse that mothers experience from their children, which ranged from name calling, to psychological abuse involving manipulation, or physical violence. As is noted by Walsh and Krienert (2007) (who looked at violence against mothers and fathers) this violence is labeled "child-parent violence [CPV]" (p. 563). The authors note that although CPV is believed to be more prevalent than child abuse or spousal abuse, it is less likely to be reported to the authorities. Keeping in mind that this study was not focusing on individuals with disabilities, it is nonetheless interesting to note that studies have shown that women as mothers are more likely to be the recipient of parent abuse, regardless of the sex of their child committing the abuse. The victims of this violence (again generally mothers) often will not report this violence, in an effort to protect their child from law enforcement, even when

it means the abuse will continue. This may also reflect a type of intensive mothering, in that these mothers, despite their own physical and emotional wellbeing, will choose to not seek assistance. While they may not want to have their child become involved with the law, it might also be that they have difficulty in asking others to help them be protected from the child whom they have raised. As the authors also point out, many people may not understand how this abuse could even happen given the difference in power that parents usually have (or at least are expected to have) over their children. Mothers who experience abuse from their children might, therefore, feel they will be judged (again pointing to mothering blame) for not teaching their child to be a respectful person, who does not act violently towards others. This was noted by the National Clearinghouse on Family Violence (2003) which discussed how parents are generally the ones who are blamed when things go wrong with their children, even though parent abuse can be influenced by different factors including family dynamics, societal values, and child development. The authors reaffirm that mothers are much more frequently the ones who experience this kind of violence. This paper goes on to explain that society often accepts and consequently perpetuates abusive behaviour, through films, television, and everyday life where teenagers witness how violence can gain them social control. Furthermore, the paper argues that women are undervalued and demeaned in our society, which may be why they are more likely to be abused by their children than the fathers. Looking specifically at development, the authors also note that while some abusive adolescents may have a developmental disorder such as ADHD or a mental illness of some kind, most who abuse their parents are typically developing and do not have mental health concerns. Regarding the effect that parent abuse can have, this article explains that parents (generally mothers) can experience anxiety and depression due to

this abuse. Further, as discussed above, there is a feeling of shame for not being able to have a healthy and happy family. Abused parents also feel isolated and unsupported by others.

Although the studies above are able to demonstrate the presence of parent violence (and specifically, violence towards mothers), it is important to note again that more research must be done on violence by children with disabilities, as this is clearly a concern which was expressed in the current study.

While the articles above looked at mothers and fathers experiencing violence from their children, other authors focus on how difficult (but not necessarily violent) behaviours presented by a child may impact their caregiver (Boström et al., 2011; Bourke-Taylor, Law, Howie, and Pallant, 2009; Home, 2008; Stuart & McGrew, 2009). Stuart and McGrew (2009) found that the greater the symptoms of autism in the children, that is, the more severely disabled the child is, the higher the burden for families, and the more stress they might encounter in caring for their child. Home (2008) also noted that while some mothers talked about their disabled children's violent behaviour, others talked about behaviours that were not aggressive in nature but were equally challenging and stressful. For example, one mother noted that each morning her daughter began the day by screaming at both her parents, while refusing to listen to instructions. Although this behaviour is not violent or aggressive in nature, one can empathize with the mother as to how difficult it would be to manage and cope with this tense environment. In their study, Boström et al. (2011) noted that mothers, more so than fathers, were most negatively impacted by children who were considered as having disruptive behaviour. The authors explained that this may be due to the fact that mothers are generally the primary caregivers of children, and therefore are more impacted by their behaviour. Another interesting aspect to behaviour challenges which Bourke-Taylor et al. (2009) discuss in their study, is the fact that

mothers dealing with their disabled child's behavioural challenges also talk about the stigma they face from their communities, and how these negative attitudes further exacerbate their daily pressures. The authors also talk about findings that suggest the correlation between maternal stress and challenging child behaviour, which implies that when a child's behaviour is harder to deal with, the mother (who is likely the primary caregiver) will face higher stress levels than if her child had no challenging behaviours.

Another formidable difficulty the mothers in this current study experienced was hearing for the first time that their child has a developmental disability. Elizabeth talked about how hard it was hearing the doctor not only tell her that her son has fragile X syndrome, but also hearing the doctor tell her all the things that he would never be able to do. Likewise, Heather noted in her interview that following her appointment with the specialist, she was given a list of things she must do in order to help with her son's development, such as taking him to a play group, working on his social skills, getting him in to see a developmental pediatrician, and having him referred to a speech-language pathologist. In both these instances, these mothers talked about this time of diagnosis as a particularly challenging one for them.

It is important to note that not all mothers in the study reported feeling stressed when they first learned of their child's diagnosis. In both Elizabeth and Melanie's case, there was actually a sense of relief when their child was officially diagnosed with a developmental disability. For Melanie this relief came from her previous suspicions that her child was delayed, and the consequent validation she received when she was able to confirm that she was not "crazy" or simply imagining things, and in fact her son did have a developmental disability. For Elizabeth, on the other hand, her relief came from the understanding that her son's disability was genetic

and, therefore, had nothing to do with the previous instances where he had almost died (therefore, releasing her from feeling like she as the mother was to blame for her son's delay).

In terms of the literature, there has not been much work done that examines the difficulty that mothers experience when their developmentally disabled children are first diagnosed by professionals. However, there has been some research done that examines the experiences of first diagnosis on mothers of children with chronic health problems, more broadly. While a developmental disability is not the same as a chronic health problem, this body of literature may prove informative nonetheless. For instance, Cadell, Kennedy, and Hemsworth (2012) discuss the challenges that parent caregivers (not mothers specifically) experience when their child is first diagnosed with a life-limiting illness (LLI), such as cancer or neurodegenerative diseases. Like mothers of children with disabilities, these authors discuss the significant changes that families make in their own lives in order to care for their recently diagnosed child, including employment changes, working with different professionals, or advocating for resources. The finding that mothers sometimes feel a sense of relief upon first diagnosis (as noted by two participants in my study) was also noted by Young, Dixon-Woods, Findlay, and Heney (2002), who looked at the experiences mothers face when living with their child who has cancer. The authors noted that for some mothers, there was a sense of relief following the child's diagnosis, as they were able to at least know what was wrong.

For the mothers in the current study, it was not only hearing that their child had a disability that was difficult, but also how this disability would affect their child both at the present time and in the future. Furthermore, the diagnosis also lead to a number of tasks or responsibilities the mothers needed to do in order to support their sons.

The mothers in the current study also noted that caring for a child with a developmental disability is difficult because not only do they need to care for their disabled child, but they also have to care for their non-disabled children who have very different needs. This is an important topic to explore further, and it will be discussed more fully in theme five, however it is important to briefly note how having multiple children can increase a mother's difficult work within the home. The mothers were quite conscious of the impact the endless appointments and responsibilities had on their non-disabled children. Mothers talked about feeling guilty because after spending so much time caring for their disabled child, they often weren't able to spend as much time with their other children. Consequently, mothers had to come up with creative solutions to spend time with, and nurture their non-disabled children, as indicated by Lesley, who took her daughter out of school so she could have alone time with her. These examples demonstrate how caring for a child with a disability in and of itself can be intensive work; however, caring for a non-disabled child as well further adds to this work, given that these children are given less attention, and the mothers must be ever-mindful of maintaining a necessary balance between their children. For Melanie, not only was she responsible for caring for her sons, but she also had to be mindful of helping her husband during challenging times with their son with autism, as her husband was unable to cope with their son's behavioural challenges on his own.

As one can see from these mothers' accounts, caring for a child with a developmental disability can be difficult, overwhelming, and stressful work. A possible explanation for this is the gendered nature of their caregiving work. All of the mothers in the study (married or single) noted that they engaged in more caregiving work for their children with disabilities than their partners or ex-partners. No doubt, the unequal gendered division of caregiving work makes the

task of mothering and caring for children (both disabled and non-disabled) more difficult. As noted in the interviews with all of the mothers in this study, they are the ones responsible for the day-to-day care of their children, including organizing the numerous programs, appointments, and services for their developmentally disabled sons. Throughout the interviews, the mothers expressed the attitude that they must do “whatever it takes” in order to help their child. The mothers articulated that the overall health and wellbeing of their child was their responsibility. Diane talked about how, even when she was married, she did everything surrounding the care of her son, and later commented that “God doesn’t give you what you can’t handle”, which might imply that she believes that if she has been given a son with a disability, she must be able to care for him, as it is her duty to do so.

Literature on the nature of parenting (whether the children have a disability or not) shows that mothers are usually the primary caregivers to their children (Guendouzi, 2006; Home, 2008). While mothers are responsible for the majority of parenting responsibilities, this work often goes unnoticed or unappreciated (Home, 2008). Like the mothers in this current study, Home (2008) discussed how not only is a mother’s work not recognized by others, but even these women do not always acknowledge all that they do, and the stress that accompanies this work. Dillaway and Paré (2008), who do not focus specifically on mothers of children with disabilities, discuss not only the gendered nature of caregiving, but also the fact that this caregiving represents the intensive mothering ideology, which believes that mothers must let go of all other commitments, and instead use this time to care for their children. In her study, Tong (2001) notes that although society has seen women and men’s roles change over time, there is still a general expectation that women should be the primary caregivers for their children. Furthermore, society continues to expect that women, from the time of their child’s conception, put their children ahead of their

own needs, and make any sacrifices necessary. The authors in these studies note how women continue to be seen as the best parent for their children (compared to fathers). This perspective also speaks to how gendered caregiving is still represented in households today, as opposed to being replaced with viewpoints that men and women can and should have equal responsibility within the home.

The gendered nature of caregiving work can also be explained by the concept of intensive mothering (Arendell, 2000; Medina & Magnuson, 2009; Wrigley, 1997), which is the notion that a woman is considered the ideal caregiver for her children and will “do everything” for them (Medina & Magnuson, 2009). This ideology not only expects that women as mothers will care for the child, but that they will do so in a labour-intensive manner (Wrigley, 1997), which is something we see in the interviews above. For example, Melanie must not only take responsibility for cleaning her home, and working outside of the home, but also be available at all times for her son with a disability, even when he is at school. For Heather, she had to stay at home with her toddler everyday of the work week, as her son was receiving therapy in the home and so she was not allowed to leave. The mothers in my study were able to discuss the busyness of their lives as mothers, and how much work this could entail on a day-to-day basis. This view is also noted by Medina and Magnuson (2009) who explain that the intensive mothering ideology implies that if women are not able to offer the necessary energy and resources to their children, these women should not be mothers. This viewpoint not only enhances a need for women to feel they are doing everything they can for their children, but I would argue that it also keeps women from asking for help, as there is a belief that mothers should not need support to fulfill their “natural roles”, but rather, should know how to mother their child or children on their own. This notion is particularly difficult for mothers of children with disabilities, as these mothers are faced

with additional stressors and overwhelming tasks, yet are still expected to do “whatever it takes” to care for their families. In all of the interviews, the mothers talked about being the primary caregiver to their child with a disability, and about the sometimes-overwhelming responsibility this presents.

The idea that mothers should be the primary caregivers to their children is relevant to the topic of mothering blame, and also something highlighted in these interviews. Literature looking at mothering blame notes that mothers are often expected to focus their time and attention on their children, in order to encourage healthy development (Dillaway & Paré, 2008). Not only does this belief create an unfair expectation on mothers, it also could be argued that it enhances the feelings of blame mothers feel when their child is diagnosed with a developmental disability. Since it is the mother who should be watching out for any atypical signs of development, while mothers may actually have no control over the delay, the blame might nonetheless be placed on their shoulders for not reacting sooner to their child’s signs of a disability.

Mothering blame is related to how mothers are feeling personally, as well as how society has set up expectations on mothers to be exceptional parents, and what happens when this expectation is not achieved. Blum (2007) further discusses how mothers of children with ADD, ADHD, or developmental disabilities will try to do everything they can for their child in order to ensure they are getting the care they need. However, if these mothers do not feel they are able to attain these goals, this leads to a sense of blame, as they witness their child continuing to display concerns. Although the topic of mothering blame did not come up strongly in my study, it must be noted that all of these mothers discussed how they are primarily responsible for their child with a disability (compared to their child’s father), whether it be by setting up respite, by managing therapy sessions, or by doing “everything” as was described by Lesley.

A surprising finding in the study was the lack of discussion on mothers' guilt and how it may contribute to the difficult nature of caring for a developmentally disabled child. In fact, of the six mothers who participated in the study, only one mentioned feelings of guilt when discussing their child's developmental disability. However, Samantha and Heather both talked about feeling guilty for not spending as much time with their non-disabled child, while Diane and Heather both talked about feeling it was harder for their daughters (without a disability) having a sibling with autism due to the extra responsibility, and having to also attend numerous medical appointments. Furthermore, Elizabeth spoke about her feelings of mothering guilt when she first believed that her son's delay was due to brain damage from two previous instances where he almost died. It is important to note that mothers were not asked specifically about feelings of guilt during the interview and therefore, did not comment on it. Because the question around guilt was not specifically asked, it is hard to know what/how the other mothers might have responded. However, there could be other reasons for mothers not articulating this concern as well. For instance, it could be due to more education being presented on developmental disabilities, including the knowledge that they are not "caused" by parents, or more specifically, mothers. The lack of guilt for these mothers might also have to do with them all having other children without disabilities. It could be argued that since the mothers have a typically developing child as well, they feel more certain that it was not something they did to cause their child's delay, or consequent behaviours, as this would likely have also caused challenges with their other child (or children).

While not looking at mothers of children with disabilities specifically, Seagram and Daniluk (2002) examined the topic of maternal guilt more in depth, in order to explore its meaning, while coming to a better understanding of what it is like for mothers who experience

this guilt. They explain that many women believe their sense of responsibility comes not only from themselves, but also from external sources, including their partner, friends, parents, and other family members. The women they interviewed explained that there was an overwhelming sense of responsibility directed at them by these external sources, and they thought they were constantly comparing their own children to others their age. The mothers in this study also discussed their feelings of being pressured to conform to prevailing parenting ideals, and believed they were being judged by society on their parenting skills. One mother emphasized that she perceived it was her responsibility to raise a child who was well-adjusted, and would grow up as a respectful human being. The tasks of teaching the child “right from wrong”, being respectful, and “getting things done” all seemed to fall within the mothering role. Furthermore, if her child did not grow up with these skills, the mother perceived this would inevitably be considered her fault. Importantly, the mothers interviewed also talked about their observation that while the fathers were recognized for doing small parenting tasks, the mothers’ larger contributions to their child or children went largely unrecognized, and appeared to be undervalued. Seagram and Daniluk (2002) highlight the fact that all mothers can experience this kind of guilt. This study might, therefore, be more in sync with Elizabeth’s experience, as Elizabeth’s mothering guilt was not actually related to her child being diagnosed with a disability, but more so with the guilt she held from believing her son had brain damage, due to two accidents that she felt could have been prevented.

Guendouzi (2006) also discusses how mothers (of children not affected by disability) are put into a position where due to the intensive mothering ideology, they feel guilt when they choose to work outside of the home, and consequently spend less time in the home with their children. The author also notes that mothers who are considered to be placing their work

interests ahead of their children can become a target for gossip amongst their peer groups.

Guendouzi (2006) notes the conflict between wanting to fulfill professional obligations while also trying to look after the needs of their families.

Given the strong cultural pressure on women to be “good mothers” (Dillaway & Paré, 2008; Jackson & Mannix, 2004; Seagram & Daniluk, 2002; Wrigley, 1997), it was surprising that the participants did not identify guilt as a prominent aspect of their mothering experience. Although the topic of mothering guilt was not a common theme identified in the present study, it has, however, been identified in the literature on mothers of disabled children (Broomhead, 2013; Cameron et al., 1992; Kuhn & Carter, 2006). Broomhead (2013) focuses on whether parents who have children with special educational needs (due to behavioural, emotional, or social difficulties [BESD]) feel guilt for their child’s difficulties. Although the study interviewed mothers and fathers, Broomhead notes that most of the parents were in fact mothers. In this study, BESD included children with ADHD, Asperger’s syndrome, and oppositional defiant disorder (ODD). Broomhead found that often the parents’ guilt would be formed by professionals (in this case, school staff) indicating that if they were better parents, and knew how to handle their children, their behavioural concerns would not be present. Broomhead also discusses maternal guilt specifically, and notes that for some mothers in her study, there was an acceptance that they were ultimately responsible for their children’s concerns, while also explaining that it was this blame that made them feel so guilty for their children’s special needs. As one mother in this article noted, she sometimes experienced guilt about whether she was following the best interventions for her child.

Cameron et al. (1992) noted that the guilt felt by mothers who have children with developmental disabilities is one of the feelings they tend to experience for the longest amount of

time following the diagnosis. These feelings of guilt often are caused by the mothers thinking about what they might have done to cause their child's disability. Kuhn and Carter (2006) also note this sense of maternal guilt, and reiterate that often mothers experience a sense of guilt when their child is first diagnosed with autism, and question if they inadvertently contributed to the diagnosis. The authors also note that for many parents, they will describe the time they received their child's diagnosis as the most stress-inducing event associated with raising their child with a developmental disability. In their study, Kuhn and Carter (2006) interviewed 170 mothers of children diagnosed with autism. These mothers were asked to complete questionnaires surrounding a number of different topics including: their feelings of competence in caring for their child (self-efficacy); how much the mothers assume an active role in their children's life and development (maternal agency); maternal guilt; and knowledge surrounding autism. Regarding feelings of guilt, the researchers asked the mothers if they felt guilt because they did not believe they were doing as much as they should be for their child with autism. If the mother responded yes to this question, she was prompted to answer the remaining questions surrounding this topic. The authors found that mothers who reported feelings of guilt more often also had lower maternal self-efficacy (or feelings of competence as a mother with a child with autism). In my opinion, this may suggest that feelings of guilt and feelings of competence may display a bit of a cycle. That is, the mother feels guilt surrounding her child's disability, which may lead her to feel less confident as a parent. However, this lack of confidence may in turn keep her from being as involved in her child's development, thus creating more feelings of guilt.

To conclude the discussion of how mothering a child with a developmental disability can be difficult, stressful, and overwhelming work, it is important to note the context in which the

study participants were mothering their children. Two of the six mothers stated they earn \$12,000 or less per year, while one mother stated she earns \$23,000 annually, as she is on disability leave. As the low-income cut-off in Canada is currently \$21,359 (Statistics Canada, 2013), this means that two mothers fall well under LICO, while the third mother, Lesley, is only slightly above it. While these mothers did not openly discuss the issue of poverty or low income and how this may affect their mothering experience, it is nonetheless an important factor to consider. While all of these mothers faced challenges when trying to care for their child's disability, three of the mothers had to do so while also receiving little monetary support. Surely, being poor or low income would only make mothering a developmentally disabled child more difficult. Again, mothers in the study did not note this, but they also were not asked questions about their low income and their mothering experience. The already-challenging act of getting a child to a doctor's appointment can be even more stressful for a mother who does not own a car, but must instead take the bus (if they can afford the bus fare). For Lesley, it would have been much more difficult for her, making \$23,000 per year with two children in the home, to seek out a paid caregiver than for Heather, whose husband works full-time, while she works part-time. Although the concern of poverty was not clearly articulated in the interviews, it is nonetheless important to acknowledge how low income mothers face additional challenges due to living in poverty. Poverty and mothering a child with a disability can also create a cycle, where mothers must give up their jobs to care for their child, however, the low income which accompanies unemployment creates more difficulty in accessing supports (such as respite or out-of-home therapy) for these mothers and their children (Public Policy Institute of California [PPIC], 2000). It may have been interesting to have asked the three participants who were not working if and

how poverty had affected their experience in order to broaden the understanding of their mothering experience.

Little research is available surrounding poor mothers of children with developmental disabilities (PPIC, 2000). As noted by PPIC (2000), in California, a significant number of the welfare population is affected by disabilities and chronic illness, with 10 to 12% of families having a disabled child (a quarter of whom reportedly having a developmental, emotional, or mental disability). Of these families, almost half discussed direct costs associated with specialized childcare, including special foods, medicine, and special clothes. The average monthly cost was \$134 for these families. Importantly, and as experienced by three of the mothers in the current study, mothers with either one severely disabled child or two or more moderately disabled children were up to 30 percent less likely (as compared to mothers with children without these concerns) to have worked in the past month. This paper also notes that families with children with disabilities were at increased risk of being extremely poor, unless they were receiving federal aid/supplemental income. These families were also more likely to face housing instability, hunger, utility shutoffs, and unpaid bills. The authors conclude that these families are more likely to experience economic strain due to being unable to earn paid employment, as well as the fact that for the money they are able to attain, these resources are generally used to care for the child's disability or illness.

While literature on poverty and mothers of children with disabilities is scarce, there is information on poverty in Canada in general. While I do not feel it is necessary to focus a great deal on this topic (as it is not specific to disabilities) it may be helpful to give a brief synopsis of poverty found in Canada. There is research which looks more generally at poverty, or at women as single mothers living in poverty (Benzies et al., 2012; MacKinnon, 2013). As discussed in

MacKinnon's (2013) article, certain groups have a higher likelihood of living in poverty, including persons with disabilities and lone parents (although, interestingly, there was no mention surrounding lone mothers). Benzies et al. (2012) also note in their article the risks related to poverty for mothers, including maternal depression, and risk of harsher parenting. Power (2005) speaks to the fact that lone mothers who have little financial assistance are put in a position where they are unable to care for themselves and their children, and yet have nowhere to turn for additional support. In reviewing the articles above, it is important to recognize how poverty can affect women as mothers, especially mothers of children with disabilities, who not only offer their children standard care, but must also look at special circumstances related to disability, such as medical appointments for their child.

Theme Three: Mothers' Fears for their Children

A third theme found in this research is the fear and anxiety that these mothers experience, including fear of their children or themselves being judged by others, worrying about their child's present circumstance, and worrying about their child's uncertain future. Four of the participants shared their fears and anxieties about them and their children being judged by others. The mothers in this study talked about feeling that their children are judged due to their difficult behaviour, and that this often impacts how their children are treated. In these mothers' statements is a fear that their sons will be treated differently (and negatively) by others. Also, there is a fear that their children will be alone, and have no friends or people to support them, due to this kind of judgment (which they are already seeing at a young age).

Regarding fear of their child being victimized by others, Heather explained that her son is already being bullied at school, while Leslie, Diane, and Samantha talked more generally about their fear that bullying will occur in the future. It is understandable the mothers in my study are

fearful for their children's physical and emotional safety and wellbeing in school and other areas of their life where they must interact with other children and peers. Indeed, mothers' fears are well-founded as research suggests children with disabilities are more likely than children without disabilities to be bullied by their peers (Lindsay & McPherson, 2012).

Furthermore, it is not surprising to see that some of these mothers also talked about fear of the future, considering that part of what we are able to observe in this study is the idea that it is hard to know what to expect when raising a child with a disability. That is, it is hard to predict what their children will find challenging, and how this will affect them in life. For example, they might find it difficult to make friends who are understanding of their disabilities and, therefore, have little social support as adults.

As noted above, part of these mothers' fears were not only related to their children and their futures, but also surrounding how others treat them and their child. This fear also leads us to the topic of judgment. Mothers' experiences of judgment by others has been noted in the literature (Bennett, 2007; Cameron et al., 1992; Seagram & Daniluk, 2002). Research suggests that it is common for mothers of children with disabilities (not specific to developmental disability) to feel judged by others, and notes that if a child's behaviour is deemed undesirable, it is the mother who is viewed as neglecting to teach her child appropriate ways to behave in public (Seagram & Daniluk, 2002). Bennett (2007) notes that the mothers in her study, who had children with ADHD, discussed facing accusations of blame by those around them. Gill and Liamputtong (2013) who focused on mothers of children with Asperger Syndrome, note that when a child is misbehaving in public, the mother is blamed if she is unable to control them, as society considers it her duty as a mother to be able to stop undesirable behaviour by her child. Furthermore, as Tong (2001) discusses, women are expected to care for their child and ensure

that they are healthy. However, these mothers are then judged if others feel she is not providing the appropriate care to her child. This suggests that others may look at a child, and feel that their delay, or the challenging behaviour being presented, is ultimately due to the mother not meeting the standards of a caring and capable parent. Cameron et al. (1992) also talked about judgment towards mothers, and noted that a theme found in their research highlighted how others, including non-family members and the general public, might not understand the situation, and therefore criticize these women as mothers. Ryan (2008) focuses on mothers of children with learning difficulties, which include children with autism, a global developmental delay, ADHD, or fragile X syndrome, and who, due to their difficult behaviour in public places, receive judgment towards both them and their children. Ryan (2008) notes that children with learning difficulties often exhibit behaviours (such as flapping their arms, making loud noises, or touching others near them) that those who do not know them would think inappropriate or odd. Furthermore, these children appear to be typically developing, which introduces further judgment from strangers. Interestingly, a number of mothers in these interviews discussed using the label of autism when their child was acting out in public, as they felt that most people are aware of what autism is, and are therefore more understanding of their children. The mothers in this study also exemplified how they would try to explain their child's behaviour without taking responsibility (or accepting blame) for it.

While the authors above focused on the mothers' fears (and their responses) related to judgment of both them and their children, Murphy, Christian, Caplin, and Young (2007) looked at the specific worries parents hold for their children with disabilities. Although the authors focused on caregivers, as is the case with much of the literature, the majority of the respondents were mothers. The authors looked at the topic of caregiver health by focusing on the caregiver's

own perspectives. One of the five themes that was presented from this research included the parents' worries about the future. In this theme, parents noted how hard it could be to enjoy the present time, when they are trying to plan ahead. All of the caregivers in this study talked about their concerns for their children should they outlive their parents. These parents talked about how this fear increased as they got older. Sadly, these parents did not feel confident that their child would be well taken care of if they passed away, and their child was still alive. While mothers in my study did not articulate this particular fear, Elizabeth did acknowledge that her son could still be living at home at 30 years old. While Elizabeth may not be thinking too far in advance at this point, the fear of what her son's life would look like without her might still appear in the future.

A final subtheme that was noted in this section was the fear mothers held surrounding their children being bullied, either as a young child, or as they grew into adulthood. Regarding mothers coping with, or experiencing their children being bullied, there is little information specifically looking at the mother's experience. This lack of literature suggests that more research needs to be done in order to understand how mothers interpret their child's bullying, as well as how they coped with this bullying.

Although not specific to bullying, in Hubert's (2011) article, she discusses the fear that mothers of children and young adults with intellectual disabilities may experience regarding their children being harmed. For many of these mothers, there was the fear that their child would be hurt by someone else outside of the home, and would not be able to tell anyone about this abuse. The mothers in this study also talked about a hope that they would outlive their children, as they worried about where they would go if the mothers died first. Hubert (2011) also notes that both mothers and fathers feared that their children with disabilities would likely never form a close

relationship with anyone, thus speaking to the belief that their child would not in fact make friends as an adult.

It is likely that all mothers (regardless of having a child with a developmental disability), fear for their children and their futures; however, it was a common theme raised by many of the participants in my study. It is important to note these concerns, as they are very telling of what it can be like watching your child with a disability grow up, and continue to worry about certain areas in their lives (such as friends and peer relationships). As was also noted above, it is interesting that many of the mothers in this study discussed this social aspect as one of their main fears for their children. These fears warrant further research on the topic.

Theme Four: Mothers' Sense of Loss

Another prominent theme identified in the present study was mothers' feelings of loss. The subthemes attached to this theme include: the expected loss of typical milestones (e.g., child birthday parties, employment, marriage, parenthood); loss of the mothers' own social lives; and the loss of career and job opportunities.

For three of the mothers in this study, who were single, their numerous responsibilities, which were related to the care of their children with disabilities, prevented them from being able to attain (and maintain) paid employment. Heather, who was married, also talked about not being able to gain employment until just before her son entered school, as she needed to stay at home while her son received his in-home therapy. The topic of employment was not specifically explored in this study, therefore, it is possible that more information might have been gathered had it been discussed more in-depth. However, of the six participants, only one (Elizabeth) worked full-time, while Melanie and Heather worked part-time, and Samantha, Diane, and Lesley were not working. The study participants' labour force attachment (or lack thereof) may

suggest that having a child with a disability makes it difficult for mothers to maintain full-time employment. For example, Diane discussed how she lost her job, as she was unable to work while also being expected to pick up her child from daycare, at a moment's notice, at any time of the day. Likewise, Samantha also talked about feeling that in order for her to be available for her son, she was unable to work in paid employment. All of these examples demonstrate that a significant aspect of the mothering experience includes tremendous loss – loss of having a “normal child” and typical milestones, loss of social and peer relationships, and loss of job or career opportunities.

Looking at the literature, Cameron et al. (1992) explain in their study that the mothers they interviewed also discussed the sadness they felt due to the diagnosis, and the feeling that they had lost a ‘normal’ child. While these mothers felt they needed time to grieve this loss, they were not provided with this time, as they needed to care for their child with a disability. Cameron et al. (2002) also note these mothers’ feelings of isolation, and their belief that they were alone with this experience of caring for a child with a disability. While the mothers in the current study did not discuss feeling alone in their role as a mother of a child with a disability, they were certainly able to demonstrate how they were often isolated from others, by not being able to work, or leave the home, due to needing to be at home to care for their child. Heiman (2002) also discussed negative reactions some parents (mothers and fathers) experienced when their child was diagnosed with a disability, and noted that often the realization that their child had a disability was considered the most shocking experience for them. For both these authors, the reader is able to understand the sense of loss that can accompany a child’s diagnosis, and the understanding that the child’s life will not necessarily follow the typical path most parents would expect their children to take.

Meirsschaut et al. (2010) noted that it can be more difficult for mothers of children with disabilities to do general, everyday activities than mothers who do not have children with disabilities, with examples including going to the park, visiting friends, or planning a vacation. Home (2008) talked about the overwhelming task of caring for a child with a disability, and noted how much responsibility can be placed on mothers when caring for their child. These examples present the losses that mothers of children with disabilities experience – that is, not doing the activities they might have believed they would do as mothers. While there is some literature that discusses mothers' experience of loss and raising a child with a disability, in general the literature is scarce.

Turning to the feminist literature on mothering, and the culture of mothering itself, one must wonder what it must be like for mothers who are told that their child will not celebrate the typical milestones (e.g., making friends, having sleepovers, dating, or getting married) that other children might enjoy. Given the centrality of motherhood in women's lives, what would the above-noted losses mean for a mother with a disabled child? As noted by Dillaway and Paré (2008), mothers are expected to ensure that their children receive the necessary resources they need in order to experience healthy development. However, what does it mean for mothers when their children do not follow typical development? Not only is it a loss when they come to understand that their child is not going to develop typically, these mothers might also experience a loss of being a "good mother" who is able to see her child grow and develop into a strong individual, as depicted by society, who is able to do the things society deems so important - such as graduate from school, get a job, get married, and raise a family. This also introduces the question of whether, when they first learned of their child's disability, they felt that, as their child could not be a "typical child", this also meant that they lost the ability to be a "typical" or "good"

mother. Because women are expected to be the primary caregiver to children, this can mean that when something does not go as planned (for example, they have a child with a disability), they are blamed or judged by society. Furthermore, this judgment insinuates that they are not “good mothers” which can be especially damaging in a society that often considers mothering as a woman’s most important job. For these mothers who feel they are “less than others”, this might evoke not only feelings of shame and guilt, but also feelings of loss. Loss of mothering a child who is typically developing, loss of getting to experience things they might have always assumed would be experienced, such as throwing a birthday party for their child, or going to their graduation and seeing their child with a group of his or her friends, or loss of simple everyday matters, such as taking their child to the park, and not worrying that a meltdown will lead to negative perceptions by others – aimed both at the child, as well as at the mother. This last point, regarding judgment, or mothering blame (Jackson & Mannix, 2004) may also be noted in Diane’s story, who talks about others judging her and her son, due to how her son behaves in public.

Meirsschaut et al. (2010) reported similar conclusions to this current study with regard to mothers working, and noted that the mothers in their study chose to leave their jobs, as they did not feel they could work full time, while caring for their child with autism. For these mothers, they expressed feeling it was a seemingly impossible task to work full-time, and then in addition care for their child with autism. Instead, mothers in this study talked about needing to be at home full-time in order to care for their children. Mothers in this study talked about not only being unable to work, but also not being able to have alone time (e.g., “date nights”) with their intimate partners, as their child did not handle being left alone with others well.

Meirsschaut et al.'s (2010) research is yet another example of intensive mothering. The mothers were put in a position where they had to set aside their own lives in order to care for their child. They lost those activities they had done in the past, such as working or socializing, in order to make their child their top priority – with nothing else getting in the way. These mothers were no longer in a position where they felt they could do things they enjoyed such as going out with friends or partners, or even finding a job where they could enjoy success as an employee (not to mention paid salary). Instead, these experiences were lost, as the mothers were put in a position where they needed to care for their child – a responsibility which took over all other aspects of their lives.

In general, all of the mothers in this study were able to talk about some kind of loss they have experienced due to having a child with a disability. While each mother has a unique story pertaining to this loss, it is critical to acknowledge that these experiences relate specifically to children with disabilities. For these mothers, having a child with a disability directly influences their ability to have their own social life, or to succeed in their own goals, such as working full or part time, or even making a commitment to spend more time with their partners or close friends.

Theme Five: Mothers' Relationships with Their Non-Disabled Children

Another major theme raised by the participants was related to balancing relationships with their non-disabled children. As a reminder, all of the participants in this study had at least one other child without a developmental disability. The mothers were quite conscious of the impact the endless appointments and responsibilities had on their non-disabled children and that because of their significant caregiving responsibilities for their disabled child, they often have less time and energy to spend with their non-disabled children. Some mothers talked about the impact that this has on their children; for example Samantha expressed concern that her typically

developing son might one day feel resentment towards his brother who takes up a considerable amount of Samantha's time and attention.

These examples demonstrate how mothering a child with a disability can be intensive and difficult work because they need to balance the time spent with their disabled and non-disabled children, which is not a simple task. Given this difficulty of finding time for both children, it might have been interesting to also explore whether these mothers felt guilt when they could not balance their time evenly, and give their non-disabled child as much attention as they might have liked. However, this question was not asked during the interviews and, therefore, little information was gathered on the subject.

Little research exists on mothers' relationships with their non-disabled children (Meirsschaut et al., 2010; Welch et al., 2012). This is unfortunate, as it is important to understand a mother's experience holistically and, therefore, requires looking at her mothering experience with all of her children, not just her child with a disability. Meirsschaut et al. (2010) found that mothers who have one child with autism, and at least one child without a developmental disability often feel guilty regarding their care of the sibling, as they may not be (or they think they may not be) giving them as much attention as they are the child with a disability. Guendouzi (2006), who does not focus specifically on mothers of children with disabilities, does however look at mothering guilt. Interestingly, the author also talks about the guilt that a mother faces when she feels that her mothering for one child is keeping her from being able to offer as much time and attention to her other child. The article also talked about the guilt that a mother in the study felt for working outside of the home, and therefore being unable to attain that 'ever-present' mothering ideal that our society often holds for women. The experience of mothering both children with developmental disabilities along with non-disabled children has not been

explored in-depth in the literature, although this is an important concept to look at by researchers, as it speaks to yet another important aspect of mothering a child with a disability. This additional aspect further highlights the fact that mothers not only need to care for their child with special needs, but also must be ever aware of the needs of their non-disabled child as well. This also demonstrates intensive mothering, as mothers are placed in a position where they are expected to offer their children all of their time and resources, in order to ensure that both children's needs (which may be very different) are being met at all times.

Interestingly, Welch et al.'s (2012) study, which focuses on the effects that short respite breaks have on siblings of children with disabilities, highlights the intensive nature of caring for a child with a disability, for both mothers (and fathers) and discusses the extra responsibility this creates while needing to try and find time for the other child (without the disability) as well. Although this study did not focus specifically on mothers, it should be noted that it speaks to the concept of intensive mothering. That is, it discusses the fact that caregivers (who are more often mothers) must not only spend an immense amount of time caring for their child with a disability, but then they must also try and ensure that they are treating their non-disabled children equally and fairly, adding to their mothering responsibilities. As Melanie noted in her interview, parenting a child with a disability is an eighty-hour-a-week job. However, one must question then how many hours it takes when the mother must also try to get quality time in with their other (non-disabled) children, and try to ensure that they are not being left out. Clearly this is not a simple task, but rather one with high demands, as they are mothering different children with different needs, yet trying to do so in a fair and equal manner. Furthermore, by trying to being a "good" mother to both children, there is also the feeling of guilt which can present itself when the mothers feel they are not measuring up to these societal standards. This situation seems to

put women in a difficult, and likely impossible, position, where they are expected to do an unreasonable amount of work for both (or all) of their children, or face mothering guilt due to being unable to meet these unreasonably high standards.

Theme Six: Mothers' Perceptions of the Helpfulness of Formal and Informal Supports

As participants talked about their experiences of mothering a child with a developmental disability, they frequently commented on their relationships/interactions with formal (e.g., social workers, doctors, and teachers) and informal networks (e.g., family and friends). The mothers were able to talk about different things they felt their service providers did in order to make them feel they had a better working relationship with them, such as understanding that they as the mothers are experts of their situations. For informal supports, the mothers described how helpful it is to have someone willing to help them care for their child, or on the other hand, encourage the mothers to go out and enjoy some time to themselves.

Mothers in the present study were asked to discuss their experiences and relationships with professionals and other formal supports. The mothers offered suggestions for how their relationships with professionals could be strengthened, including more accessible supports, offering compassionate and non-judgmental services, recognizing that they as mothers are experts of their own situation, and having a united front with these professionals. As will be discussed below, many of the qualities these mothers spoke of are reflective of Family-Centred Practice (FCP) (Hiebert-Murphy, Trute & Wright 2011; Wright, Hiebert-Murphy, & Trute, 2010; Trute et al., 2007).

Given the discussions on formal supports, what does this mean for *mothering* children with developmental disabilities within the context of service delivery? For example, how do professionals or formal supports/services represent mothers, how does mothering get shaped by

services, and how does this affect the services mothers receive? Although these questions were not specifically asked of the participants, some of their responses may be able to shed some light on them. In Diane's case, she specifically stated that she lost her job due to the school always calling her while she was at work, and asking that *she* pick up her child – not her son's father. Also, in Melanie's interview, she talked about needing to take responsibility for her son due to her husband not being able to do so. Although the mothers in this study did not directly say that service providers come to rely on them more than they do the fathers, it is noteworthy that all of the mothers stated they take on more responsibility for their child than the father. The interviews with these mothers suggest that not only are mothers considered by family, and the public at large, to be primarily responsible for their child, but these notions are also, if not held, at least accepted by service providers. Furthermore, if the mother is already the one picking up the responsibility for services, this acceptance of meeting solely with the mother only places more demands on her in caring for her child with a disability. A question that might come out of this is whether or not part of the responsibility felt by mothers has been created or at least perpetuated by professionals. It may be that service providers tend to rely on mothers more than on fathers and further contribute to the mothers' experiences of "intensive mothering",

As will be discussed below, there are a number of studies that demonstrate that mothers (and parents in general) can be supported by formal supports; however, the question still remains of whether professionals treat mothers different than fathers, or influence their mothering in any way. This appears to be a topic that has not yet been looked at in-depth in the literature.

Focusing now on the relationship between mothers and service providers, it is a good reminder to look at how professionals relate to mothers at different stages of their child's diagnosis. Mitchell and Sloper (2002) reviewed ways that parents of children with different

physical or developmental disabilities or health concerns, such as congenital heart disease, can be informed by professionals in a sensitive and understanding manner. The authors note that while parents want to be informed of their child's disability, it is important for professionals to appreciate what the mothers are going through, and be sensitive and empathetic to their experiences. This was demonstrated in Elizabeth's interview, who explained that she found it quite frustrating and overwhelming when the doctor told her multiple things that her son would never do. At this moment, Elizabeth was dealing with a new diagnosis, as well as the loss of a typically developing child. However, her story highlights the doctor's lack of sensitivity to these feelings of loss, and the doctor's seeming unawareness of how to present the information empathetically. While the doctor might have deemed this conversation important, Elizabeth's perception of it exemplifies how there can be a "right time" to share this kind of information. This example also highlights the fact that professionals must be aware of the fear and/or discomfort mothers might experience when hearing for the first time that their child has a developmental disability, and consequently understand that this kind of conversation should be held in a compassionate manner. Stainton and Besser (1998) also talked about the need for professionals to work well with families. In their study, the families interviewed talked about the negativity they received from professionals (often doctors). The families noted that they often felt there was an underlying message from these professionals that to have a child with a disability was something negative. This finding further illustrates why professionals (and the public) should not assume that having a child with a disability is a negative experience, but rather, explore how the family feels about their child's diagnosis.

Dinnebeil, Hale, and Rule (1996) note that the relationship between parents with children with disabilities and professionals is essential in the success of early intervention efforts. The

authors were interested in learning what parents and service coordinators believed helped collaboration between the two groups, and what they thought compromised it. Both parents and service coordinators were able to list a number of factors related to positive collaboration, including the other person being friendly, patient, sincere, and optimistic. The authors also noted that there was a need for trust, and that if parents did not feel that their workers trusted them to make good decisions for their child, their relationship was compromised. These examples reflect the need for parents and professionals to have a united front, and to work together collaboratively, while trusting one another with the decisions being made. This issue of trust also highlights the need for parents to be recognized by professionals as experts of their own situation. Parents want others to understand and respect that they know their children best, and thus trust that they are making decisions based on their knowledge.

As briefly mentioned above, one approach that focuses on the need for helpful, sensitive, and family focused strategies for working with families is Family-Centred Practice (FCP) (Hiebert-Murphy et al., 2011; Wright et al., 2010; Trute et al., 2007). According to Bailey, McWilliam, Winton, and Simeonsson (1992), as cited by Wright et al., (2010), FCP has nine key elements. The authors note that FCP services must be: 1. family-focused; 2.) ecologically based; 3.) culturally sensitive; 4.) individualized; 5.) needs based; 6.) enabling as well as empowering 7.) normalized; 8.) coordinated; 9.) and collaborative.

When looking at the perceptions of families, Hiebert-Murphy et al. (2011) found that there are four key elements central to the effective delivery of services, including having service coordinators with good relationship skills, practice skills, and a service system which is adequately resourced and organized around family needs. The need for an adequately resourced service system was something also highlighted in the current study. As noted by Lesley, it can

be frustrating and unhelpful when services are unable to assist families due to waitlists. In order for any service to be truly effective, it needs to be available to families when they need them. It is also important to recognize that mothers do not want to be taken care of, or relieved of their duty as parents. Rather, they would like to work collaboratively with professionals, while determining what decisions are necessary, and serve the best interest of their family.

Although FCP does not focus on working with mothers specifically, it does speak to the need of treating the parent as the expert and respecting the ideas that they have to share. This was also articulated by the mothers in the present study, who discussed the importance of their workers recognizing that they as mothers know their sons best. As such, if a professional were to enter a home where the mother is the primary caregiver of the child, they would follow certain principles that emphasize a family-centered approach.

As noted by Hiebert-Murphy et al. (2011), part of the successful implementation of FCP includes the workers having good relationship skills, and being able to work well with the families. However, as was also noted in this article, it is important that professionals have adequate resources, in order to be able to assist the families they are working with.

Although FCP is an approach that can be used with anyone (male or female), I believe that the principles of FCP demonstrate the same principles related to feminist theory. For example, both FCP and feminist theory note the importance of respecting that the parent (who is more often the mother) is the expert, and has valuable information to share with professionals. Feminist theory also highlights the importance of allowing women to be respected and feel that their voices matter, while also recognizing them as experts on their own experiences and situations. This too is something that FCP can uphold, as it discusses the importance of working as a team, and understanding that the professional is not the only one with valuable information

and solutions to share. As was noted while discussing the theoretical framework of this study (i.e., feminist theory), it is essential that professionals understand mothers' experiences and viewpoints. This is also a necessity for FCP, as it would be very difficult indeed to assist in a situation if you do not understand all aspects of it. For example, when meeting with a mother with a child who has a disability, you must, according to feminist theory and FCP, understand who she is, where she is coming from, and what she hopes to accomplish from working with you. In order to do this, you must listen to this mother, and hear what she is telling you, and above all, respect what she is telling you. Clearly, FCP and feminist theory share many of the same concepts, and can certainly be used congruently.

While the importance of having a positive relationship with service providers was illustrated in this study, an additional finding that came from this research is that these mothers recognize the importance of informal supports, and how crucial it is to receive assistance from friends and family when possible. The mothers in this study spoke positively about the informal supports that they have, and talked about how essential it is to have a strong informal support network.

As has been noted in a number of different articles, informal supports are crucial in the continuum of care for these mothers of children with disabilities and their families (Lindblad, Holritz-Rasmussen, & Sandman, 2007; Stuart & McGrew, 2009; Trute & Hauch, 1988). Stuart and McGrew (2009) found evidence to suggest that the more social support a family has, the lower the caregiver burden. The mothers in this study spoke about the importance of acknowledging the assistance that friends and family can offer them and their families. This was also noted by Tehee, Honan, and Hevey (2009), who look at what factors contributed to parental stress, for both mothers and fathers, when raising a child with autism. The authors discuss the

need for social support to be present for these parents, as this support can assist parents to cope well with their stressors. This social support can come from both formal supports, as well as informal supports such as family and friends. However, the authors also highlight that for any support to be effective, it must be considered as a helpful resource by the family, and must ultimately be what the parent is looking for at that time. That is, if the support is deemed unhelpful, or not supportive in the way the family needs, then this support is ineffective.

Lindblad et al. (2007) found that for some mothers of children with autism, informal supports were considered to be more effective in reducing their stress than the assistance they receive from formal supports. For example, mothers in their study talked about the value of being able to share their concerns with other mothers of autistic children. In their study, Lindblad et al. (2007) discussed how important it is for mothers and fathers of children with disabilities to have informal supports, such as family and friends who are open to hearing about their worries, concerns, and feelings.

Trute and Hauch (1988) also discuss the importance of informal supports in their study, where they looked at 40 families with children with disabilities that were considered to function quite well given the stress associated with having a child with a disability. The authors determined that having a strong informal support network, such as an extended family system that could provide tangible help, emotional support, and physical assistance, was a key factor in reducing family stress. Trute and Hauch (1988) also found that having friends was important in providing social activities for parents of disabled children. They argue that professionals must be aware of the benefits informal supports can offer families, and ensure they assess the potential support that they can provide. Furthermore, the authors note that professionals should keep in

mind that it might be helpful for them to assist families in utilizing social supports, considering the positive consequences these supports can have on parents of children with disabilities.

In a time of increasing government cutbacks, mothers of developmentally disabled children may find themselves more reliant on informal supports, as support from professionals may become harder to attain. Lastly, although this was not discussed during the interviews, informal supports can hold great value and importance for women in general, but perhaps more so for some cultural groups, who believe that when needing assistance, they should turn to their personal circles, as opposed to professional agencies. In McConkey, Truesdale-Kennedy, Chang, Jarrah, and Shukri's (2008) article, the authors note that child-rearing practices can be different depending on certain cultures. Further, mothers' coping strategies could be influenced not only by their culture, but also by the informal supports offering to assist these mothers. One of the topics the authors explored was the informal supports mothers from different cultures (and locations) received. The mothers in this study were recruited from Taiwan, Northern Ireland, and Jordan. In general, the mothers in this study spoke positively of their information supports, including friends and family, and discussed their overall helpfulness. As one mother from Taiwan noted in her interview, her family was her most important support resource. This mother talked about how important it was to be able to talk to her mother and her sisters about her problems. Another mother from Jordan also talked about her brother being the only support her family has, and how he assists them psychologically, and tries to help with her child. Not surprisingly, the authors of this study also found that the mothers in this study were more likely to struggle with poorer family functioning, the fewer informal supports they had.

Summary of Discussion

The present study illuminates the fact that for these mothers, although their experiences might be different than mothers of non-disabled children, they do not want sympathy for their situation, but rather wish to share the many positives that this experience can hold. These mothers have shared how they have grown as individuals, how they have learned to defend their children when necessary, and how wonderful an experience it is when they are able to teach their child something that they will hold for the rest of their lives.

Although the experience of mothering a child with a disability has many positives attached to it, there are also difficulties presented, such as managing difficult behaviour, dealing with stressful and overwhelming situations, holding fear for their child, and coping with different feelings of loss. These mothers were able to discuss what it has been like to raise not only their child with a disability, but also their other child or children who have not been diagnosed with a disability. These mothers have illustrated a dedication to their children, and have been able to demonstrate how much they do to assist their child with being the best he can be. The examples the participants gave regarding all that they have done to parent their child with a disability also illuminates the concept of intensive mothering, and the expectation that women as mothers take responsibility for their child, and set aside their own goals in doing so. The mothers also spoke about the different fears they hold, namely the fear of others judging them and/or their children, fearing for their children's uncertain future, and worrying that others will bully their children (although for some mothers, they noted that this was already happening). Furthermore, the mothers talked about their own sense of loss, and discussed losing typical milestones with their children with disabilities, such as them dating or getting married. The mothers also discussed the loss of their own social lives, and needing to put their own goals aside (for example, working) in order to care for their children.

The mothers in this study talked about the different things they find helpful from professionals, including compassionate and non-judgmental support; being recognized as the expert of their own situation; and having a united front with professionals. The mothers also noted the importance of having services that are accessible to them and their families. The information provided by the mothers in this study also assisted in highlighting how some approaches, such as Family-Centred Practice, offer principles that are not only beneficial for meeting with families, but also hold the same principles as those found in feminist theory. For example, they both highlight the importance of listening to the voices of the client, respecting what they have to share, and working together as a team, as opposed to attempting to take on a role where they as the professional have all the answers, thus belittling the person they are working with. While there was more discussion surrounding formal supports for these women, it must be noted that there was also evidence of the assistance and support that informal networks can offer mothers, and this is something which must be noted by any professional working with mothers of children with disabilities, as it is crucial to understand the large role these informal supports can play for families.

While the discussion section was able to explore the existing body of literature that is consistent with the themes identified in this study, it also identifies areas where research is lacking. This will be the focus of the next chapter.

Chapter Seven: Conclusion and Recommendations

This study examined the experiences of mothers with children with developmental disabilities. Six mothers of developmentally disabled children participated in this study and were asked to talk about their experiences through the use of open-ended questions. Six themes were developed, and these themes are valuable in assisting others to understand the mothering experience for mothers of children with disabilities. Below is a discussion surrounding the implications of this research for social workers and other professionals who work with mothers of children with disabilities, as well as recommendations for future research.

Implications for Social Workers and Other Professionals Working with Mothers of Children with Developmental Disabilities

The information gleaned from this study should prove useful to social workers or any professional working with mothers with children with developmental disabilities, as it demonstrates the different experiences mothers of children with disabilities can go through, both positive and challenging. The mothers in this study were able to list a number of positive aspects related to mothering a child with a developmental disability. These include feeling pride for their children as they grow and learn new skills. The mothers also described how they have also been able to grow as individuals. As one mother noted, she has become a more patient person due to having a son with autism. Furthermore, these mothers spoke about their own learning that was directly related to having a child diagnosed with a developmental disability. These women read books about their children's disabilities, or joined groups that discussed disabilities, in order to understand what the disability meant for their child. Importantly, these mothers made it clear that they did not consider their situations a burden, or something they wanted pity for, but rather, described this as a pleasurable experience, which they were able to share through their stories.

Through the interviews with mothers, a common observation that was presented was that of intensive mothering. These mothers provided a number of examples for how they do more work for their child with a disability than the fathers, and many also talked about the goals and aspirations they have put on hold for themselves in order to offer their child more time and dedication. Professionals must be aware of the extra responsibility that mothers take on for their children, and how this affects them as a whole. That is, there must be a recognition that mothers are generally expected to care for their child with a disability, while also caring for the home, possibly working, and supporting the family. These responsibilities can be challenging, exhausting, and create feelings of stress and anxiety, and professionals must be cognizant of how much these mothers are doing, and whether or not they are able to handle all of these responsibilities, or whether they need more support from others.

As noted in the discussion, one approach which aligns nicely with feminist theory is FCP, which seeks to also hear the voices of those being worked with, ensuring that there is respect and understanding being displayed throughout this working relationship, while ensuring everyone is being treated as equals. FCP also demonstrates many of the qualities the mothers in the current study considered as helpful, including providing compassionate care, being treated as the experts of their own situation, and having a united front with professionals. Furthermore, the mothers in this study also spoke about needing to feel like they were being heard, and not being categorized with all of the other families. In other words, these mothers appreciated being treated as individuals, with their own stories. Professionals must also recognize, however, if and how they perpetuate the intensive mothering ideology. We must be aware of the fact that these mothers generally pick up more responsibility than their partners (if in fact they have partners) and often set aside their own goals in order to care for their children. It might be helpful then for

professionals to try to ensure that both parents are present at meetings when possible. Furthermore, professionals must be aware of what they are asking families to do, and ensuring that they are not solely asking the mothers to accomplish the tasks necessary. Parenting a child with a disability can be difficult, and requires large amounts of time and energy. However, this time and energy could be diminished if we as professionals are able to assist families in finding ways to cope together, and take on responsibilities as a family, and not just looking at the mother to do so. Furthermore, in terms of assisting families with support, this thesis not only illustrates the importance of connecting families with formal supports, but also with helping them to connect with informal supports, who, as noted in the discussion section, offer critical assistance to these families – whether it is by assisting with caring for the child with a disability, or by spending time with the parent(s) alone, and ensuring that they are able to have respite themselves.

As was noted in the findings section, these mothers named a number of losses they have experienced, including loss of typical milestones, loss of employment, and loss of a social life. These findings are important for professionals to recognize, as workers must understand how mothers' responsibilities for caring for their children affect them on many different levels. Furthermore, professionals should explore these losses with the mothers, in order to gain a better sense of how the experience of mothering a child with a disability has shaped their lives. By gaining this understanding, there is also the hope that professionals could support mothers with these losses (for example, coping with the loss of typical milestones), while also exploring whether some of these losses could be worked on, such as assisting a mother to be able to spend time with family and friends, and to engage in self-care.

The findings from this study may also be helpful to share on an organizational level, as it is well known that in order for social workers and other professionals to be able to offer the best services, they must be supported by the organizations they work for. As such, it is my hope that these findings will be shared at higher levels, in order to ensure that services are being offered to families, and specifically mothers, in the most effective and efficient manner. By sharing the findings from this study with social workers that work with mothers of children with developmental disabilities, I hope to assist them to better understand the experiences of these mothers. That is, I hope to promote the idea that it is inappropriate to assume that mothers of children with disabilities are sorry for their situation, or wish it was different.

As was also noted in this study, there are a number of ways these mothers felt assisted by professionals, such as being able to call the worker without worrying about judgment, receiving strategies from professionals for their child with a disability, and being offered accessible services that are readily available to the family.

It was also brought up in the interviews, the need for more education surrounding what it means to have a child with a developmental disability, and what these different kinds of disabilities can look like. It was noted during the interviews that some of the participants believed that part of the judgment, which comes from the public, is due to their lack of awareness about disabilities. As such, a final recommendation from this study includes looking at effective ways to educate the public, which not only would benefit the child or individual with the disability, but also his or her support system.

Recommendations for Future Research

While this study was able to provide a holistic perspective of the experiences of mothers with children with disabilities, there are certainly some areas where future research is warranted.

Through the literature review it became apparent that much of the research to date has focused on parents and/or caregivers' experiences in relation to raising a child with a disability – not on mothers' experiences specifically. In fact, relatively few articles focused specifically on mothers. This was surprising, as many articles have admitted that mothers are often the primary caregivers to their children, yet they do not attempt to listen specifically to these women's voices. Through the interviews carried out in this research, the mothers were able to describe how they took on more responsibility than their partners regarding disability issues, whether they were married or not. For this reason, it is imperative that future studies start to not only acknowledge that mothers, as women, are often the caregivers for their children with disabilities, but also start to focus research on what this means to mothers as a whole. While some studies have focused on the relationship between mothers of children with disabilities and mothering blame, further research should be looked at. Presently, many articles discuss literature on mothers of children with ADD or ADHD, however not as many focus on disabilities such as autism, or similar disabilities. In general, more research could be done on the relationship between mothers and their children with disabilities, as this is a topic which has not been researched sufficiently.

As was noted in the discussion section, there are some important areas related to the mothering experience that have not been highlighted enough (if at all) through research. This includes mothers coping with their disabled child getting bullied, which is an area that offers very little research, although it was an area discussed by many of the mothers in the current study. As the fear of bullying seemed to be an important topic for these mothers, it might be beneficial to explore how mothers are affected when they witness their child being bullied by others. A second area not highlighted enough in the literature includes mothers of children with

disabilities living in poverty. As was noted in the current study, two of the six mothers interviewed were living in poverty, while a third mother was very close to the poverty line. Also, as has been discussed above, mothering a child with a developmental disability often keeps mothers from being able to attain paid employment, which further puts them at risk of living in poverty. For these reasons, it is important to continue to research mothers of children with disabilities living in poverty in the future.

Another area that seems to be lacking research is the experience of mothering both a child with a disability, as well as a child without a disability. This could be an interesting area to explore, and might also further illustrate how these mothers often follow an intensive mothering ideology (whether they are aware of this or not) not only in caring for their child with a disability, but also in caring for their non-disabled child. Finally, there is also a large gap in the literature surrounding how service providers respond to mothers specifically, and whether or not they influence these mothers' roles in any way. This is an important question to look at, as it would allow professionals to understand how mothers can be supported, without being put in a position where they feel all of the responsibility for caring for their child is placed upon them. While professionals may not state that they expect mothers to do more for their children than fathers, their actions might imply this, for instance, by calling the mother, and setting up a time to meet with only her. While these professionals may wish only to support the mothers (and thus meet with them to discuss their questions or concerns) the workers should be mindful of whether or not the father could also attend, in order to ensure both parents are not only being supported, but also that any recommendations made are being given to both the mother and father, as opposed to the mother only. Future studies may be able to assist professionals in understanding

what they may be doing that puts mothers in a position where they are primarily responsible for their child, and what changes they could make to balance these responsibilities in the future.

It might also be useful to interview more mothers from different backgrounds, whether that be mothers from different cultural and ethnic backgrounds, or mothers from a number of different income brackets. It is likely that both culture and income shape the mothering experience. In this study, five of the six mothers self-identified as Caucasian, and three of the six mothers were in a high-income bracket (while two were in poverty and one near the poverty line). If we want to better understand the experiences of mothers with children with disabilities, it would be beneficial to ensure that we are hearing the voices of many mothers, from many different backgrounds.

As noted above, all of the children with disabilities in this study were male. It would be interesting to see if the findings might have been different if there had been mothers with daughters in this present study, and this might also be an interesting area to explore in future research. Although there was an acknowledgement in the current study that all of the children were boys, this was not explored in-depth in the actual interviews. While there was an effort to gain literature on the topic of the experience of mothering boys specifically with developmental disabilities, there appears to be little research on this topic. As such, further attention could certainly be provided to this area of research.

While this thesis has provided insight into the experiences of mothering a child with a developmental disability, it is my hope that further studies will be held with mothers, as one of the key points noted in this paper is the fact that each experience is different. Due to the uniqueness of every mother's story, it is imperative that researchers continue to listen to the voices of these mothers, in order to understand how they could be better supported in the future.

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Appendix A

STUDY PARTICIPANTS NEEDED**Exploring the Experiences of Mothers Who Have Children With Developmental Disabilities**

I am a Social Work student at the University of Manitoba conducting research that explores the experiences of mothers who have children with disabilities. I am interested in hearing more about what it was like for you as a mother to have a child diagnosed with a developmental disability, including the kinds of emotions that you have experienced (and continue to experience). It is my hope that my study will assist researchers and professionals to better understand the needs of mothers caring for children with disabilities. If you are interested in participating and meet the following criteria, please contact me at the number listed below for more information.

You may be eligible for the study if:

- 1. You are a mother of a child (under 18 years of age) with a developmental delay who has been diagnosed by a professional.**
- 2. Your child was diagnosed with a developmental disability at least two years ago.**
- 3. Must be the biological mother of the child.**
- 4. You are able to participate in a face-to-face meeting that may last from 30 minutes to 2 hours.**

For your participation in the study, you will receive a \$25.00 honorarium in appreciation of your time and effort. Your participation is completely voluntary and confidential. If you are interested in participating in the study or would like more information, please contact me at:

Courtney at _____.

All phone calls and emails are confidential.

Appendix B

Interview Questions

1. Tell me a little about your child/children?
 - ⇒ Prompt personality, behaviour, personal strengths.
2. What has it been like to be a mother of a child with a developmental disability?
 - ⇒ Do you feel your parental demands are different for you than for mothers with children without a developmental disability? If yes, how so?
 - ⇒ Can you tell me about any positive mothering experiences you've had as a mother of a child with a disability?
 - ⇒ Have you encountered any specific challenges related to mothering a child with a disability? If yes, what, if any, coping strategies do you use?
3. *IF MOTHER HAS ANOTHER CHILD WITH NO DIAGNOSED DEVELOPMENTAL DISABILITY: How has it been different mothering a child with a developmental disability versus a child without a developmental disability?*
4. What supports would be, or currently are, helpful to you as a mother raising a child with a developmental disability?
 - ⇒ Informal supports, such as family and/or friends?
 - ⇒ Formal Supports, such as doctors, social workers, or other professionals working with you and your family?
5. What would you like others to know about what it means to be a mother of a child with a developmental disability?
6. Do you have any other thoughts that you would like to include?

Thank you for your time.

Appendix C

Demographic Face Sheet

1. Case ID: _____
2. Pseudonym: _____
3. Participant Age: _____
4. Current employment?
 - Full time 1
 - Part-time..... 2
 - Casual..... 3
 - Not employed..... 4
5. What is your education level?
 - Grade nine or less..... 1
 - Some high school 2
 - Completed high school 3
 - Some post-secondary (technical) 4
 - Completed post-secondary (technical) 5
 - Some post-secondary (university) 6
 - Completed post-secondary (university)7
6. What is your current annual income approximately? _____
7. What is your racial background?
 - Caucasian (white) 1
 - Aboriginal origin (Native descent) 2
 - Black 3
 - Asian (Chinese, Japanese, Korean, Vietnamese)..... 4
 - South East Asian (East Indian, Pakistani, Bangladeshi). 5
 - Middle Eastern (Lebanese, Syrian, Iraqi, Afghani) 6
 - Pacific origin (Filipino)..... 7
 - Central/South American (El Salvador) 8
 - Other 9
8. What is your marital/relationship status?
 - Married..... 1
 - Legally separated 2
 - Divorced..... 3
 - Common law 4
 - Boyfriend/girlfriend 5
 - Ex-boyfriend/girlfriend ... 6

Same-sex relationship 7
Single8
Other 9 Explain _____

9. How many children do you have? _____

10. Age of Children: _____

11. How many children have a disability? _____

12. Age of child with a disability: _____?

13. What is child's diagnosis? _____

14. Number of years since child's diagnosis: _____

Appendix D

Demographics Table

	PART. 1 Samantha	PART. 2 Heather	PART. 3 Diane	PART. 4 Lesley	PART. 5 Elizabeth	PART. 6 Melanie
PART. AGE	35	39	40	34	41	31
EMPLOYMENT	Not employed	Mother works part-time	Not employed	On disability	Mother works full-time	Mother works part-time
EDUCATION LEVEL	Completed post secondary (BA)	Completed technical college/ some university	Some university	Completed college	Completed university/ working on Masters Degree.	Some post secondary (University)
ANNUAL INCOME	\$12,000/ year	\$100,000/ year (including partner's salary)	\$12,000/ year	\$23,000/ year	\$90,000/ year (including partner's salary)	\$71,000/ year (including partner's salary)
RACIAL BACKGROUND	Aboriginal	Caucasian	Caucasia/ European	Caucasian	Caucasian/ European	Caucasian
RELATIONSHIP STATUS	Single	Married	Legally separated	Separated	Married	Married
# OF CHILDREN	2	2	2	3	3	2 (plus husband's two from previous marriage)
AGES OF CHILDREN	8 ½ years old (only including child with disability's age)	5 and 7 years old	10 and 16 years old	14, 11, and 7 years old	18, 16, and 12 years old	6 and 10 years old; Step children - 18 and 23 years old
CHILDREN WITH DISABILITY	1	1	1	1	1	1
AGE OF CHILD/RENT WITH	8 ½ years old	7 years old	10 years old	7 years old	16 years old	10 years old

DIS.						
CHILD'S DIAGNOSIS	ASD	PDD	Autism	Autism, ADHD, anxiety, PTSD, ODD.	Fragile X Syndrome	Autism
NUMBER OF YEARS SINCE DIAGNOSIS	3 years	5 years (prior to that, diagnosed with PDD Nos in 2008)	8 years	Diagnosed with autism four years ago.	11 years	5 years



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Appendix E

Informed Consent

Sample Consent Form to be on Institutional Letterhead

Research Project Title: Exploring the Experiences of Mothers Who Have Children With Developmental Disabilities

Principal Investigator and contact information: Courtney Bond (Masters of Social Work Student) - Phone: _____ or _____.

Research Supervisor (if applicable) and contact information: Dr. Kendra Nixon – _____ or _____.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Research: The purpose of this study is to explore the experiences of mothers parenting a child or children with a developmental delay. The information gathered from this study will be published in a thesis document, and will be available for the general public, as well as professionals to review. There is also a possibility that the findings from this research will be referenced in other articles or publications as well. However, identifying information, including your real name, and specific information about you, will not be shared in the research.

Study Procedures: This interview will consist of one meeting with the researcher, where you will be asked approximately six questions, and will likely take between 1 to 2 hours to complete. In order to ensure accuracy, the interview will be audio taped, and the researcher may take notes as well. You will be asked to fill out a brief form asking for your demographic information, such as your age, how many children you have, and their diagnoses (if any). Neither these sheets, nor the audiotape will contain your real name, but instead will be assigned a pseudonym. If any answer or statement is shared in my thesis, it will be under the pseudonym, and it will not be accompanied with any additional information that could be linked to you directly. I will also fill out a participant contact form, which confirms whether you would like to participate in the study, and how I can best contact you in case of a cancellation, or the need to reschedule. This form will also be stored in a locked filing cabinet in my home.

Description of Confidentiality: No one will have access to your responses aside from myself. All methods of data collection (e.g., audio tape, written notes, demographic face sheet, transcripts, participant contact sheet) will be kept confidential, and stored in a locked cabinet, which only I have access to. Upon the completion of this research, confidential data (names of participants, their contact information, and any forms you have signed) will be destroyed. This should take place no later than December 2013. Anonymous data (the notes for each interview that do not have identifying information and transcripts) will be kept for five years following the publication of my research, at which point it too will be destroyed.

There are limits to confidentiality which you must be aware of. If you would like to meet at St Amant, other staff and/or visitors may see you at the site, and know that you are meeting with me for this study. Also, please be aware that researchers are required by law to report past and current unreported child abuse or situations that are dangerous to children, to the legal authorities.

Once the thesis report has been completed, the findings will be published and available to the public to read. However, as noted above, all responses will be provided using a pseudonym. Also, please note that this research is not connected to St. Amant or any other agency, and no responses or decisions to not participate in the study will affect your relationship with St. Amant, or any other organization.

Description of risk: While the risk for participating in this study is minimal, I would like to acknowledge that some of the questions, based on your own experience, might be difficult to consider, and may be upsetting. If during the interview there are any questions you are not comfortable answering, or would like to stop discussing, please tell me right away, and we will proceed to the next topic. Also, near the end of the meeting you will be provided time to reflect on your thoughts, and debrief about the interview, and will also be given a handout with additional resources whom you could call should you feel you would like to talk further to a professional.

If you do decide to participate in this study, you will receive a \$25.00 honorarium for your time here today, which will be given to you at the beginning of the interview. You may withdraw from the interview at anytime by explaining you no longer want to be a part of the study, and will not be penalized in any way for doing so. You will also still receive the \$25.00 honorarium.

The answers you share may benefit others in the future who look over my thesis, as it will give more information and understanding to the experience of mothering a child with a disability.

Feedback to Participants: If you would like to be notified of the findings for this research, please provide the information for how you would like to be contacted below. A brief 1-3 page summary can be sent to you with information on the findings of this study, which is anticipated to occur approximately one year after the research study commences.

I would like to receive information about the study findings: _____ Yes _____ No

I would like to receive the information by:

_____ Mail (Please provide complete mailing address):

_____ Email (Please provide email address): _____

I would like to thank you again for the time you have taken to meet with me for this research.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Questions/Concerns

If you have any further questions or would like clarification on something, please do not hesitate to contact me at _____ or _____.

This research has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature _____

Date _____

Researcher's Signature _____

Date _____

Appendix F

List of counseling resources

Thank you again for participating in this research study. If you feel that some of the discussion today has upset you, and you need to talk with someone other than a family member or friend, please find below a list of resources for counseling services in Winnipeg.

List of counseling resources provided to participants can be found at:

<http://www.cmhawpg.mb.ca/documents/CMHAMentalHealthResourceGuide16thEdition2012.pdf>