Blurred lines: A phenomenological study of maternal-child interconnection.

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BLURRED LINES: A PHENOMENOLOGICAL STUDY OF MATERNAL-CHILD INTERCONNECTION

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DISSERTATION

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Abstract

This phenomenological study explored the lived experiences of maternal-child interconnection among 12 mothers raising children with developmental disabilities who also had communication challenges. During semistructured interviews, mothers told stories of maternal-child interconnection that described a sacred, mutual, and unique interpenetration of experiences between mother and child that was nurtured and sustained by ongoing togetherness. Maternal-child interconnection allowed mothers to understand their children’s unique communication; therefore, they effectively advocated for their children amid health care environments. Mothers noted that their children’s care was compromised when their unique “knowing” of their children was ignored. The results indicated similarities to the existing literature that defined a complex, leaky body and challenged the traditional notion of Cartesian dualism, as well as offered insight into the value of maternal knowledge. Theologically speaking, the results of this study explored pastoral and spiritual care within communities that endorsed a supportive, affirming, and nonanxious form of authentic friendship for caregiving mothers who might vicariously enter their children’s experiences. Similarly, the *imago Dei* was considered as a source of insight for interconnected, embodied knowledge.

*Key words:* intersubjectivity, maternal knowledge, caregiving, disability
Acknowledgements

Completing a PhD was a daunting undertaking. Finding the words to express my gratitude for the many people who have supported my journey was particularly challenging. I must start by expressing my deepest gratitude to the 12 women who so generously and graciously shared their time and stories. Their willingness to offer a glimpse into some of their most intimate maternal moments humbles me.

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Carol Bayubay joined our family 10 years ago and has been Matthew’s “other mother” ever since. Knowing my son is in the hands of a devoted and loving caregiver has allowed me the freedom to think about caregiving, not just provide it. I am also grateful for the skilled and loving care of Melanie Wagner-Mohanty, and Kaitlyn Martin.

Finally, there are the men in my life. To even attempt to express the depth of my gratitude will forever be beyond my ability. Robert, Matthew, David, and Bill—your love, support, patience, and enduring faith, are my most precious gifts. I love you all.
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Chapter 1: Introduction

Several years ago, I brought my son (a nonverbal teenager with profound physical and intellectual disabilities) to his pediatrician to diagnose and treat what appeared to be chronic pain. Matthew was not sleeping at night and spent his days crying. He was miserable, and by extension, so was I. Despite numerous medical tests, his primary physician could not identify the problem and refused to treat pain that he could not diagnose. I was convinced my son was in pain and advised the doctor that his inability to diagnose my son’s pain should not lead to my son’s suffering. The doctor seemed unhappy with me, a difficult mother, and begrudgingly prescribed pain medication for Matthew. However, his parting comment as he stepped out of the treatment room provided the foundation for this study. As he closed the door, he stated to me, “Perhaps by giving your son pain medication, it will calm you down, Mom”. The physician’s statement indicated that he would address my embodied experience by treating my son’s body. With that single sentence, perhaps without even knowing he did so, the physician acknowledged that the embodied experiences of my son and me were interconnected.

Eisland (1994) in her book The Disabled God: Toward a Liberatory Theology of Disability introduced Diane Devries. Devries was born without legs, as well as congenital, bilateral, above-the-elbow amputations. As part of her narrative, Devries shared a story of coaching her younger sister, who was dancing. As her sister danced, Devries described the experience of entering her sister’s actions in an embodied manner: “I felt her movements. In a sense, part of her body was mine too” (Eisland, 1994, p. 38). For Devries, her sister’s movements were absorbed into her lived experience. For a moment in time, the sisters’ bodies and experiences were one.
As a mother of a child with disabilities, I have experienced a rich and supportive community of mothers navigating a journey similar to mine. We have often shared stories of our experiences over coffee, in the hallways of hospitals and clinics, during support groups, and through the Internet. The ability to talk with mothers who “get it” has been affirming; in these safe spaces, mothers (including myself) have shared stories with candour not always exhibited in other social contexts. Therefore, I knew I was not the only mother whose “gut” was somehow connected to their child and who could rely on her “sixth sense” to make informed decisions about her child’s care. The mothers in my personal world shared similar stories. These stories of interconnection often contrasted the Western medical model that aligned more closely with Cartesian dualism. For the caregiving mothers of children with disabilities in my extended social circle, this embodied interconnection often formed the crux of their maternal knowledge that guided their care, particularly in situations when a child could not communicate in more traditional ways. In other words, mothers knew to be concerned about their children’s bodies because of experiences within their own bodies.

Shildrick (1997) advocated for a feminist critique of the body that challenged the dominant, masculine tendency to limit, even ignore, corporeality in favour of an understanding of embodiment that honoured the body as the site of rich and informative subjectivity, even intersubjectivity. Kearney (2015) echoed Shildrick’s (1997) thoughts, stating that a corporeal worldview would develop both provocative and complex questions. Drawing on these insights, I considered how mothers and children might be interconnected in ways minimised by the Cartesian philosophy that informed much of how people view the body in contemporary Western society, which founded the professional environments that mothers and children with disabilities visited.
Research exploring the lived experience of intersubjectivity was rare. Studies exploring the interconnected experiences between caregiving mothers and their children with disabilities were almost nonexistent. I did not find studies exploring intercorporeality among mothers caring for children with disabilities. I found a handful of studies in the caregiving literature that explored enmeshment between caregiver and the person for whom they cared (Churchill, 2012; Fritsch 2010). Researchers have discussed intersubjectivity within the discipline of philosophy (Heidegger, trans. 2010, 2013; Husserl, trans. 2013, 1913/2017; Merleau-Ponty, trans. 2010, 1964; Shildrick, 1997, 2002), but the exploration of the lived experience of intersubjectivity had received little attention. Conversations exploring enmeshed embodiment have remained theoretical, perhaps because of the significant challenges associated with “fleshing out” the contours of a lived experience that often happens beyond words and observations. I found developing the parameters to explore such an embodied experience challenging.

**Purpose of the Study**

The participants of this study included mothers, biological or adopted, of children of any age who lived with both a developmental disability and communication challenge. In other words, I sought the stories of mothers who needed to rely on their embodied experiences to understand their children’s wants and needs. The purpose of this study was to explore the mothers’ lived experiences of embodied interconnection.

**Research Question**

Reflecting on my own lived experiences as a mother, as well as the stories of mothers navigating similar paths to my own, I found myself turning to the literature to seek answers. I asked the following question: What are the intercorporeal experiences of mothers raising developmentally delayed children?
Overview of Thesis

In this study, I share the results of that journey, and I explore the intercorporeal experiences of mothers in each chapter. In Chapter 2, I summarise the available literature exploring the body, intercorporeality, and caregiving. In Chapter 3, I review the phenomenological method to explore the lived experiences of maternal-child interconnection among a random sample of 12 mothers raising children with significant disabilities. The chapter includes a brief introduction to the 12 mother-child dyads. In Chapter 4, I outline the findings of this study and provide a detailed discussion of the three overarching themes that emerged after analysis. In Chapter 5, I consider how the findings connect with existing literature, focusing on the postmodern body, maternal knowledge, and pastoral and spiritual care. I share a personal and theological reflection. In Chapter 6, I conclude the study by summarizing both the strengths and limitations of the findings, as well as ethical concerns and future directions of inquiry. The final pages include the appendices that show copies of all relevant study documents.
Chapter 2: Literature Review

The literature related to the topic of maternal-child interconnection is divided into two distinct themes: (a) maternal caregiving and children with disabilities and (b) the body and intersubjectivity. Each of these two themes is subdivided into subthemes to ensure a comprehensive review of each subject. The topic of maternal care for children with disabilities is explored through the following four specific themes:

- Canadian caregiving demographics, as these related to mother raising children with disabilities.
- Caregiving literature regarding the care of people with disabilities.
- Literature showing the lives of maternal caregivers of children with disabilities.
- Literature and research showing the experiences of maternal-child interconnection, regarding post-modern, feminist interpretations of embodied, caring relationships.

Caregiving researchers addressed spousal care, eldercare, paid caregiving, and so on. Similarly, there was a vast body of literature exploring the journey of mothering. Because the maternal care of children with disabilities was a specific subtheme of the caregiving literature, these general topics were excluded from the literature review to maintain a focus on mothers’ experiences with raising children with significant disabilities.

Literature exploring the body was a diverse topic. Cox Miller (2004) argued, “Anyone who approaches the topic of the body today must do so with some trepidation, given how problematic and complex it has become in a wide variety of disciplines” (p. 393). To explore the experience of the interconnected body, the literature was explored through the following lenses.

- The body as viewed by ancient philosophers and communities.
- The interconnected body as described by philosophers.
• The interconnected body as described by theologians.

**Canadian Caregiving Demographics**

I could not obtain a precise estimate of the number of Canadian mothers caring for children with developmental disabilities. Caregiving statistics often contain data on family caregiving, including eldercare and spousal care, which made isolating specific information about maternal caregivers challenging. Moreover, researchers exploring maternal caregiving have often separated care offered to children under the age of 18 from the care that mothers have provided to their adult children with disabilities. Additionally, researchers have noted that mothers caring for a younger child with disabilities may not self-identify as caregivers because it is difficult to separate what society expects regarding care of a young child from the extraordinary care required by a child with complex needs (Change Foundation, 2018).

Statistics Canada (2013) indicated that over 8 million Canadians would qualify as unpaid caregivers. Statistics Canada (2013) encompassed all caregiving, including care offered to family members, as well as support offered to friends. In Ontario, Change Foundation (2016) estimated that 3.3 million (approximately 29%) of the provincial population provided some form of caregiving. Of these 3.3 million Ontario caregivers, Change Foundation (2016, 2018) estimated that approximately 6% to 7% (about 200,000) parents were caring for a child with disabilities.

Leaders of both federal and provincial agencies have described caring for a family member with a developmental disability as one of the most demanding forms of care (Change Foundation, 2016; Statistics Canada, 2013). Over half of the caregivers supporting an individual with a developmental disability provided a minimum of 10 hours of care per week, with many providing more than 30 hours per week of care (Statistics Canada, 2013). In cases of significant
developmental disabilities, such as the children in this study, it was estimated that some caregivers provided more than 100 hours per week of care (Change Foundation, 2016).

Statistically speaking, women were significantly more likely to assume caregiving responsibilities when compared to their male counterparts. This applied to all caregiving categories including spousal care, eldercare, and in particular parental care. Further, when compared to male carers, women were more likely to spend a greater number of hours per week caregiving (Statistics Canada, 2013). The only category of care where men provided more assistance than women was in the area of home-maintenance. In cases of very severe disabilities it was more likely that employment responsibilities were reduced, or altogether eliminated. Mothers of children with severe disabilities were most likely to modify their employment responsibilities, with 71% of mothers reducing employment or quitting work altogether (Statistics Canada, 2002).

Disability

Historically, scholars have defined disability as bodily flaws, personal failings, or tragedies. In the 1960s, self-advocates living with disabilities argued that many of their limitations were not the result of their bodily impairments but the consequence of physical and attitudinal barriers encountered within the environment (Barnes & Mercer, 2010). Today, scholars have defined disability as a complex term subject to ongoing conversation and nuance (Shakespeare, 2006; Titchkosky, 2007, 2011). Therefore, disability should be explored at length. However, to focus the conversation to themes specifically relevant to the body, disability, and interconnection, the following four models that dominated disability studies were reviewed: the medical model, the social model, the biopsychosocial model, and the limits model.
The medical model. Until the 1960s, the medical or functional-limitation model informed medical conversations. Researchers of the medical model have defined a “typical body” as having variations identified as deficits. Researchers have defined disability as deriving from a human body that does not perform within the range of “normal” human capacity (Barnes & Mercer, 2010; Creamer, 2009).

Two assumptions inform the medical model. First, disability is a medical or biological condition. Second, if one has an impairment of function, then one is considered “disabled”, regardless of context (Creamer, 2009). For example, according to the medical model, if one cannot hear, then one is disabled, even if living within a Deaf community where the ability to hear deviates from the norm (Creamer, 2009).

The social model. In contrast to the medical model of disability, researchers of the social model of disability have argued that disability does not stem from deviations to the human body but from systems of oppression and discrimination that disadvantage certain bodily characteristics (Barnes & Mercer, 2010; Creamer, 2009; Eisland, 1994; Oliver, 2009). For example, the social model of disability shows that the limitation for a person in a wheelchair is not paralysis but the physical inaccessibility of the world. Changing the environment, such as ensuring wider doorways, ramps, and elevators, mitigates the disadvantage.

Inherent to the social model is the concept of ableism. Like other -isms, ableism is a worldview entrenched in stereotypes and assumptions that regard people with disabilities as incapacitated and morally, physically, intellectual, and/or spiritually inferior to able-bodied individuals (Creamer, 2009). According to the social model, ableist attitudes, rather than embodied differences, cause disability.
The biopsychosocial model. The World Health Organization (WHO) (2011) combined themes from both the social and medical model of disability and acknowledged that limitations resulted from both the environment and the body. The WHO (2011) linked human functioning to the following three interconnected areas of human performance: impairments, activity limitations, and participation restrictions. The WHO (2011) defined impairments as problems associated with body structure or function, such as blindness or paralysis. Activity limitations include difficulties walking or eating, often due to impairment. The WHO (2011) defined participation restrictions as problems with daily living due to discrimination or physical inaccessibility. Disabilities can be physical or intellectual, resulting from mental health challenges. Additionally, symptoms of health conditions can cause disabilities. For example, cardiac disease can limit mobility. The WHO (2011) defined an individual as disabled when difficulties in human performance were encountered because of any combination of impairments, activity limitations, or participation restrictions.

The limits model. Creamer (2009) introduced the limits model. Creamer used the limits model to assert that limits were an intrinsic part of the human condition. All people are limited in some way; thus, human limits need not be considered defective or unusual. Drawing on the model of early Christian communities, Creamer defined dependence on God and each other as an essential part of the human condition. The limits model is an attempt to draw disability, as a concept, away from a binary model of able/not able and toward an ever-changing spectrum of human limits, dependence, and interconnectedness.

Developmental Disability

The WHO (2011) defined developmental disability as the following:
A state of arrested or incomplete development of mind, which means that the person can have difficulties understanding, learning, and remembering new things, and in applying that learning to new situations. Also known as intellectual disabilities, learning disabilities, and formerly as mental retardation or mental handicap. (p. 305)

Developmental disabilities include lifelong limitations of intellectual functioning that interfere with conceptual, social, and practical skills. For example, people with developmental disabilities may struggle to communicate, understand commands and requests, read, or solve problems. Developmental disabilities are diagnosed before the age of 18 and can be acquired or congenital. Developmental disabilities can range from mild limitations to profound intellectual impairments. Acquired developmental disabilities are often linked to some form of brain trauma, such as asphyxiation, tumour, or birth injuries. Congenital disorders include chromosomal anomalies, such as Down syndrome (Statistics Canada, 2002). In some situations, such as with autism spectrum disorders, aetiology is not well understood.

Although estimates vary, the Developmental Disabilities Primary Health Care Initiative (2011) estimated that 1% to 3% of all Canadians had a developmental disability. Statistics focused on children with disabilities indicated that over 30% of children with disabilities had a developmental disability of some form (Statistics Canada, 2002). The variation in incidence between pediatric and adult statistics was linked to the occurrence of children with very severe intellectual disabilities dying before adulthood.

Communication Challenges

People with developmental disabilities often have concurrent communication challenges (Developmental Disabilities Primary Health Care Initiative, 2011). Morris (1993) defined communication as “the ability to transfer information from one person to either another person or
a group of people” (p. 44). A communication disorder interferes with the transfer of information and can be expressive, receptive, oral, or linguistic (van der Gaag, & Dormandy, 1993). For autism spectrum disorders, researchers have considered impairments of verbal and nonverbal communication as diagnostic criteria (Meadan, Halle, & Ebata, 2010).

People with mild communication challenges can engage in and initiate conversation, understand and use abstract language, and follow commands. In cases of more severe communication disorders, a person may experience restricted communication to simple sentences of only a few concrete words, at times augmented by nonverbal cues. Some individuals may repeat words (i.e., echolalia; Morris, 1993). In situations of profound communication impairment, individuals may be nonverbal with comprehension limited to people, objects, and events in the immediate environment. Some individuals may appear nonresponsive (Developmental Disabilities Primary Health Care Initiative, 2011).

Caregiving and Disability

**Care.** I found defining care difficult. A review of the literature about care and caregiving rarely offered a succinct definition. As Held (2006) summarised, “There is not yet anything close to agreement among those writing on care … definitions have often been imprecise, or trying to arrive at them has simply been postponed” (p. 29).

Researchers described care as both a practice and a value (Bubeck, 1995; Phillips, 2007). As a practice, care encompassed a broad range of active work on behalf individuals and groups. Bubeck (1995) defined caring as the following:

The meeting of the needs of one person by another person where face-to-face interaction between carer and cared for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself. (p. 129)
According to Bubeck (1995), people preparing meals or performing tasks for family members who cannot do so themselves are in the act of caregiving.

As a value, care referred to an attitude of concern toward an individual or situation. Concern that may, or may not, include concrete action to address an identified need (Held, 2006; Phillips, 2007; Tronto, 1993). Further, an ethics of care indicated that all humans are fundamentally dependent creatures; therefore, individuals and society should care as a moral imperative (Held, 2007; Noddings, 2003; Ruddick; 1995; Slote, 2007; Tronto, 1993). The caregiving literature did not consistently show boundaries concerning analyses of care, caregiving, and ethics of care. Hence, this discussion reflects the imprecise distinction among the terms. For this literature review, prominent themes noted by relevant caregiving theorists are summarised, particularly regarding the caregiving relationships between mothers and children with disabilities.

Care was often expressed as a value regarding feelings of warm concern about an idea, situation, or person (Phillips, 2007). A person who cared accepted responsibility for another (Tronto, 1993). Slote (2007) considered empathy to explain his description of care. Empathy refers to the concern a person had for another, particularly if that person is suffering. Slote (2007) argued that a person’s concern for another translated to a sharing of his or her experiences of pain or suffering: “It is as if their pain invades us” (p. 13).

Noddings (2013) defined caring as a person having an inclination or regard toward someone or something. In addition, Noddings (2013) distinguished caring as a value from caregiving as a practice. She argued that a person could care about an individual for whom he or she did not provide direct caregiving assistance. A person could provide assistance for someone for whom he or she did not care; for example, a person might care about the welfare of a
neighbour or have humanitarian concerns about a distant country but not provide concrete assistance. Furthermore, Noddings (2013) argued that a person could separate the emotion of caring from the act of caregiving. Tronto (1993) acknowledged that a person might provide the service of caregiving without concern for one’s charge and argued that the quality of care was improved when there was an emotional connection to the act of caregiving.

**Tronto’s four phases of care.** Tronto (1993) described the following four separate but interconnected phases of caring: caring about, taking care of, care-giving, and care-receiving. I found the four phases helpful in exploring how care could lead from a value to an action.

The first phase, caring about, refers to concern for a situation or individual, absent of action. For example, one may be concerned about the plight of children in war-torn countries or about a neighbour recently discharged from hospital. Like care as a value, “caring about” remains an idea or warm feeling without concrete action. The second phase, taking care of, refers to active caring. The person responds to the call for care but does not provide direct caregiving. For example, a person may donate money to a humanitarian agency to fund the care of malnourished children, thus providing indirect care. The third phase, caregiving, refers to a person providing direct care, such as changing diapers, feeding, providing medical care, and so on. For example, in caregiving, a person may prepare meals or do the laundry for a sick friend. The last phase, care-receiving, refers to the care offered and provides feedback to the care-provider. For example, a care provider will receive feedback about the efficacy of his or her care when the neighbour offers gratitude for prepared meals or folded laundry.

**Care is relational.** Although care can be provided without emotional connection (Bubeck, 1995; Noddings, 2013), most ethicists have argued that care is relational (Harrington, 1999; Held, 2006; Kittay, 1999; Noddings, 2003, 2013; Phillips, 2007; Ruddick, 1995; Slote,
2007; Tronto, 1993). Unpaid care is often offered within families to individuals with whom the carer has an emotionally strong bond, such as care offered by parent to child (Freitag, 2018; Harrington, 1999; Kittay, 1999; Landsman, 2009), child to parent, or spouse to spouse (Phillips, 2007).

These emotionally close relationships mean the caregiver focuses on the care-recipient’s best interests when offering care. However, Freitag (2018) worked with extreme caregivers and noted that the emotional intensity of family caregiving could heighten the emotional demands for caregivers. Similarly, Kittay (1999) echoed this assertion when studying dependency workers. Kittay assumed that familial caregivers offered care willingly and accepted the commensurate personal limitations and she defined care as an act of love and altruism. In some cases, particularly when caring for a parent or spouse, Phillips (2007) defined care as an opportunity for a person to express gratitude for care received over a lifetime.

The relational aspect of caregiving often ensures excellent care for a loved-one. However, the emotional connection between care provider and care recipient can also pose significant challenges. Because care is offered to family members within the intimacy and privacy the family unit, the need for external supports may be ignored or remain unseen (Phillips, 2007). The emotionally intense bond between care-provider and dependent can complicate caregiving decisions (Freitag, 2018). Many caregivers have provided care because of their deep concern for their family members. For many family carers, they do not choose caregiving, but they must provide care because of their connections to their loved ones (Kittay, 1999; Noddings, 2013). Because of their concern for their loved ones, caregivers risk facing overwhelming situations where the needs of their loved ones threaten their abilities to engage in self-care, thereby making the caregiver vulnerable as well (Bubeck, 1995; Freitag, 2018; Kittay, 1999).
Both caregivers and care recipients face vulnerability because of the relational aspect of care. Essential to the caregiving relationship is that the cared-for people must be willing to accept care, which is not always the case (Noddings, 1996). Some care-recipients may resent their dependence on another and resist care. When an individual has an intellectual impairment, the care-recipient may be confused and uncooperative. In extreme situations, both caregivers and care recipients risk injury (Noddings, 1996). Care recipients may receive inadequate or incompetent care. Care recipients may be aware of the demands of their care and minimize their needs for support to protect their loved ones.

Caregiving is women’s work. Although demographics are beginning to shift to include more men, most caregivers are women. Statistics Canada (2015) identified that mothers were more likely to care for young children than fathers. Mothers usually assume the primary care of children with disabilities (Statistics Canada, 2002, 2013). Women are significantly more likely than men to care for vulnerable family members, such as parents or siblings. Researchers have viewed care as falling within a feminine skillset, beginning with motherhood and extending into elder care (Bubeck, 1995; Harrington, 1999; Noddings, 2003; Nussbaum, 2006; Kittay, 1999; Ruddick, 1995). Paid care positions, such as child-care providers, nurses, and teachers, are also female dominated fields of work. Because scholars have historically viewed women as natural care providers and caregiving as an inherent part of a relationship rather than work, scholars have minimised the demands of caring (Bubeck, 1995; Kittay, 1999; Nussbaum, 2006). In the 1960s, feminists began to explore the gendered aspect of care for both the public and private spheres, thereby leading to a more robust and nuanced analysis of care than previous generations (Phillips, 2007).
Care is labour. Because caring is relational, care refers to an emotionally laden act of devotion lavished on a valued other. Scholars have associated caring with love, attachment, concern, and affection (e.g., Nouwen, 1997; Vanier, 2008). Caregiving scholars have emphasised the spiritual and transformative experiences of caregiving, and they have framed caregiving as a deeply valuable experience, rather than burdensome labour (e.g., Nouwen, 1997; Vanier, 2008). Although maternal caregivers characterised mothering as a valuable journey (e.g., Kittay, 1999; Landsman, 2009), most defined caregiving as overwhelming (Freitag, 2018; Kittay, 1999; Landsman, 2009). Researchers have echoed this theme by exploring maternal care more broadly (Held, 2006; Noddings, 2003; Phillips, 2007; Ruddick, 1995).

The popular narrative of care as a spiritual journey may obscure the demanding labour associated with caregiving. To emphasise labour intensive caregiving, Kittay (1999) used the term *dependency work* to describe caregiving. She mothered a young woman with significant disabilities; she emphasised several key themes inherent to dependency work and dependency workers. According to Kittay, the isolated, gendered, and marginalised nature of dependency work meant that both dependency workers were as vulnerable as their charges requiring care.

Care includes myriad activities. Caregiving includes feeding, providing household assistance, providing transportation, providing emotional support, and providing medical support. Caregiving includes the provision of intimate care acts, such as toileting, dressing, bathing, and supporting sexual activity. However, Bubeck (1995) argued care could not be summarized with lists because the activities of care could vary with environments, people, and contexts.

Caregiving includes mothering children, providing spousal and elder care, as well as caring for children with disabilities. Care includes paid and unpaid labour, both traditionally
performed by women. In the case of paid labour, personal caregiving performing bathing and toileting has often been viewed as the domain of unskilled workers who are poorly paid. More affluent women who wish to reduce their caregiving responsibilities often hire less privileged women at lower wages to assume their caregiving responsibilities (Harrington, 1999). Thus, paid caregiving remains the labour of invisible, undervalued women who may work long hours for low wages.

In situations of unpaid care, care providers may be exploited because personal relationships are regarded as beyond the contractual realm; rather, society expects private caregivers, such as mothers of children with disabilities, to provide skillful care with little desire to establish the boundaries that public, contractual relationships mandate (Nussbaum, 2006). In the case of family caregiving, this issue often translates to caregivers working long, unpaid hours at personal costs; therefore, both recipient and care provider face vulnerability.

**Care involves bidirectional vulnerability.** Kittay (1999) not only emphasised that caregiving was work, but she also highlighted the vulnerability of both the dependent person and dependency worker. The dependent individual was vulnerable because he or she required assistance for essential tasks of daily living. However, Kittay noted that the dependency worker was vulnerable. In situations of extreme dependency, the needs of the dependent individual may outstrip capacity of the care provider, so even a devoted and attentive care provider may not fully address all needs. Therefore, dependency workers may face situations that exceed their abilities to care. Complicating the scenario, dependent family members may insist family provide their care, particularly intimate care, thereby placing familial caregivers in situations where their abilities to set boundaries become compromised.

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1 I completed this study and could earn a PhD due to the caregiving assistance offered by many wonderful women, particularly Carol Bayubay.
Women often enter caregiving because of their genders and relationships to dependent family members. Society assumes women are natural caregivers; in situations of need, women often enter caregiving roles. Because society may view care as women’s work, particularly in the case of mothering, women may struggle to differentiate between “typical” care and extraordinary care. Thus, some women do not self-identify as caregivers, even when facing extraordinary care demands (Bubeck, 1995; Change Foundation, 2018).

The vulnerability of care providers may be complicated because society may expect “good” mothers, daughters, and wives to care for their loved ones, even to the point of self-sacrifice and personal cost. Care is a private endeavor performed behind closed doors by providing intimate tasks, such as bathing a loved one or providing toilet assistance. People who care shield society from recognizing the issue of overwhelmed care providers. Further, the isolated, gendered, and private nature of care means that caregivers’ work remains invisible and undervalued; therefore, it is rarely a political, financial, or social priority (Harrington, 1999; Held, 2006; Kittay, 1999; Noddings, 2013; Ruddick, 1995).

**Extreme caregiving.** Freitag (2018) explored the notion of caregiving through the lens of parents caring for profoundly disabled children. Freitag defined extreme parental caregivers as parents, almost always mothers, who cared for a child of any age who required prolonged, intensive, emotionally intense, and often medically complex care. Freitag asserted that the care of children with significant disabilities was not synonymous to the care of typically developing children. The care of typically developing children does not last for decades or require medical support performed by skilled health professionals, such as nurses. Extreme caregivers provided life sustaining, complicated care to an individual with whom they were emotionally connected. Further, extreme caregivers lived with the constant awareness that mistakes could have dire or
life-threatening consequences. Freitag echoed Cohen’s (1995) study exploring the lived experiences of parents raising medically complex children. Cohen indicated that parents who engaged in extreme caregiving described their situations as living with the unpredictability of a “time bomb”. They did not know when their children’s health might deteriorate or the severity of the consequences, regardless of the quality of care.

**Ethics of care.** Ethics of care is founded on the assertion that human beings are dependent creatures, and throughout their lives, they require varying levels of care. In infancy, all people are dependent beings. Disability and/or illness may involve periods of dependence. Ethics of care indicates that the provision of responsive, compassionate, and competent care is both a moral imperative and necessary for human flourishing (Held, 2006). Ethics of care centers on care and caregiving being relational, interdependent, gendered, private, and bidirectional; therefore, these ethics were subject to social, political, and economic influences (Harrington, 1999; Held, 2006; Kittay, 1999; Noddings, 2013; Ruddick, 1995).

**Caregiving Mothers**

**Mothers of children with disabilities.** Most researchers have described the lives of mothers raising children with developmental disabilities as challenging. Researchers have highly correlated maternal caregiving with increased caregiver burden and stress (Khanna et al., 2011; Murphy, Christian, Caplin, & Young, 2006; Plant & Sanders, 2007; Raina et al., 2005; Sawyer et al., 2009; Smith et al., 2010), sleep disruption (Bourke-Taylor, Howie, Law, & Pallant, 2011; Lee, 2013; Murphy et al., 2006), social isolation (Leonard, Johnson, & Brust, 1993; Sawyer et al., 2009), and loss of control in daily life (Murphy et al., 2006; Raina et al., 2005). Although mothers of children with developmental disabilities reported poorer quality of life when compared to the general population, Meadan et al. (2010) suggested mothers of children with
autism spectrum disorders were most at risk. The reasons for this heightened stress among mothers was unclear, but the authors postulated that increased stress might be associated with caring for a child with a disorder of unknown etiology, as well as the fact that autism was often associated with challenging behaviours. Mothers of behaviourally challenged children often face societal judgment (Meadan et al., 2010).

Researchers have associated pressure to advocate for their children amid a professional environment with heightened maternal burden (Landsman, 2009; Stainton & Besser, 1998). Mothers of children with developmental disabilities were more likely than mothers of typically developing children to experience depression, anxiety, and mental health symptoms (Lee, 2013; Murphy et al., 2006; Raina et al., 2005; Sawyer et al., 2009). Not surprisingly, mental health challenges increase when mothers have a more than one high-needs child (Bourke-Taylor et al., 2011) or when the child has significant behavioural issues (Khanna et al., 2011). Mothers of children with disabilities have noted fewer opportunities to engage in personal self-care (Murphy et al., 2006).

Overall, researchers have strongly correlated poor maternal health with parenting a child with a disability, and researchers have defined the severity of the child’s disability as a highly predictive factor (Khanna et al., 2011; Leonard et al., 1993; Wei & Yu, 2012). Researchers have correlated maternal health with the severity of childhood disability based on mothers who cared for children with significant disabilities; researchers have found these mothers as more likely to experience poor health (Khanna et al., 2011; Leonard et al., 1993; Wei & Yu, 2012). On average, fathers’ health is less likely to be negatively influenced by having a child with a developmental disability. Burton, Lethbridge, and Phipps (2008) argued that the negative influence on maternal health might be linked to societal definitions of a “good mother.” Societal
norms indicate mothers, more so than fathers, should choose their children’s needs ahead of their own, even if that choice influences their abilities to engage in self-care or compromises maternal well-being (Murphy et al., 2006). In contrast, society views “good fathers” as providers working outside the home (Murphy et al., 2006).

Researchers have noted financial stress as a challenge for families raising children with disabilities (Burton & Phipps, 2009; Stabile & Allin, 2012). Researchers have linked financial stress to both direct and indirect costs for families raising children with disabilities (Burton & Phipps, 2009; Stabile & Allin, 2012). Direct costs included the need to purchase equipment, medications, and additional care. Indirect costs have included lost employment incomes and employment opportunities (i.e., promotions).

The mother usually faces limitations to employment subsequent to caregiving (Burton & Phipps, 2009). In all studies, the researchers noted that mothers were more likely to leave or reduce employment, as well as decline promotions, because of their children’s disabilities (Burton & Phipps, 2009; Stabile & Allin, 2012). Researchers correlated severity of disability with families embracing traditional gender roles. The more severe the disability, the more likely the mother would withdraw from employment and remain at home as a full-time caregiver (Burton et al., 2008; Stabile & Allin, 2012). The resulting financial burden from reduced employment would influence the lives of mothers. Researchers associated greater financial resources with better access to helpful services that improved maternal coping; constrained finances translated to an inability to purchase medical equipment/supplies or badly needed respite services, while exacerbating overall stress (Leonard et al., 1993).

The research has shown caregiving mothers face high stress levels; however, researchers have explored strategies to improve the lives of overwhelmed maternal caregivers. For example,
Soresi, Nota, and Ferrari (2007) explored strategies to improve quality of life among parents of children with disabilities. Results indicated that access to information about their children’s condition and opportunities to develop constructive advocacy skills would improve quality of life among parents. Additionally, researchers have highly correlated maternal flexibility and resilience, meaning the ability to accommodate to life’s demands was associated with positive maternal mental health (Grein & Glidden, 2015; Larson, 2010; Peer & Hillman, 2014; van Ingen, Moore, & Fuemmeler, 2008). Researchers have strongly associated access to social support (Khanna et al., 2011; Peer & Hillman, 2014; Plant & Sanders, 2007; Raina et al., 2005; Sawyer et al., 2009) and respite (Burton & Phipps, 2009; Murphy et al., 2006) with improved maternal health.

Historically, scholars have defined raising a child with a disability as a family tragedy and threat to the marriage of the parents. However, research has indicated that although parenting a child with disabilities is stressful, parents do not always face divorce. Risdal and Singer (2004) found a marginally higher risk of divorce among parents of children with disabilities, but the risk was minimal and smaller than predicted. They noted those parents who remained married reported a strengthened marriage. Meadan et al. (2010) found that parents raising children with autism had a greater risk of marital breakdown when compared with other parents of children with developmental disabilities; however, the reasons for this finding remained unclear. Stainton and Besser (1998) noted parents raising children with developmental disabilities reported positive aspects associated with their parenting journey, such as improved sense of community, family unity, closeness, joy, and sense of purpose. Overall, parents of children with developmental disabilities, when considered over the course of a lifetime of marriage, had a
divorce rate like that of the general population (Namkung, Song, Greenburg, Mailick, & Floyd, 2015).

Van Ingen et al. (2008) studied parenting styles among parents of children with disabilities and noted differences between overinvolved parents and healthy parenting. These researchers noted struggling parents micromanaged their children’s care, emphasised their children’s disabilities rather than strengths, struggled to work with professionals, and created conflict in collaborative relationships. A potential factor contributing to these negative coping strategies was the correlation between poorly resolved grief and difficulty coping. In contrast, healthy parents worked collaboratively with professionals, accepted the limits of professionals and the system, balanced their caregiving lives with other important roles and relationships, and maintained lives separate from their children.

**Mothers of adult children with developmental disabilities.** Until recently, most researchers of parenting have focused on mothers parenting children under the age of 18 (see Rowbotham, Carroll, & Cuskelly, 2011). Normal childhood development researchers have assumed that adult children require little to no parental involvement; however, “the commitment made by mothers of adults with disabilities often exceeds the typical maternal experience in terms of intensity, complexity, and its temporal unfolding” (Thackeray & Eatough, 2015, p. 265). Studies have indicated that the extraordinary demands of parenting a child with a disability can persist into adulthood. Mothers continue to bear the burden of caregiving and experience heightened levels of stress, depression, and anxiety (Rowbotham et al., 2011; Smith, Greenberg, & Seltzer, 2012, Weeks, Bryanton, Kozma, & Nilsson, 2008). Mothers of typically developing children may return to work as their children enter school and become more independent (Statistics Canada, 2015). Conversely, mothers of adult children with disabilities rarely return to
employment and continue to experience corresponding financial stressors (Weeks et al., 2008). Like the paediatric research, parents of adult children with autism often live more stressful lives than both parents of the general population, as well as parents raising children with developmental disabilities other than autism (Burke & Heller, 2016).

Anxiety about the future care of their vulnerable child can cause maternal stress as the children age (Thackeray & Eatough, 2015). Researchers have associated having a plan to address the future care of the child with reduced stress (Burke & Heller, 2016). Parents have expressed that having this sense of control about the future was helped when facing a lack of support systems following school graduation and/or transition to adulthood (Taylor & Seltzer, 2011).

Researchers have found positive coping strategies persist into adulthood. Researchers have correlated resilience and accommodation with improved coping and increased social support (Smith et al., 2012; Piazza, Floyd, Mailick, & Greenberg, 2014). Pruchno (2003) explored later parenting years and identified that positive and helpful social support could originate from the adult child with a developmental disability. They also noted that most caregiving models considered social support as support received from outside the caregiver/cared-for dyad. In cases of older, isolated mothers, the findings indicated that helpful social support also emerged from within the caregiving dyad. For example, an aging mother might benefit from the companionship of her adult child with a disability who remained living at home.

**Intersubjectivity, Intercorporeality, and Interconnection**

Although disability and care are important elements of this literature review, I aimed to explore the experience of interconnection between maternal caregivers and their children with a
disability. Throughout this study, I used the term of interconnection, particularly when interviewing mothers, for ease of communication. Researchers also used the terms of intersubjectivity and intercorporeality to describe the porous boundaries between bodies.

Embodied interconnection between caregivers and care-recipients was a relatively new focus of study. Disability theorists have problematized the body and advocated for a more nuanced view of the body (Shildrick, 2009). Rather than understanding the caregiver and cared-for as distinct bodies with sharp boundaries, emerging postmodern caregiving researchers have viewed bodies as complex assemblages, where bodies intersected with machines (wheelchairs and feedings tubes), animals (seeing-eye dogs), and/or one another (partners, friends, caregivers, lovers) in egalitarian and collaborative structures (Churchill, 2012; Fritch, 2010; Gibson, 2006; Price & Shildrick, 2002).

Caregivers have complicated the relationship between bodies because their caregiving has involved sharing personal space and providing care during socially taboo personal functions (elimination, sexual engagement, dressing, and eating; Fritch, 2010). As asserted by Goodley, Lawthom, and Runswick (2014), “Disability necessarily demands and affirms interdependent connections with other humans, technologies, non-human entities, communication streams and people and non-peopled-networks” (p. 348). Disability theorists exploring the postmodern body have defined bodies as complex, interdependent, and porous (Breckenridge & Volger, 2001; Gibson, 2006; Goodley et al., 2014; Hughes, McKie, Hopkins, & Watson, 2005).

Churchill (2012) described the intercorporeal reality of caregiving. Churchill defined caregiving moments as “we” experiences when souls connected. Implied within this we-ness was a form of deep attunement that created shared resonance between bidirectional bodies. Churchill (2012) stated, “In the ‘selfless’ attitude of the caregiver … I have this capacity … in
which the other’s joy or despair or pain or sadness resonates in me”. (p. 5). Churchill (2012) emphasised that the experiences of the caregiver, while deeply attuned to the care-recipient, remained independent experiences, thus creating a paradoxical overlapping of bodies.

Disability advocates have noted that society has denied people with disabilities power, voice, and agency (Charlton, 1998; Oliver, 2009; Price & Shildrick, 2002; Titchkosky, 2011). Therefore, researchers and disability advocates can view discussions of interdependence and intercorporeality as threatening hard-won advancements in independence and autonomy for people living with disabilities (Hughes et al., 2005). Scholars of intersubjectivity have acknowledged the importance of combining the voices of both an abled-carer and a person with a disability. However self-advocates have viewed combining voices as threatening the autonomy of a person living with a disability. Despite this assertion, Price and Shildrick (2002) argued for a postmodern intercorporeal deconstruction of embodied boundaries that mingled experiences, bodies, and voices.

In one of the few qualitative studies exploring intercorporeal relationships, Fritsch (2010) studied blurred boundaries amid caregiving. The results indicated that the provision of intimate care for another, such as bathing, dressing, or toileting (particularly facilitating sexual expression), disrupted the notion of a sovereign, professional self; promoted porous bodily boundaries; and leaked the self into the other. Fritsch defined caregiving as a form of embodied interrelationships that challenged the prevailing notion of bodies as discrete and autonomous.

Nishida (2017) completed a qualitative study using focus groups to explore affective relationality between care providers and their charges. Nishida focused on vulnerability within a caring relationship. Nishida indicated that within caring relationships, care providers and care recipients encountered one another, not as neutral subjects, but as bodies laden with emotions
and presuppositions. Caregiving facilitated an innate and mutual sense of one another’s needs. Not only did those providing care interpret the needs of their charges, but individuals receiving care became attuned to the needs of their care providers. For example, one care recipient noted, “When you’re working with a person eight hours, nine hours, five days a week, seven days a week, you start to know …. what their habits are …. you can almost anticipate what their needs are” (Nishida, 2017, p. 95; emphasis in original).

**Maternal-child interconnection.** Although disability scholars have discussed the notion of intersubjectivity, particularly within the context of care, few have explored the experiences of interconnection between a mother and their children with a disability. For biological mothers, interconnection begins during awareness of pregnancy. Mother and child are interconnected. When parenting infants or toddlers, mothers must rely on their sense of interconnection with their children to provide care, particularly when the child is preverbal. The journey from interconnection begins at birth when parenting a typically developing child.

**Caregiver engrossment.** Noddings (1996) described the experiences of engrossment and receptivity and defined engrossment as “a total conveyance of the self to other, a continual transformation of individual to duality to new individual to new duality” (p. 23). Engrossment was not a rational experience. Caregiving was not an intellectual exercise or problem to be solved because such an approach risked dehumanizing the care-recipient. An engrossed mother or caregiver stepped outside her detached, rational self and embraced the experiences of another. As Noddings (2003) stated, “The seeing and feeling are mine, but only partly and temporarily mine, as on loan to me” (p. 30).

Extending the idea of engrossment, Noddings (2003) described the experience of reciprocity and defined reciprocity as when the individual being cared-for responded to and
affirmed the care offered. Affirmation from the cared-for enhanced the caring relationship, provided feedback about the efficacy and value of care, acknowledged the work of the carer, and ensured the caregiving experience was not dehumanized. Noddings (2003) stated that not all people receiving care would acknowledge care, and a care provider could not expect and demand reciprocity. Noddings (2003) focused on mothering and teaching relationships and did not explore reciprocity concerning disability; therefore, she did not explore the challenges of caring for someone who could not respond.

**Extreme caregiving and responsiveness.** Although Noddings (1996, 2003) did not explore the caregiving relationship regarding disability, Freitag (2018), a physician, ethicist, and sibling of an adult with a disability, discussed responsiveness and disability. Freitag noted that care recipients with profound disabilities often could not provide feedback to the caregiver about care received. In such situations, the caregiver must read and interpret embodied cues, behaviour, and other forms of subtle nonverbal communication to assess the efficacy of their care. Hence, these caregiving relationships inevitably engendered a close relationship between the mother and child, thereby posing unique ethical challenges, including the total self-abnegation of the mother. Freitag (2018) stated the following:

> The bond, formed out of responsiveness to the day-to-day meetings of needs, can be perilous for both caregiver and cared-for, as both can be lost in, but also enriched by, their shared identity …. Parents seeking to understand who their child is, and to help their children thrive to their maximum potential, must take care not to impose their hopes and expectations on a child who becomes entwined with them and may never be able to contradict them. (p. 169)
Freitag (2018) expanded Tronto’s (1993) notion of care-receiving by proposing that parents engaged in this caregiving/care-receiving not only to enhance effective care but also to define a narrative for their children with compromised communication. Freitag (2018) argued that children with significant disabilities could not tell their own stories and required assistive voices to tell their stories; therefore, caregiving parents created meaningful narratives for their child. Through the care provided to the child, the parents could define their children’s wants, needs, likes, and preferences to share these stories with the world. For example, in caring for my son, I constructed a narrative about Matthew that included his love of the outdoors, hockey games, family gatherings at the cottage, Disney movies, bubbles, and jazzy music. However, I have no means of confirming this narrative with my son. Correspondingly, Freitag stated that because experiences were sufficiently intertwined, true authorship of parentally constructed narratives remained unclear.

The Body

Cartesian dualism separates the mind and the body, as well as bodies. The foundation of Western philosophy, particularly the medical model, rests on Cartesian dualism. However, I explore the body as it has been viewed throughout history, with a particular emphasis on intersubjective bodies, in the following subsections.

Ancient communities and the body. In ancient Greco-Roman cultures, the separation between mind and body that pervades contemporary understanding of the body did not exist (Martin, 1995). Aristotle (384-322 BCE, as cited in J. Barnes, 2010) explored the body by analysing the soul. Aristotle did not view the body as separate from the soul or a vessel in which the soul resided; rather, Aristotle viewed the soul as a psychic power that formed the essence of
the living body. The soul and body were indivisible, and the soul coexisted with a body for which it was specifically intended, forming an indivisible and holistic whole (Barnes, 2010).

Plato, Aristotle’s teacher, adopted a more dualistic worldview. Plato believed that soul and body were distinct (as cited in Gonzalez, 2013). Souls were indivisible and possessed reason, while bodies were not (Gonzalez, 2013). However, Martin (1995) argued that although classic Platonism might be more closely aligned with Cartesian dualism, the early Christian communities embraced “a ‘Platonic tradition’ that no longer subscribed to the radical dualism of Plato” (p. 12) but included a more integrated sense of body and spirit. This Greco-Roman worldview likely did not emerge until later in the first century. Until that time, the prevailing understanding of the body among the early Christian’s rested on a favourable view of the body as expressed by the Hebrew Bible.

Writers of the Hebrew Bible provided a positive view of the body. In Genesis 2:7 (New Revised Standard Version [NRSV]), God used the dust of the ground to create man, and then later used the same matter to create additional creatures of the earth and sea (Genesis 2:19; NRSV). The idea that all bodies on the earth, both creatures and humankind, were connected to one another through a shared emergence from holy dust lends a unique perspective to the notion of intersubjectivity. Extending this idea of intersubjectivity, in Genesis 2: 21-25 (NRSV), God used Adam’s rib to create another human being. Early Jewish communities would have based their understandings of the body on such Biblical narratives. These narratives indicated that bodies did not exist in isolation but were connected from their very beginnings (T. Hegedus, personal communication, December 1, 2018).

As the first century approached its conclusion, many early Christian communities gravitated to a gentile view of the body. These early Christian communities viewed the body as
animated by pneuma (Martin, 1995). Pneuma is difficult to describe in contemporary language, but for ancient cultures, society defined pneuma as an immaterial substance that supported “perception, motion, and life itself” (Martin, 1995, p. 21). When addressing the Corinthians, Paul understood pneuma as “spirit” (Martin, 1996, p. 96). Pneuma existed both within the body, comingling with blood and nerves, and the atmosphere surrounding the body. Pneuma moved freely within and between bodies. Thus pneuma, unlike the Aristotelian soul, was not attached to a body or space. Although this pneumatic movement does not speak directly to intercorporeality, the movement of animated matter between and among bodies suggests a more porous conceptualization of the body.

The body was not an individual entity but tended to be considered part of a communal whole. The body, formed of sarm (flesh) and soul, was an earthly entity standing in contrast to a wholly divine God (Robinson, 1952). The boundaries of the body, common today, did not exist in ancient communities. Fleshly humans in ancient Judaic cultures were viewed not as individuals but as mortal creatures living within a divine and communal world in solidarity with one another (Robinson, 1952). Unlike Cartesian dualism that would follow some centuries later, the spirit and body were wholly intertwined within earthly bodies that were interdependent of one another and with God.

Philosophy and the body. Historically, scholars have discussed philosophy and the body (Descartes, trans. 1998; Gascoigne, 2002; Hobbes, 1962; 1651/1996; Husserl trans. 2013, 1913/2017; Locke, 1962). The following subsections offer a brief description of these scholars and their discussions.

Rene Descartes (1596-1650). By the late 16th and early 17th centuries, theological and philosophical thought underwent radical revisions. Skepticism refers to the belief that all
thoughts can be doubted and subsequently challenged, a practice rigorously engaged by Descartes. Skepticism dominated philosophical discourse for at least a century before Descartes (trans. 1998) published *Meditations and Other Metaphysical Writings* in 1637 (Gascoigne, 2002). Descartes (trans. 1998) emphasised a separation between body and mind. Descartes defined the human body as not only distinct from other bodies but also as a mechanistic vessel of bone and muscle that supported the vastly superior mind. Descartes (trans. 1998) emphasised the human being as a discrete and independent “thinking thing” (p. 25).

As a skeptic, Descartes (trans. 1998) questioned ideas broadly. He discussed philosophy and daily life. Part of this journey of doubt led Descartes to question his personal experiences of mind and body. During this process, he arrived at *cogito* or the knowledge that one existed. In the sixth meditation, Descartes explored the distinction between mind and body and concluded that the body existed as separate from other bodies, as well as minds.

Descartes (trans. 1998) defined the body as divisible; for example, a person could lose an appendage while the mind remained untouched. He argued that only an injury to the portion of the brain responsible for common sense would affect the mind; further, the mind and the act of thinking were superior to the body. The mind was present to the body like a pilot navigating a ship. Both appeared to be closely joined and operated in harmony, but the pilot was separate from the ship and ultimately responsible for the actions of the ship. Descartes (trans. 1998) revolutionised the way that researchers and philosophers viewed the body and mind, thereby dominating Western philosophical and scientific thinking for centuries.

*Thomas Hobbes (1588-1679).* Hobbes (1962; 1651/1996) was both a contemporary and critic of Descartes (trans. 1998; Duncan, 2019). Although Hobbes (1962; 1651/1996) was most well-known for his political theory, he explored a range of philosophical topics, including logic,
mathematics, and the body, particularly optics (Malcolm, 1996). His early work on materialism or physics influenced his views about the body and mind, thereby causing Hobbes (1962; 1651/1996) to disagree with Cartesian dualism. Around 1640, Hobbes and Descartes engaged in a series of written interactions where Hobbes voiced his objections to Descartes’s ideas (as cited in Duncan, 2019; Malcolm, 1996). This correspondence was published in a later edition of Descartes’s (trans. 1998) *Meditations* (Duncan, 2019; Malcolm, 1996).

Extreme Cartesian dualists argued that a mind could exist without a body and a body without a mind. Descartes (trans. 1998) stated,

> I think of a human as some kind of machine made from bones, nerves, muscles, veins, blood and skin so that, even if there were no mind in it, it would still have all the motions it has at present which do not result from the control of the will and, therefore, the control of the mind. (p. 66)

Descartes (trans. 1998) defined the body and its parts as material objects because a person could observe these parts using the senses. The mind was not part of this collection of material objects. Conversely, Hobbes (1962; 1651/1996) believed that nothing existed beyond identifiable matter (Duncan, 2019; Sorell, 1986). Thus, Hobbes (1962; 1651/1996) believed that the material mind was connected to and part of the material body. He believed to separate the two was nonsensical.

From his work on physics, Hobbes (1962) argued that the “organs of sense” (p. 9) of a sentient being generated phantasms or sensations that influenced body and mind. Hobbes (1962) defined the nerves and vessels of the body as supplying the mind. These material connections were observable; therefore, any force on the body that involved the nerves or blood vessels must
include the mind by virtue of material connectivity (Hobbes, 1651/1996). Hobbes (1651/1996) wrote the following:

   The cause of sense, is the external body, or object, which presseth the organ proper to each sense, either immediately, as in the taste and touch; or mediately (sic), as in seeing, hearing, and smelling: which pressure, by the mediation of the nerves, and other strings, and membranes of the body, continued inwards to the brain and heart. (p. 9)

   Thus, force on any part of the body impacted the brain due to the body’s material connectivity. The body and mind were interconnected entities. Unlike Descartes (trans. 1998) who stated that bodies were separate, Hobbes (1651/1996) focused on the mind/brain separation rather than the interrelationship of bodies.

   **John Locke (1632-1704).** Like Hobbes (1662), Locke (1836/2008) discussed political philosophy and humanity, conscious thought, and the body. While attending Oxford University, Locke was influenced by Descartes (trans. 1998; Lamprecht, 1928). Locke (1836/2008) disagreed with Descartes (trans. 1998) on key areas; for example, Lamprecht (1928) characterized Locke (1836/2008) as “unwilling to identify the soul with the activity of thought … Descartes left deep traces on his philosophical system. Locke incorporated Descartes’s proof for the existence of the self as the most indubitable of all truths” (p. ix).

   Although Descartes (trans. 1998) defined humans as “thinking things” (p. 25), capable of ideas through reason alone, Locke (1836/2008) defined humans as a sheet of paper where experiences of the senses and material world existed. Locke further defined the human mind as a “blank slate,” where only engagement with the world would lead to formulating ideas. Rational thought alone was insufficient material for the formation of ideas. Locke (1836/2008) wrote, “external objects furnish the mind with the ideas of sensible qualities, which are all those
different perceptions they produce in us: and the mind furnishes the understanding with ideas of its own operations” (p. 55; emphasis in original). Contrasting Descartes’s (trans. 1998) assertion that thinking could happen in isolation, Locke (1836/2008) argued that abstract reflection could only happen after a person formed ideas through human experience with the world.

In his review of Locke (1836/2008) and dualism, Oodegard (1970) asserted that Locke (1836/2008) endorsed a form of embodied dualism in which a human possessed both a mind and a body. Not only did Locke believe that the mind was separate from the body, he also believed the mind could exist outside the body (Oodegard, 1070). Despite this assertion, Locke’s (1836/2008) views appeared to have shifted by his later writings. According to Oodegard (1970), while Locke (1836/2008) accepted dualism his later work suggested a theoretical possibility of a human existing as a single entity possessing both mental and physical attributes. Like Hobbes (1962), Locke (1836/2008) focused on the relationship of the mind and body, rather than the interrelationship between bodies.

**Edmund Husserl (1859-1938).** Researchers have defined Husserl (trans. 2013, 1913/2017) as the founder of phenomenology (Kaufer & Chemero, 2015). Kaufer and Chemero (2015) defined phenomenology as the study of that which makes “a shared, objective world intelligible” (p. 2). Husserl (trans. 2013, 1913/2017) presented a fifth cartesian meditation to explore embodiment and intersubjectivity (Duranti, 2010). Duranti (2010) characterized Husserl (trans. 2013, 1913/2017) as the following:

> Intersubjectivity was the most basic quality of human existence, which is constitutive of the Subject and of the very notion of an objective world … Husserl comes to see intersubjectivity as a domain of inquiry that spans the entire scope of human experience. (pp. 16-17)
As a phenomenologist, Husserl (trans. 2013, 1913/2017) studied how beings or subjects experienced the world, as well as the world’s objects. Husserl (trans. 2013) defined the subject and object as existing within a world where meaning existed (Duranti, 2010). Husserl (trans. 2013) argued that experience was meaningless unless it imposed the consciousness of a thinking, rational being. This being then drew on his or her existing knowledge to interpret present experiences in relation to past experiences and knowledge. Experience did not exist in isolation; rather, experiences existed on a scaffold of pre-existing personal actions and knowledge. Experiences formed the basis of a personal narrative where meaning was organized around past, present, and anticipated future experiences. Husserl (trans. 2013, 1913/2017) defined these life expressions as infused with meaning and communicated to the greater world. The lived experience was not only how an individual attached meaning to his or her lifeworld but was also the way that he or she expressed meaning about his or her lives (Husserl, trans. 2013).

Husserl (trans. 2013) defined subjects or “egos” as not only intertwined with the objects of their world but with other subjects as well. Husserl (trans. 2013) defined intersubjectivity as the manner in which an “I” and an “other” became “we,” and how this “we” could then experience a shared world together (p. 20). Duranti (2010) summarised Husserl’s understanding of intersubjectivity as the following:

The condition whereby I maintain the assumption that the world as it presents itself to me is the same world as it presents itself to you, not because you can “read my mind”, but because I assume that if you were in my place you would see it the way I see it. (p. 21)

Husserl (trans. 2013) defined intersubjectivity as a delineation between the self and the other. Only once the bodily integrity of the self was established could the identity of another be appreciated. In other words, an “I” could only understand the uniqueness of a “you”, if it first
understood itself as an “I”. Only when the unique identities of “I” and “you” were established could a “we” be known. The “we”, as it navigated a shared world, was motivated to understand the experiences of the other while maintaining those experiences as distinct. A blurring of experiences was not implied.

I found Husserl’s (trans. 2013) description of pairing important when studying intersubjectivity. Pairing occurred when two beings met, and their experiences of the world expanded to include a common “overlaying” of the other. There was “a mutual transfer of sense— that is to say: an apperception of each according to the sense of the other” (Husserl, trans. 2013, p. 113). This pairing evolved to empathy for the other. Each being sensed another being and developed an appreciation for others’ experiences.

Relevant to the discussion of intersubjectivity and disability, Husserl (trans. 2013) considered the experiences of beings who experienced the world differently. For example, Husserl (trans. 2013) considered how a typically sighted person might engage with a blind person. Because Husserl (trans. 2013) defined intersubjectivity as concerning shared experiences with the world, he argued that a body with a disability would sense and experience the world differently compared to one without a disability. Therefore, the two bodies would not have similar sensory experiences of the world. In these situations, Husserl (trans. 2013) prioritised the experience of the able-bodied “I” over the dissimilar “other”. Despite his emphasis on empathy, he did not explore the notion that empathy might bridge the gap between distinct sensory experiences.

*Martin Heidegger (1889-1976).* Husserl (trans. 2013) educated Heidegger (trans. 2010) who did not specifically discuss intersubjectivity; however, he explored Dasein and contributed to the discussion (Ferencz-Flatz, 2015). Dasein described self-aware beings as being aware of
their beingness, as well as their *worldness* (as referenced in Heidegger, trans. 2010). In other words, Dasein described beings who understood their existence within the larger world. Beings both constituted and were constituted by their worlds. For Heidegger (trans. 2010), the egocentricity or “I-ness” of Dasein was understood. Dasein did not include an overlapping awareness of another’s being-in-the-world (O’Brien, 2014). Rather, the world into which a person was thrown and subsequently experienced was their own and was viewed from an “I” perspective. Heidegger (trans. 2010) argued, “This world is always already from the outset my own” (p. 115). Like Husserl (trans. 2013), Heidegger (trans. 2010) translated the egocentricity of Dasein to an awareness of one’s own “I-ness primarily in contrast to another’s ‘I-ness’” (p. 115).

Heidegger (trans. 2010) believed that the “other” in one’s immediate world was less “other” than anything or anyone that existed outside his or her immediate world by virtue of shared experiences. Beings occupied that same world, thereby enhancing their similarities without transgressing boundaries. According to Heidegger (trans. 2010), Dasein struggled with the dual nature of an individual and a social being (O’Brien, 2014).

Heidegger (trans. 2010) hinted at intersubjectivity in his discussion of care and concern. He described two forms of caring: One form involved “leaping-in” (p. 118). Heidegger (trans. 2010) defined leaping-in as a person caring for another, but when doing so, he or she displaced the person. The term “leaping ahead” (p. 119) described a person providing care without compromising the integrity of the cared-for person. The former was a replacement for authentic solidarity and friendship, while the latter honoured both beings-in-the-world (Ferencz-Flatz, 2015).
**Maurice Merleau-Ponty (1908-1961).** Heidegger (trans. 2010) and Husserl (trans. 2013) studied the ways that beings attached meaning to experiences. Merleau-Ponty (trans. 2010, 1964) extended the conversation about the engagement of meaning and experience by emphasizing embodiment. Merleau-Ponty (trans. 2010, 1964) defined the body not simply as an appendage of a being but as the direct mediator of all experiences (Barral, 1965). He argued that one must consider the role of the body as a conduit. Further, as embodied beings navigated their worlds, Merleau-Ponty (trans. 2010) asserted that they would meet and experience other bodies. Some bodies would have overlapping and enmeshed experiences: “We have learned in individual perception not to conceive our perspective views as independent of each other; we know that they slip into each other” (Merleau-Ponty, trans. 2010, p. 411).

In contrast to Husserl (trans. 2013), Merleau-Ponty (trans. 2010) considered how differently abled bodies experienced the world and he extended the boundaries of the physical body to include objects employed by the body. For example,

The blind man’s stick has ceased to be an object for him, and is no longer perceived for itself; its point has become an areas of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight. (Merleau-Ponty, trans. 2010, p. 165)

The cane of a visually impaired person, rather than a physical instrument, was an appendage of the body that provided important sensory information to the user. This idea of a cyborg body with extensions beyond the skin offered new insight about interconnected bodies.

Rather than exploring the body/mind/soul relationship or the role of the body with experience and knowledge, Foucault (1965/1988, 1995) analysed the manners whereby social, religious, and political power structures governed bodies. Foucault (1965/1988) noted that in Europe during the 1600s, asylums and workhouses emerged as warehouses for poverty and deviance. Ill or poor people were confined to such facilities where both their illnesses and poverty levels were attributed to inadequate moral and ethical attributes: “(I)t was made quite clear that the origin of poverty was neither scarcity of commodities nor unemployment, but ‘the weakening of discipline and the relaxation of morals’” (Foucault, 1965/1988, p. 59). He argued that historically, societal and political control was achieved by confining and regulating “unfit” bodies, and the “fitness” of bodies had moral and ethical dimensions (p. 59).

Foucault (trans. 1995) explored societal control of bodies, not by physical confinement, but through the physical and mental control of bodies. In *Discipline and Punish* (trans. 1995) Foucault introduced a description of torture, noting that imprisonment and the threat of torture throughout history were a means of controlling bodies. Foucault (trans. 1995) traced the evolution of societal control from physical punishment and domination to society’s contemporary control of bodies through the *domination of the soul*. However, he did not mean soul in the Christian sense but the human psyche. Human psyches and, by extension, bodies were dominated through a hierarchy of social tactics that could be so effective that the individual self-regulated overt social influences. According to Foucault (trans. 1995), control was achieved through work, schooling, and societal divisions that introduced and enforced societal norms and expectations. These less brutal but equally powerful means of managing bodies had influence like that of physical control. Foucault (trans. 1995) argued that control of the bodies,
Since it is no longer the (physical) body … must be the soul. The expiation that once rained down upon the body must be replaced by a punishment that acts in depth on the heart, the thoughts, the will, the inclination. (p. 16)

**Erving Goffman (1922-1982).** Foucault (1965/1988) expressed similarities to Goffman’s (1963) work on stigma and spoiled identity. Goffman authored multiple books exploring discrimination and stigma. Goffman argued that bodies were regulated through the insidious and powerful societal influence of stigma. Stigma was the means by which deviant bodies were labeled, and life opportunities were limited.

Goffman (1963) noted three types of stigmatised bodies. Some bodies wore physical marks of deviance through deformities (i.e., the “abominations of the body”; Goffman, 1963, p. 4). Other bodies had physical and cultural differences, such as differing skin colours. Finally, others were stigmatised by their blemishes of character, such as having mental health issues. Goffman (1963) noted that stigmatised bodies were controlled and regulated not through formal societal and political structures, as Foucault (trans. 1995) argued, but through societal discrimination that placed limits on bodies that deviated from societally defined norms.

**Charles Taylor (1932-).** Taylor (1989, 1991) is a Canadian philosopher who focused on the self and identity, particularly regarding hermeneutics and epistemology. However, Taylor (2008) argued that the reigning dualistic view of the mind and body allows people to imagine a buffered self rather than a porous self. A buffered self purports to allow bodies to keep feelings and experiences outside embodied boundaries; however, a porous self allows experiences to penetrate the body. Illustrating a porous body in a pre-modern era, Taylor (2008) provides the example of black bile; historically, black bile in the body represented melancholy. If black bile was in a person’s body, then he or she was depressed. Correspondingly, if a person was
depressed, black bile was within the body. Depression represented a fully embodied state (Taylor, 2008). For the buffered body, depression is understood to be a feeling in the mind, as distanced from personal experiences by a division between mind and body. By contrast, for the porous self the erosion of embodied boundaries allowed outer experiences, such as the pain of another, and inner experiences such as depression, to penetrate the self.

**Promising directions: Carnal hermeneutics.** The emerging study of carnal hermeneutics has shown promise for studies exploring embodied intersubjectivity. Scholars of carnal hermeneutics have stated that all meanings and interpretations have begun and ended with the body (Kearney, 2015; Kearney & Treanor, 2015). The world and other bodies are experienced through the sensible body (Thompson, 2016). This sensible body encounters other sensible bodies within its world: “(E)very sensible body that is seen, smelled, heard, touched, or moved presupposes another body that sees it, smells it, touches it, or moves it” (Henry, 2015, p. 131). Therefore, not only do bodies navigate the world through embodied experiences, bodies also experience other bodies in an embodied manner. Although in its infancy, the study of carnal hermeneutics has shown promising directions for the study of embodied intersubjectivity.

**The Interconnected Body and Theology**

Thus far, researchers focused on the body and philosophers described interrelated bodies, caregiving ethics, and health science research. The final subsections include a brief review of the theological literature, specifically of four key theologians who explore relationships between caregivers and people with disabilities.

discussed intersubjectivity; however, they discussed living with and caring for people with developmental disabilities, thereby providing insights about how people’s experiences who cared for one another could become complicated.

In 1964, after a distressing visit to an institution for people with developmental disabilities, Vanier invited three men with disabilities to live with him (as cited in Spink, 2005). Spink (2005) stated,

This naïve but irreversible step was one born, by his own account, of a desire to “be good” and “do good” to people with disabilities. He had no idea at that time that those people would “do good” to him. (p. 1)

Vanier’s (2008) decision to invite the men into his home and life derived from his Christian faith, especially his commitment to the Beatitudes (Matthew 5: 3-12), the Biblical passage emphasizing blessings for society’s most vulnerable.

Vanier’s (2008) decision to share his life with people with disabilities led to the formation of L’Arche. L’Arche is a global, Roman Catholic initiative where people with disabilities live in communities with individuals who do not have disabilities (Nouwen, 1997; Spink, 2005; Vanier, 2008, 2012, 2014). Within L’Arche homes, people are not labeled as caregivers and care-recipients or staff and clients; rather, in L’Arche homes, all members of the community enter relationships of mutual caring where all bring unique gifts and abilities to the relationship (Vanier, 2008). The core belief of L’Arche is that people depend on one another and God (Nouwen, 2011; Spink, 2005; Vanier, 2008, 2012). To emphasise the dependency of people with disabilities ignores that all humans have needs that require the support of others. Similarly, the philosophy of L’Arche affirms that all people bring unique strengths and gifts to relationships.
Nouwen (1997, 2011) was an ordained Catholic priest who served as the spiritual advisor and chaplain for a Toronto area L’Arche home during the last decade of his life. Nouwen (1997, 2011) wrote several books on caregiving due to his work with L’Arche. In particular, Nouwen (1997) wrote about his relationship with a young man, Adam, for whom he provided daily care. Nouwen (1997) admitted that he originally did not wish to be responsible for Adam’s morning care. Adam had significant disabilities and required much support. Nouwen (1997) worried that Adam’s needs outstripped his ability to care. As his relationship with Adam grew, Nouwen (1997) admitted that he treasured his time with Adam and viewed this relationship as both egalitarian and spiritual. Nouwen (1997) began to see Adam as his spiritual guide, teaching him important lessons about community, faith, God, and relationships.

Of relevance to the conversation of intersubjectivity was Vanier (2008, 2012) and Nouwen’s (1997) emphasis on interdependence and a blurring of boundaries between caregiver and care-recipient. Nouwen (1997, 2011) described an interconnected relationship between he and Adam. Because Adam was nonverbal, Nouwen (1997) had to respond to Adam without clear verbal direction; thus, Nouwen learned to sense Adam’s needs and wants. However, Nouwen (1997) also shared that he was surprised by Adam’s ability to respond to his behaviour. For example, when Nouwen (1997) rushed Adam’s morning routine, Adam would protest by having a seizure. As the relationship between Adam and Nouwen (1997) grew, boundaries between carer and cared-for became blurred. Nouwen (1997) wrote the following:

My daily time with him had created a bond that was much deeper than I had originally realized. Adam was the one who was helping me to become rooted not just in Daybreak but in my own self. My closeness to him and to his body was bringing me closer to myself and to my own body. (p. 49)
Although both Nouwen (1997, 2011) and Vanier (2008, 2012) failed to address intersubjectivity, they emphasised the deep interconnection that might emerge within caring relationships. The philosophy of L’Arche affirmed that people are their most human selves only when they enter mutually interdependent and vulnerable relationships.

John Swinton (1957-). Swinton (2000a, 2000b) is a Scottish theologian who discusses care and disability regarding mental health challenges and dementia. Swinton (2000a, 2000b) advocated that caregivers should offer non-anxious presence with those who suffered; therefore, caregivers would enter the chaos and pain of another. Interconnected relationships often happened spontaneously, even taking the caregiver by surprise as in Nouwen’s (1997) story. Conversely, Swinton (2000a, 2000b) advocated for friendships, where a person would choose to enter a relationship with someone who might face stigma, and in Christ-like solidarity, this friend would absorb the other’s chaos.

Swinton (2000a) explored the interconnected nature of human relationships. Drawing on the notion of perichoresis, the interconnected nature of the Holy Trinity of God, Christ, and Spirit, Swinton (2000a) argued that human beings, as imago Dei or the image of God, were designed to be interconnected relational beings.

Stanley Hauerwas (1940-). Hauerwas (1977) is an American theologian who discusses caregiving and disability, drawing on the theology of Vanier (2008) and L’Arche. Hauerwas and Vanier (2008) coauthored Living gently in a violent world: The prophetic witness of weakness. Hauerwas (1977) considered the nature of human interconnection through the notion of shared narrative. Hauerwas (1977) argued that people were formed by their individual, communal, and divine stories. People with profound intellectual disabilities, who may not be able to articulate their stories or need assistance living out their stories, embody narratives within the embrace of
Christian communities. These Christian communities who embrace people with disabilities should appreciate the diversity of God’s creation and live Christian lives in accordance to the inclusive life of Christ (Hauerwas, 1986, 1990). By entering Christian friendships with all people, including people who cannot tell their stories, Christian communities embody communal, interconnected narratives where voices and experiences comeingle.

**Summary: Themes Emerging From the Literature**

I explored the topic of embodied interconnection by reviewing two distinct bodies of literature. The caregiving literature indicated that mothers raising children with disabilities often faced significant responsibilities that made them as vulnerable as their children with disabilities. Researchers stated that mothers were often overwhelmed, isolated, and struggle with mental health challenges, such as depression. Caregiving ethicists suggested that caregiving relationships, by virtue of close connections, might involve interconnected relationships between caregiver and care-recipient. Despite this suggestion, few studies of the lived experiences of interconnection between mothers and their children with disabilities have been completed.

A review of the literature indicated bodies were viewed as porous and deeply relational by ancient communities, as well as early Christians. A division between body and mind, as well as bodies, became entrenched in the Western worldview following the influential work of Descartes (trans. 1998) in the 17th century. This dualistic worldview has informed Western philosophy, science, and medicine ever since. Contemporary philosophers challenged a dualistic view of the body. Emerging postmodern and feminist writers defined bodies as porous, complex, interconnected, and deeply relational, thereby providing support for a study exploring the lived experiences of interconnection.
Chapter 3: Research Design and Methodology

Research Question

The purpose of this phenomenological study was to explore the following research question: What are the intercorporeal experiences of mothers raising developmentally delayed children? For this research project, I did not define developmental disability nor communication challenge. I asked interested mothers of children of any age whether their children’s developmental and communication challenges led them to rely on their maternal-child interconnections to discern their children’s needs and wants. I invited mothers who responded affirmatively to this statement to participate in the study.

Research Design

I used a qualitative, phenomenological research design (Creswell, 2013; Smith, Flowers, & Larkin, 2012, Van Manen 1990, 2014) for this study. The following subsections contain details about this design.

Phenomenological research. I employed a phenomenological research design. Creswell (2013) defined a phenomenological study as a method of inquiry where researchers explored the common meaning emerging from shared lived experiences among a group of individuals. Van Manen (1990) asserted that the “lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence” (p. 36). For example, a phenomenological researcher might explore the shared experience of grief, heart surgery, or job loss among a group of research participants to determine the shared essences of the phenomenon.

Phenomenological researchers focus on human beings as sense-making creatures, they link experience with meaning (Creswell, 2013; Moustakas, 1994; Smith et al., 2009; Swinton &
Mowat, 2006; Van Manen, 1990, 2014). Phenomenology is an interpretive endeavor (Smith et al., 2009; Swinton & Mowat, 2006; Van Manen, 1990, 2014). Phenomenological researchers focus on the meanings that people connect to their lived experiences. Phenomenologists “want to know in detail what the experience for this person is like, what sense this particular person is making of what is happening to them” (Smith et al., 2009, p. 2). Phenomenologists engage a double hermeneutic, where the researcher interprets the sense-making journey of the participants (Smith et al., 2009).

**Suitability of phenomenological research design.** Phenomenological researchers focus on the lived experiences and meanings that emerge from such experiences. A significant challenge for maternal caregivers is that their experiences of caregiving can occur behind closed doors, thereby minimizing opportunities to share their stories. Caregiving is taken-for-granted work usually performed by women (Freitag, 2018; Harrington, 1999; Held, 2006; Kittay, 1999; Landsman, 2009; Noddings, 2003; Ruddick, 1995). Despite research of caregivers indicating stories of sacrifice, hardship, and loss there might be implicit and explicit pressure on caregivers to share less threatening narratives, such as those that emphasise their devotion, love, support, and learning (Frank, 2013). This tendency to view caregiving as a journey of profound meaning and dedication is perpetuated by mainstream published stories of care that often emphasise spiritual growth, learning, and redemption (e.g., Johannesen, 2011; Langston, 2009; Nouwen, 1997; Schwartz, 2006; Vanier, 2008), while minimizing the isolation, exhaustion, and demands associated with maternal care.

Freitag (2018) argued that maternal care often resembled a chaos narrative. Because chaos narratives are threatening to those outside the narrative, these are often actively muted, and the stories are not heard (Frank, 2013). Frank (2013) described three illness narratives. A
restitution narrative describes stories where a cure is available, and a person gets well. A quest narrative refers to a story where, in the absence of a cure, closure is achieved through spiritual growth or personal redemption. With few exceptions, published caregiving stories are usually quest narratives. Finally, a chaos narrative refers to a story that lacks coherence, trajectory, or a tidy ending. A chaos narrative is a story of loss, pain, disempowerment, confusion, and loneliness; the story is often absent of meaning. Chaos narratives exacerbate feelings of powerlessness in the listener; therefore, chaos narratives are threatening and muted by society.

The greatest challenge for people living in chaos is to be heard.

Phenomenological research refers to research that values experience and seeks to hear stories of experiences. This method provides rich opportunities for participants to have their stories heard and valued. Because phenomenological researchers value meaning and meaning making, informants have opportunities to mine their experiences for meaning and share those stories with a researcher who will honour their meanings. The experience can be a cathartic experience for overwhelmed caregivers who are more likely to have quest narrative meanings attached to their stories by others.

During this research project mothers shared that excitement to tell their stories; they felt encouraged that their stories, as well as their meaning-making, could be told in an unfiltered way and would be valued by a mother-researcher who “got it”. Further, in situations of chaos meaning can be both elusive and muted, thereby causing suffering (Frank, 2013). The opportunity to reflect and explore meaning in one’s story can be a powerful and cathartic moment (Soelle, 1975). In this study, mothers appreciated the opportunities to explore and discuss their meaning-rich relationships with their children. The mothers appreciated that their
interconnections with their children were valued and understood, rather than viewed with skepticism or suspicion.

During the postanalysis member-check, several mothers identified that sharing their stories had been a meaningful experience. One mother noted that the tentative results “resonated in her soul”. Another mother wondered if the interconnection that mothers experienced with their children exacerbated the often-unexplored emotional work of caregiving. Overall, the mothers involved in the study shared that the opportunity to be heard was empowering. The phenomenological method was the most appropriate strategy for exploring the lived experiences and subsequent meaning-making of interconnected mothers and children living invisible lives with unheard stories.

Experience and meaning: Philosophical foundations of phenomenology. Swinton and Mowat (2006) defined phenomenological hermeneutics as resting at the crossroads between qualitative research methods and philosophical hermeneutics. Phenomenologists could address both epistemological and ontological questions.

As a philosophical tradition, phenomenology began with Husserl (trans. 2013) in the late 1800s; philosophers then studied the interrelationships between experiences and meanings (Kaufer & Chemero, 2015). Husserl (1913/2017) asserted that actions and experiences were meaningless until these imposed on rational beings who attached meanings to those experiences. Meanings emerged as experiences were integrated within personal narratives of past, present, or future events. Husserl (1913/2017) defined such meaning making as a conscious act as well as a process that allowed individuals to make sense of their experiences, thereby communicating this meaning-making to their broader communities. Husserl (1913/2017) stated a rigorously
descriptive and intentional exploration of experience would provide opportunities to show the
essence of experiences previously undiscovered.

Dilthey (1985), a hermeneutic philosopher of the late 1800s and early 1900s, emphasised
the contextual nature of experience and meaning making. Dilthey argued experience could not
exist in isolation, but rather was viewed through the lens of past memories or an anticipated
future. Dilthey (1985) stated, “Experience is a temporal flow in which every state changes
before it is clearly objectified because the subsequent moment always builds on the previous one
and each is past before it is grasped” (p. 150). Thus, all experiences are remembered moments
subsequently interpreted. In its original form, experience is prereflective, and meaning making
ensues after.

Heidegger (trans. 2013) continued the study of meaning and experience. Like Dilthey
(1985), Heidegger (trans. 2013) was committed to the importance of context. According to
Heidegger (trans. 2013), humans were thrown into an environment where they proceeded to
engage a world that was infused with meaning. Therefore, experience was infused with meaning
because self-aware beings faced navigating meaning-rich environments.

Although Dilthey (1985) argued that meaning-making followed experience, and
Heidegger (trans. 2013) suggested that meaning was present in an environment, Sartre (2007)
argued that beings took a more deliberate hand in meaning-making. In *Existentialism is a
Humanism*, Sartre (2007) asserted that meaning preceded experience. An experience was
infused with meaning before the action even occurred, specifically because the actor selected the
experience accordingly. For example, Sartre argued that a student would receive expected
advice from a mentor because the student chose to solicit advice from that specific mentor. For
Sartre, meaning was not something that was revealed nor found following an action; rather,
meaning was willed, chosen, or imposed on experience with the experience occurring as expected.

A challenge for qualitative researchers and phenomenologists involves navigating a research project with enough wonder, while acknowledging elements of their own lives that they have taken for granted. Therefore, Husserl (1913/2017) proposed the phenomenological method of *epoché* where researchers isolated or bracketed their personal narratives and familiar experiences with a sense of curious naiveté. This allowed the researcher to view the expected and mundane with curiosity essential for revealing previously unappreciated meanings. The practice of bracketing continues as a recommended strategy among researchers employing phenomenological methods, particularly because many researchers engage in projects amid personal communities (Smith et al., 2009). The current research project was no exception. The goal of bracketing involved setting aside all that I knew and expected about the phenomenon of interest, thereby causing new learning and insights to emerge.

**Intersecting Horizons: Personal Connection With Data**

Although Husserl (trans. 2013) advocated bracketing, phenomenological research methods aligned with the naturalist paradigm that acknowledged that objectivity and pure detachment was impossible. Lincoln and Guba (1985) argued that the naturalist paradigm assumed the following: Realities were multiple and constructed; the knower and known were inseparable; experience was shaped by context, and cause and effect were indistinguishable; and inquiry was always value bound. The naturalistic paradigm assumed that all inquiry and all research instruments were value-laden, and objectivity was an illusion. Within the naturalistic paradigm, the value-laden human researcher was the data-gathering instrument of choice. This
means that as the data-gathering instrument I must explore how my interests and values might influence data collection and analysis.

Throughout this research project, I set aside my experiences and values to ensure my informants’ stories informed the results. However, I must acknowledge that as a member of the community of interest, elements of my story might still influence emerging data (Lincoln & Guba, 1985; J. A. Smith et al., 2009; Swinton & Mowat, 2006). Lincoln and Guba (1985) identified several strategies to assist a qualitative researcher in monitoring how their values and story might engage the research process, several of which were engaged during this study.

During active data collection, I maintained a field journal and documented thoughts before and after interviews. During data analysis, I noted moments when an informant’s story might have connected with my own. Journaling during the research process allowed me to consider and explore when my ideas and stories might begin to blur with a participant’s stories. Further, as data analysis approached completion, I reviewed quotes and emerging themes with both the study supervisor and a disinterested peer to ensure emerging themes resonated with the informants’ raw data. Briefly sharing my story for the reader might provide insight into moments when my story intersected with the narratives of the research participants.

I found Gadamer’s (2013) notion of the hermeneutic horizon compelling. Heidegger (trans. 2013) educated Gadamer (2013) concerning philosophy and hermeneutics (Meuller-Vollmer, 1985). Like Heidegger (trans. 2013), Gadamer (2013) believed that experience and meaning making were influenced by context. Gadamer used the image of a horizon to explore the interrelationships between experiences and meanings. One’s horizon referred to a collection of their environments, experiences, traditions, histories, and understandings. A horizon could be narrow, expanded, renewed, and imagined. Horizons were never static but shifted to

Following Gadamer (2013), I could not erase or bracket my horizon and fully transpose myself into another’s horizon. My horizon always moves with me, infusing my understanding of another’s horizon. As Gadamer asserted, when imagining walking in another’s shoes, I could not help but bring my own shoes along. When sharing the results of this study, I honoured the stories of the study informants to the greatest extent possible. In sharing my story and personal connection with the research question, I identified those moments when mutual horizons between researcher and participant might meet and overlap.

I am the mother of three sons, ages 18, 20, and 22 years. My 20-year-old son experienced prolonged asphyxiation at birth, resulting in serious brain trauma. The result is that my son, Matthew, lives with profound intellectual and physical disabilities. He is also considered medically fragile and technologically dependent. Medically fragile means that his health status can deteriorate rapidly, thereby resulting in serious and/or life-threatening complications. Technologically dependent (see Rosenbaum, 2008) means that Matthew requires a form of technology to sustain a typical, bodily function; in his case, he requires a feeding tube.

Matthew is nonverbal and has been diagnosed with a profound intellectual impairment. Despite this diagnosis, he responds with enthusiasm and joy to familiar faces, activities, and routines. All assessments indicate that receptive language, in a formal sense, is either limited or, more likely, absent. He does not respond to simple commands or requests and does not appear to understand sophisticated or abstract concepts. For example, he would not understand that I am his mother. He does not use augmentative communication or assistive communication devices in a meaningful way, and it is unclear if nonverbal responses, such as reaching for a toy, are
intentional or random. Communication is limited to nonverbal cues, such as smiling in response to an enjoyed cartoon or activity like blowing bubbles.

As an occupational therapy student in the late 1980s, I remember professors describing the “enmeshment” often observed between mothers and their children with disabilities. The professors indicated that this interconnection was troubling because it led to a blurring of boundaries between mother and child. In the medical environment that dominated health care in the 1980s, a relationship that challenged the limits of individual bodies was problematic. As a young student with little life experience beyond the classroom, I accepted this wisdom without question. Most mothers I met on clinical placement demonstrated strong connections with and investments in their children with complex disabilities. One supervisor cautioned that this perceived overlapping of identities and interests bolstered the identity, self-esteem, and worth of an overly involved mother with little advantage for the child.

I feel pained to write the above paragraph now. As a student barely in my 20s, I knew so little about caring for someone with complex disabilities whose health would rely on my rapid and accurate ability to interpret and speak to their body and experiences. Nine years after completing my undergraduate degree in occupational therapy, I gave birth to Matthew. As I began to navigate the world of childhood disability as a mother rather than a professional, I found that troubling forms of extreme mother-child enmeshment existed, but the interconnection that I had with Matthew was a powerful source of information. I could use this information to provide the best possible life for my son who could not communicate his wants and needs.

As I began to reflect on my experiences with Matthew, I believed that this blurring of boundaries between mother and son was not a prop for my self-esteem or the sign of a hyper-vigilant “mama-bear,” as my undergraduate supervisor might have suggested, but it was an
inevitable part of my journey mothering Matthew. Although health care stories, such as my opening vignette, offer dramatic examples, I can share everyday anecdotes describing our interconnection, such as our shared joy during sunny walks or when watching a local hockey game. Similarly, I can share stories of when Matthew’s distress was so great that I vicariously entered his pain.

Matthew and I are connected in a manner that I do not share with my two typically developing sons, not to diminish my relationship with Matthew’s brothers. My interconnection with Matthew is unique and responsive to his disabilities and communication challenges. I wanted to explore whether my experiences were unique or were shared by other mothers parenting children who struggled to communicate.

**Participants/Informants**

Following approval by the Research Ethics Boards (REB) at Wilfrid Laurier University (see Appendix A), I commenced active recruitment of informants and employed a snowball sample of convenience. Leaders of Waterloo Region Family Network, Sunbeam Centre, Bridges to Belonging – Waterloo, and CanChild assisted with recruitment efforts by sharing the research poster (see Appendix D), letter of information (see Appendix B), and informed consent (see Appendix C) through social media sites, newsletters, and personal connection. I shared the research poster on Facebook and invited friends to share the information. Mothers of children who had both a developmental disability and a communication challenge (nonverbal or limited verbal skills) were invited to participate in semistructured interviews of approximately 60 to 90 minutes in length at a location of their choosing.

I obtained ethical approval to allow for telephone interviews with mothers who lived beyond Southwestern Ontario. The opportunity to complete interviews by telephone not only
allowed for the participation of mothers who lived beyond the region but, in the case of extreme caregiving, also provided opportunities for the participation of mothers whose caregiving demands allowed limited opportunities to leave the home.

I interviewed 12 mothers using a semistructured interview guide (see Appendix E). Nine face-to-face and three telephone interviews were completed. Of the 12 mothers, nine were married, and three were either divorced or separated. Eight mothers lived in the region of Kitchener-Waterloo (KW). Two mothers lived outside KW but within Ontario, and the remaining two mothers lived outside Ontario. Although Kitchener-Waterloo was a diverse, multi-cultural community, this sample was homogenous with all members of the dominant culture.

Most mothers ($n = 8$) parented adult children between the ages of 22 and 42. Four mothers were parenting children under the age of 19 (ages 4, 4, 7, and 15). Three mothers noted that their children with special needs was an only child, while the remaining nine had at least one sibling. Ten women were the biological mothers of their children. Two mothers adopted their children, one at the age of 3 and the other at the age of 4. All the children had a formal diagnosis of developmental delay. Developmental diagnoses included autism ($n = 4$), Down’s syndrome ($n = 1$), and global developmental delay subsequent to a chromosomal deletion or abnormality other than Down syndrome ($n = 2$). One child had a dual diagnosis of both Down syndrome and autism. Five children were diagnosed with global developmental delay (GDD) following birth trauma or severe childhood illness/brain trauma. One child had a diagnosis of GDD of unknown origin. Many participants’ children had multiple diagnoses in addition to developmental disabilities, including cardiovascular disorders, cerebral palsy, and seizure disorder/epilepsy.
Five of the children were nonverbal, and the remaining seven had limited verbal abilities. Speech patterns and fluency varied widely among the verbal children. Three of the four children under the age of 18 were verbal, but their mothers reported significantly delayed verbal skills when compared to typically developing children. For example, the mothers described their children’s sentences as limited to a few words describing concrete objects, garbled speech, and/or limited to stereotypical speech patterns, such as repetitive statements (“happy day, happy day”). Many mothers of verbal children noted that even their children’s father could not understand their children’s communication. Of the four adults who were verbal, two had restricted verbal skills limited to echolalia (echoing spoken words); repetitive speech patterns (“car in garage, car in garage”); or simple, concrete two to three word sentences (“bad thread”, describing a loose thread on their clothing). Two mothers shared that their adult children spoke in complete sentences but could not express or initiate complex, abstract, or emotion-based statements. For example, one mother noted that although her adult child could speak in sentences, she or he could not initiate ideas or respond with clear direction to specific requests. If asked a question, the child would respond with “that is a wonderful idea”, regardless of the suggestion. All mothers of verbal children identified with the study theme of maternal-child interconnection as the foundation for understanding their children’s wants and needs, even though their children had some verbal abilities.

Data Collection

Following a review of the letter of information (see Appendix B) and obtaining informed consents (see Appendix C), all mothers participated in digitally recorded semistructured interviews (see Appendix E) by exploring their sense of interconnection with their children. The same semistructured interviews were used for all interviews, though I explored divergences as
appropriate. All interviews were between 60 to 90 minutes in length. All interviews were digitally recorded and transcribed by a transcription service familiar with academic transcription. After receipt of the transcribed interviews, all documents were reviewed, and all confidential and potentially identifying data were removed or altered to protect the privacy of the participants. Sanitized documents were stored on my password-protected computer, and any documents with personal information, such as informed consent forms, were stored in a locked cabinet.

Data Analysis

Swinton and Mowat (2006) noted, “Data analysis is the process of bringing order, structure, and meaning to the complicated mass of qualitative data that the researcher generates during the research process” (p. 57). In qualitative research, data analysis is an ongoing process that begins with data collection (Smith et al., 2009; Swinton & Mowat, 2006). I heard stories during the interviews and reflected on the participants’ stories following meetings and when completing fields notes or typing and sanitising textual data. Finally, once the interviews were transcribed and edited for privacy, I began formal analysis by repetitively reading the text to isolate words, “chunks”, descriptive categories, and resonant themes.

Qualitative analysis methods often take a hybrid approach; however, I utilized Van Manen’s (1990) thematic analysis to categorize and interpret data. Van Manen (1990, 2014) described a method of analysis that involved researchers studying textual data with three approaches: a wholistic approach, a selective reading approach, and a detailed line-by-line approach. A wholistic approach involved one reviewing the text in its broader context to gain essential meanings about a phenomenon or experience. Selective and line-by-line reading of a text narrowed the focus of analysis to the concentrated study of particular words, phrases, sentences, and word clusters (Van Manen, 1990). I alternated between these analytic approaches
to uncover what a word, phrase, sentence, or larger “chunk” of textual data revealed about the fundamental essence of described experiences or phenomenon.

Once all interviews were completed and transcribed into textual format, I reread data and conducted a coding process. The interviews were initially read in entirety to isolate key themes about experiences of interconnection. As the analysis became more focused, words, sentences, and themes describing experiences of maternal-child interconnection were isolated. I highlighted information chunks about the child, family, communication styles, or any interactions between the mother and professionals.

I transferred these chunks of data to a Word document. Once I read all interviews and analysed these several times, I printed a collection of quotes. I labeled all quotes with an informant number. I cut the Word document into strips yielding a vast collection of individual quotes and sentences. I organized these quotes on a table in my home, and these were grouped and regrouped until clear themes emerged. I reviewed these themes with the research supervisor, a disinterested peer, and the informants.

As part of data analysis, I completed a member check through email (Appendix F). Member checking is considered a crucial technique when establishing credibility. Emerging themes are shared with study informants who provide feedback to the researcher (Lincoln & Guba, 1985). I aimed to ensure that themes accurately represented participants’ lived experiences. Following data analysis and once themes were identified, a 2-page summary of research themes (see Appendix F) was shared with the informants via email. I invited participants to respond and provide feedback either by email or scheduled phone call.

Six of the 12 mothers provided feedback during the member check process. The six mothers all indicated that the study affirmed their experiences, and they appreciated the
opportunity to share their stories and have their unique knowledge of their children honoured. One mother valued having her “knowing” understood. Another mother indicated that she “saw herself all over” the results. A third mother indicated that the study “captured my experiences very well”. The responses of these six mothers indicated that the emerging themes showed the experiences of the mothers involved in this study.

Ethical Considerations

The community of mothers raising children with complex disabilities was small. This issue was both an ethical liability, as well as a research strength. Mothers expressed interest and motivation to share their stories with a peer who they trusted to honour and value their voices. Many mothers in the community were disappointed that I could not interview mothers with whom I had a personal connection. I had to seek a revision by the Wilfrid Laurier University REB to allow several interested mothers to tell their stories. However, having a small sample raised concerns about privacy; therefore, I took care to ensure confidentiality remained assured and sustained.

Similarly, phenomenologists focus on meaning-making on behalf of the research participant (Swinton & Mowat, 2006; Van Manen 1990, 2014). Thus, I must honour silences and moments when the participant considered the essence of her experience. I refrained from initiating my own meaning making during interviews and deferred analysis until after the mother had the opportunity to mine her own experiences for meaning.

Trustworthiness

Conclusions emerging from research projects are assessed based on criteria appropriate to the paradigm within which the question was asked. For example, within the scientific method, conclusions are assessed based on whether these are truthful, applicable, consistent, and neutral
(see Lincoln & Guba, 1985). These qualities are demonstrated through rigorous methods that evaluated the validity, measurability, reliability, reproducibility, and objectivity of the research methods, data collection, analysis, and emergent conclusions (Lincoln & Guba, 1985). Quantitative researchers aim to apply results to a general population (DePoy & Gitlin, 1998).

Researchers of the naturalistic paradigm assess trustworthiness differently. Lincoln and Guba (1985) advocated for the following four criteria to assess the rigour of qualitative work: credibility, confirmability, dependability, and transferability. Credibility acknowledges that in qualitative work truth is subjective; therefore, credibility means that informants’ experiences are accurately represented by the results (Creswell, 2013; Lincoln & Guba, 1985). Confirmability indicates that the raw data supports the emergent themes, and an outside researcher will reach similar conclusions when accessing data. Dependability refers to the consistency of a study (i.e., if the study is repeated in a similar context, the results will be similar; Lincoln & Guba, 1985). Finally, transferability involves the goal of ensuring “thick” data are available to allow the study results to be used in other contexts (Lincoln & Guba, 1985). Qualitative findings do not claim to be generalizable.

Based on the four criteria of Lincoln and Guba (1985), Creswell (2013) suggested eight strategies to support trustworthiness. The eight strategies were the following:

1. Prolonged engagement and persistent observation.
2. Triangulation.
3. Peer review or debriefing.
4. Negative case analysis.
5. Clarifying research bias.
6. Member checking.

8. External audits.

I met five of the eight proposed strategies to support trustworthiness based on Creswell (2013). I addressed peer reviews and debriefing by soliciting feedback from both a disinterested peer and study advisor when reviewing raw data and emergent themes. Clarifying researcher bias involved me maintaining a reflective journal to clarify personal engagement with data. Rich, thick description involved me providing detailed quotes and raw data to support emergent conclusions. I used multiple verbatim quotes throughout the discussion of findings. I completed member-checking, considered the hallmark of trustworthiness, by soliciting feedback from informants about the accuracy of emergent themes. For triangulation, I used multiple trustworthiness strategies to arrive at emergent themes.

The three trustworthiness criteria not met included completing negative case analysis, prolonged engagement, and an external audit (see Creswell, 2013). I completed single interviews with the informants over a period of approximately five months. To meet the requirement of prolonged engagement, I would have spent prolonged periods observing and interviewing informants. For negative case analysis, I would have analysed codes or themes that significantly digressed from the emergent themes. The 12 informants told surprisingly similar stories, thus making negative case analysis difficult. For an external audit, I should have involved an external consultant to review all raw data and emergent themes. Within the timeframes of this study, I could not perform such an audit.

**Emergent themes and informant quotes.** To satisfy the requirement of thick description, I used verbatim informant quotes throughout Chapter 4 to provide illustrative textual data showing mothers’ experiences of interconnection. To ensure the integrity of the mothers’
stories, I identified when the shared quotes deviated from the mother’s verbatim words. Words in brackets were not verbatim quotes, but I included these to eliminate potentially identifying information, insert a word or phrase such as when the audio recording was unclear, or provide contextual or clarifying information. I deleted extraneous words and comments, such as “like”, “ummm”, and so on that did not add additional information from quotes; I replaced these with an elipses. Similarly, when a quote was abbreviated or words deleted for any reason, absent words were indicated by an elipses.

In all cases, when the mother referred to her child, I replaced the child’s name with a pseudonym without brackets. Similarly, I modified pronouns that indicated sex, such as his, her, he, and she, in all verbatim quotes to obscure the sex of the child. Modifications to pronouns or the child’s name were not indicated in brackets because such editing was evident to the reader and did not interfere with the overall content or integrity of quotes.

**Translating intercorporeal during interviews.** Intercorporeality and intersubjectivity are academic terms rarely used in everyday language. For ease of communication during interviews the terms intercorporeal and intersubjectivity were replaced with the term interconnection. The *Oxford Dictionary* defined *interconnection* as a shared connection between two or more things or people (“Interconnection”, 2012). Connection was further defined as a relationship that linked people or things, or the act that connected two or more objects or people.

For this study, I defined maternal-child interconnection as the relationship between a mother and child. I wanted to understand better the experiences of interconnection among mothers of children of any age, who could not explicitly identify their wants and needs. A challenge for this study was that mothers often attempted to describe a relationship that happened beyond spoken language by using verbal communication.
Demographics

Before identifying the emerging themes among the 12 mothers, I provide a brief introduction to each of the 12 mother-child dyads participating in the study. All mothers participating in the study self-identified as parents of children who lived with both developmental disabilities and communication challenges that interfered with their children’s abilities to communicate their wants and needs effectively. Over half of the mothers parented children with some verbal ability, but they still strongly identified with the research question of interconnection. Although most mothers received some assistance caring for their child, all mothers involved in this study were primary caregivers, decision-makers, and care-coordinators for their children. Except for one adult child who had a shared-care arrangement with a local group home, all children lived at home with their mothers or both parents. Over two-thirds of the mothers ($n = 8$) parented adult children. Five children were in their late 20s, two adult children were in their 30s, and one adult child was in early 40s; therefore, the mothers reflected on and shared decades of wisdom and experiences.

To protect the privacy of all participants, as well as their families, I omitted or altered all identifying information, including names, locations, hospitals, and diagnoses. I replaced all names with pseudonyms. For the mothers, I selected strong female characters from my favourite childhood novels who did not resemble any cultural characteristics, religions, ages, and places of residence to the mother named.

The mothers’ children’s names were selected from my son’s favourite Disney movies, and these similarly did not resemble the children described. Chosen names for the child included an animal’s name, a snowperson’s name, or the name of a mythical creature; for example, Blaze was the name of a bumblebee, Nemo a fish, Koda and Winnie were both bears, and Olaf was a
snowperson. All children’s names were intended to be gender-neutral\(^2\). Further, when referring to children throughout the chapter, I used gender-neutral pronouns (they, s/he) or the child’s pseudonym to protect the informants’ privacy by obscuring children’s genders. Because all children involved in the study had a developmental disability (DD), only diagnoses in addition to the DD were identified.

**Anne Shirley, mother of Winnie.** Anne was a stay-at-home mother of two school-aged children, both diagnosed with a DD. However, for the interview, she described her relationship with her younger child, Winnie. According to Anne, Winnie enjoyed attending school and recently started using single words and brief sentences to communicate after being nonverbal for the first several years of their life. Anne described her family life in the following way:

> So, we’ve been pretty steady for the last seven years. (My partner) is Winnie’s father and basically, it’s just us living at the home. We’re pretty young as well … Basically … we’re a nice little family, it’s just us. The structure is, I would say, pretty normal. [My partner works] nights, so it’s mostly me and my kids throughout the day.

**Lizzie Bennet, mother of Koda.** Lizzie, like Anne, had two school-aged children with DDs, though Lizzie identified that her older child’s condition interfered less with daily living. Lizzie worked part-time from home and lived with her husband and father of both children. For the interview, Lizzie shared her story of parenting Koda, her younger child. Koda was verbal. Of all the children described during the study, Koda was described as the most verbal. Koda’s verbal communication was usually limited to concrete ideas. Lizzie shared that Koda often spoke in fragmented and “codified” sentences that were unclear. Even Koda’s involved father

\(^2\) Olaf is a masculine name. Within the context of Matthew’s favourite Disney movie, Olaf was a snowperson. For the purposes of this study, Olaf is meant to be androgynous.
struggled to understand Koda’s speech and respond to Koda’s needs. Lizzie described her family life as the following:

We are a family of four. My husband and I have two kids, [our older child] is nine, and Koda is seven. [Our older child] was actually recently diagnosed [with a DD], as well, at the age of eight. But, Koda was diagnosed when in preschool. We’re both—[my husband] and I are both highly educated, avid readers.

Nancy Drew, mother of Nemo. Nancy was the single, retired mother of her adult child, Nemo. Nancy shared that Nemo enjoyed attending day programs and participating in art classes. Like Koda, Nemo could express concrete ideas with simple, verbal sentences. As Nancy described, Nemo could not verbally articulate complex needs, communicate emotions, or understand sophisticated or abstract ideas. Nancy described family life as the following:

Basically, it’s just Nemo and I. I’m 61 now, so I’ve been at this for a really [long] time. It feels like forever, since s/he was born. I had problems in my pregnancy so I kind of knew that there was going to be some problems. It started from Day 1. I’m divorced. I’ve been divorced since forever and so it’s just me and [Nemo] of course.

Heidi, mother of Willow. Heidi was the single, employed mother of teenager Willow. Willow did not speak; however, s/he sometimes could communicate basic needs by using forms of nonverbal communication. For example, Heidi described that Willow could take an individual by the hand to the fridge if she or he was hungry. Heidi shared that Willow loved specific television programs and was recently thrilled to meet a favourite television character. Heidi described life with Willow in the following manner:

Willow is oh, 15 and a half, s/he will be sixteen in January. Willow is nonverbal … I’m divorced …. Willow loves to swim, watch [their favourite TV show], very social, s/he
wants to be the centre of attention, really doesn’t like being ignored, very communicative physically.

**Jo March, mother of Jessie.** Jo was the stay-at-home mother of school-aged Jessie. According to Jo, until very recently, Jessie had been nonverbal. Following Jessie’s participation in school and therapy programming, they recently began using single words to communicate, though Jo reported that significant communication challenges remained. Like Lizzie and Koda’s story, Jo shared that despite some verbal abilities, Jessie’s involved father struggled to understand his child’s needs and requests. Jessie’s verbal skills were limited to a handful of single words. Jo shared that Jessie employed a range of nonverbal and verbal skills to communicate their needs:

So, my [child] is almost four … and s/he just started school at [our local children’s treatment centre] this year, which is great…we just recently got a diagnosis of Global Development Delay and there’s a chromosome deletion so we’re waiting to see a geneticist and … s/he’s this happy, loving, full of energy bouncing off the walls …. And s/he’s not really verbal, s/he’s starting to get a few words, so that’s been really exciting, but quite delayed in a lot of areas as well.

**Elpheba, mother of Remy.** Elpheba was the mother of two adult children. Elpheba’s younger child, Remy, lived part time with the parents and part time in a nearby group home. Remy had been a typically developing child until experiencing a significant brain trauma during early childhood. In addition to a developmental delay, Remy had complex seizure activity that required ongoing medical management, as well as numerous medications. Elpheba described Remy as verbal, but they engaged in highly restricted, limited, repetitive speech patterns that might only peripherally express an idea. For example, if Remy was excited about being at home,
Remy might repetitively say “car in garage, car in garage”. Remy described her home life in the following way:

I have two [children]; my eldest is 24, and s/he is graduated from university and now works at a job and s/he's really doing well, and s/he no longer lives at home. Then my second [child] Remy, who is my high-needs [child], s/he is 22 and s/he is in a situation between us and a group home, shared care.

Remy’s diagnosis really is severe brain injury. Like when all is said and done, it's severe brain injury … Remy has grand mal seizures so s/he's on lots of meds for that. And then s/he also has lots of emotional and behavioural problems, because with … any kind of brain trauma, you get these very bad mood swings. So, we had a difficult time, even with their education, because people would think oh this is behaviour and it's not behaviour. So, s/he can get rather aggressive to very, very emotional and teary, to very, very, happy—all very quickly.

**Lucy Pevensie, mother of Robin.** Lucy was the adoptive mother of Robin, as well as the biological mother of Robin’s two older siblings. Robin’s mother, Lucy, was married and worked outside of the home in the social services sector. Lucy, along with her husband, were raising two children when they learned of Robin, a young child with severe disabilities who needed a “forever home”. Lucy and her husband adopted Robin at approximately the age of 3. Robin had lived in foster care for much of their early life. Lucy described Robin as an active, social, artistic young adult who enjoyed spending time outdoors and painting. Robin was nonverbal, as explained in the following narrative:

(M)y husband and I have been married for 36 years, …. we have two (children) born to us, (elder child) and (our younger child) … Robin we adopted when s/he was three …
When we started going through the process to meet Robin … we were not looking to adopt, and we were not looking to adopt anyone other than Robin …. S/he was two years old and Children’s Aid had already said, you know, hard to place, global—the MR word, I don’t say that anymore and I don’t have to, it’s not a medical term, but that was our presentation to Robin.

So today, Robin is a determined young [person] to brave the world, s/he’s kind of sick of mom and dad …. So [Robin] loves spending time with their support [worker], loves, loves, loves to be downtown. S/he’s a beautiful artist, s/he started painting I think about five years ago.

**Ramona Quimby, mother of Fawn.** Ramona was an employed mother of two adult children, both with exceptionalities. Ramona remained at home as her children’s primary caregiver until both children were into adulthood; she then returned to work in the social service sector. Fawn was the younger of Ramona’s two children. In addition to a developmental delay, Fawn had significant medical challenges, including complex seizures and cerebral palsy. Fawn spent much of childhood in a hospital due to these complex medical issues. Fawn was nonverbal. Ramona described Fawn as fond of watching sports, playing basketball, and engaging in community outings. Ramona described family life with Fawn as the following:

I’m a mom of two adult [children] …. They both have identified exceptionalities; one, has multiple needs and has since the day s/he was born. First related to health issues and then [those needs] evolved into developmental needs; mental health needs as well as physical needs and communication needs. Fawn is technically considered medically fragile and technologically dependent; however, s/he has improved [since their early childhood years].
Fawn’s cognitive level is very, very hard to understand because there’s not, there really isn’t a lot there, it’s very basic. It’s very basic, but what’s basic is very functional for them and allows them to be able to function and enjoy life, but I think it’s—and there’s probably more going on in there than I give Fawn credit for, or I assume.

**Sue Barton, mother of Nala.** Sue was a mother to two adult children; Nala was the older child. Like Ramona, Sue remained at home parenting and homeschooling both children until they were both young adults; she returned then to work in the social services. As Sue described, Nala lived with complex DDs, including a dual diagnosis of a chromosomal anomaly and autism. Nala lived with physical disabillities due to a childhood injury. Sue described Nala as an introvert who enjoyed quiet times, books, music, art, gardening, and movies shared with one or two special friends. Nala could speak in simple sentences but struggled to communicate complex ideas or emotions. Sue described Nala using a highly codified form of verbal communication, where Nala would use characters and events from favourite stories to communicate ideas.

[The] people in our family. [There is] mom and dad. Mom is me. We have 2 [children] … Nala has challenges and a different kind of life than her (sibling) who is fairly typical …. So, Nala’s life is pretty much from home (and) s/he has a list of labels that are connected to her diagnoses. So, s/he has [a particular] syndrome, and s/he has [a developmental disability], and s/he has a (progressive disorder) that is stable right now. It's called [names] disease and so s/he has … s/he's physically compromised …. I think Nala’s biggest challenge is presented by their autism that gives Nala a different read of almost everything sensory wise and in other ways, but that said I think s/he's pretty happy in
their life and I think s/he … has something to look forward to every day which was our goal for Nala.

**Pippi Longstocking, mother of Olaf.** Pippi was a stay-at-home, married mother of two adult children. Her elder child, Olaf, lived with multiple disabilities, and her younger child was a student. As Pippi shared, Olaf loved the going outdoors, swimming, paraskiing, participating in social activities, and listening to loud rock music. In addition to living with a significant intellectual disability, Olaf experienced complex seizures and had cerebral palsy. Olaf was nonverbal. Pippi described her child as the following:

Olaf had a difficult birth and suffered an ischemic … episode, lack of oxygen, and as a result has significant disabilities. So, s/he has cerebral palsy, s/he has a seizure disorder. I often will say that s/he has a communication disorder and is nonverbal.

Olaf is the type of kid who likes to be engaged. S/he likes to be involved in things. S/he likes to be out and about. S/he loves school. S/he likes being around his peers. S/he doesn't like to sit around, and S/he doesn't like to be ignored …. Olaf definitely communicates their likes and dislikes. Yeah, so anyway, so s/he loves to [engage in outdoor activities], s/he loves to go for [walks].

**Jerusha Abbott, mother of Riley.** Jerusha was the retired mother of adopted, adult child, Riley. At the time of the study, Riley was in their early 40s, making Jerusha and Riley the most veteran mother-child dyad. Like many mothers in this study, Jerusha’s employment experience, when she worked, was in the social services and caregiving sector. Riley experienced brain trauma at a young age and was adopted by their mother as a preschooler. Prior to adoption, like Robin, Riley lived in foster care. Jerusha noted that one of the concerns that motivated her to adopt Riley was that she became aware of conversations about placing Riley in
an institutional care setting. Jerusha shared that these days, Riley enjoyed attending day
program, spending time with the support worker, going for country walks, attending community
outings, and gardening. Riley was nonverbal. Jerusha described her first meeting with Riley as
the following:

So Riley is a chosen child. I was working in [names location] … I ended up doing
community development work in social services and one of the things I did [was]
research on persons with disabilities within the region, …. and I met Riley and s/he went
like this [holds hands up as if embracing] and went up, melted my heart …. Then, they
were going to send her to a large institution in [location]….s/he's nonverbal, disabled …. what do you think would have happened to that young [child]?

Mary Lennox, mother of Blaze. Mary was a retired, married mother of two adult
children. Prior to retirement, Mary worked in the health care sector. Mary’s child, Blaze, was a
typically developing child until experiencing severe brain trauma during childhood. Since that
time, Blaze lived with both a DD and physical challenges.

Blaze lived at home with the parents and enjoyed attending a day program, as well as
spending time with family. Mary described Blaze as able to speak in complete sentences but
unable to initiate ideas or express complex thoughts and emotions. For example, Mary noted
that when discussing wants and needs with Blaze, she must give Blaze a choice of X or Y. Mary
shared that if she were to ask what Blaze might want, s/he could not name a need or want but
could respond to a direct, concrete prompt, such as identifying whether a banana or an apple was
desired for a snack. Hence, Mary shared that she strongly identified with the theme of
interconnection because she constantly drew on her connection with Blaze to identify the correct
questions to ask to elicit helpful information. Mary described Blaze’s journey as the following:
There’s been radical changes because Blaze was diagnosed with [a neurological condition] when s/he was [school aged] so that was a time of significant change. But, the essence of Blaze is still the same.

A year later, [the neurological condition] came back again, they couldn’t do any surgery [at that time]. Blaze was already in a wheelchair and their eyes were crossed because the muscles had gone on them. Blaze was 12-years-old and 56 pounds.

**Summary of Methodology**

I used a phenomenological research method to explore the meaning making among a group of participants who shared common-lived experiences; I studied the interconnected experiences shared by 12 mothers parenting children with DDs. These mothers participated in audiotaped, semistructured interviews, and they shared their personal stories of intersubjectivity. I transcribed the resulting transcripts verbatim and analysed these for emerging themes. In Chapter 4, I explore the emergent themes of the study. The findings show the three overarching themes emerging from data analysis, as well as the corresponding subthemes.
Chapter 4: Findings

Twelve mothers participated in semistructured interviews. I interviewed them to explore the following: research question: What are the intercorporeal experiences of mothers raising developmentally delayed children? In Chapter 4, I provide a detailed review of the themes emerging from the interviews.

The 12 women who participated in this research project each told their own story of parenting 12 unique children with complex needs. Each journey was unique. The stories provided a rich opportunity to understand the experience of maternal-child interconnection and to challenge the Cartesian understanding of the body. However, as true for all qualitative research, the stories shared by the mothers could not be generalized beyond this particular context and not to all mothers parenting children with both DDs and communication challenges (Lincoln & Guba, 1985). This chapter summarises the common themes of maternal-child interconnection.

Informant Quotations

To illustrate the common themes, I used quotes to provide illustrative textual data capturing mothers’ experiences of interconnection. To ensure the integrity of the mothers’ stories, I identified when a quote deviated from the mothers’ words. Words in brackets were not verbatim. Brackets indicated when I eliminated potentially identifying information or inserted a word or phrase when the audio recording was unclear, or a comment required clarification. I used a series of periods to indicate when a quote was abbreviated. For example, I deleted words that did not add to the substance of a quote, such as “like”, “ummm”, and so on. Similarly, if a quote was condensed for any reason, I indicated the occurrence of absent words using the same series of periods.
In all cases, when the mother referred to her child, the child’s name was replaced with a pseudonym. Similarly, I modified all pronouns that indicated sex, such as his, her, he, and she, to obscure the sex of the child. I did not indicate modifications to pronouns or the child’s name in brackets because such editing was evident to the reader and did not interfere with the overall content or integrity of the quote.

**Translating Intercorporeal**

Intercorporeality and intersubjectivity are academic terms rarely used in everyday language. For ease of communication during interviews, I replaced intercorporeal and intersubjectivity with interconnection.

**Themes**

Following coding and analysis of the mothers’ interviews, three overarching themes emerged that indicated the mothers’ experiences of interconnection with their children. Each of the following three themes was divided into subthemes:

1. Maternal-child interconnection:
   1. Can be difficult to describe with words.
   2. Means our boundaries are blurred.
   3. Means I enter my child’s experiences.
   4. Is reciprocal.
   5. Is a mom thing.
   6. Is built upon a foundation of prolonged and committed care.
   7. Is a sacred relationship.

2. Interconnection with my child allows me to speak their language.
   1. Non-verbal children.
2. Verbal children.

3. Maternal-child interconnection: Professionally speaking
   1. I often know when something is wrong.
   2. When our interconnection is ignored, my child’s care suffers.
   3. My child benefits when providers trust my knowing.

**Mother-child interconnection.** I first found the theme of mother-child interconnection. This theme was divided into the following seven subthemes of interconnection: can be difficult to describe with words; means our boundaries are blurred; means we share experiences; is reciprocal; is a mom thing; is built upon a close, ongoing togetherness; and is a sacred relationship.

**Interconnection is difficult to describe with words.** One of the challenges of this project was that the focus of inquiry explored both a relationship and a form of communication, which happened outside verbal and nonverbal language. Yet, I asked mothers to describe this embodied relationship and communication with words. One prospective participant declined to participate in the study after reading the interview questions. She admitted that she was concerned about her ability to describe her interconnected relationship with her child to her satisfaction. Prior to the commencement of the interview, many mothers expressed concerns about their abilities to describe their interconnected relationships with their children. Yet, once invited to share stories about their relationships with their children, the mothers shared rich and descriptive stories.

The 12 mothers who participated in the study used a variety of terms to describe their interrelationships with their children. Common terms to describe the connectedness between mother and child included **knowing, hunches, read, intuition, sense, and attunement.** For
example, when describing her relationship with Nemo, Nancy used the word “intuition” to describe the wordless communication that occurred between her and her child. Nancy shared, “It’s happening beyond (language). It’s intuition. I call it intuition. I just know because I can look at Nemo and say, “You’re getting a migraine, aren’t you?” Sue, mother of Nala, an adult child with limited and codified verbal skills described her sense of interconnection as built on hunches that allowed her to ask focused questions. Sue observed, “I think I have hunches around what might be going on and so I know to ask questions about those things”. Mary admitted that her ability to read her verbal child, Blaze, allowed her to ask questions that defined Blaze’s needs; Blaze could not isolate these needs without prompting or assistance. Mary shared, “So reading Blaze, most people don’t read Blaze, they don’t know how to read …. s/he often doesn’t even think about [their] needs…. s/he often doesn’t communicate those needs”.

Two parents described their relationships with their children as a form of shared energy. Jo described her relationship with Jessie as a form of energy: “[M]y brain would just say we’re energy and so it must just be our energies vibrating off of each other that’s like my belief”. Lucy similarly described her relationship with Robin as a form of shared energy:

We are very deeply connected, and we very much share each other’s energy. So what you need to know about [my child] is Robin has such great anxiety that s/he has to be touching somebody, either their support [worker], their dad right now, or with me, like I can’t even be in another room of the house. So, Robin needs that connection, so we’re sharing energy all the time.

Jo also used the metaphor of a dance to describe the wordless communication that happened with Jessie: “It’s [I]ike dance, because it’s like our everyday life is kind of like the
dance floor and we’re both moving in our own ways but together and I think that’s the best metaphor for Jessie and I.”

Jerusha used emotional attunement to describe her connected relationship with her adopted child, Riley. Jerusha noted that this emotional attunement allowed her to enter her child’s world:

It's emotional attunement. And it's that—so one of the reasons I am a good caregiver … is the fact that I have empathy up the yin yang, right? And so, I do have that ability to go into someone else's world, you know, no matter what.

Mothers told stories or used images to capture their experiences of interconnection with their children. For example, Nancy discussed picking Nemo up following an activity and immediately sensing and knowing Nemo had a disappointing experience:

I have to look at Nemo’s face and realize and just sense that something’s not right. I know. I can tell you. S/he’s been taking this little art program at a day program and the first day went really, really well. S/he was excited and s/he came home and she had drawn a heart and s/he was really excited. When I went to pick her up on Saturday, I pulled up in front of the building, and the minute Nemo came out the door, I knew things didn’t go well …. I could just tell from the way s/he was walking and the way s/he was looking at me that s/he had something to say that wasn’t okay.

Several mothers found that using images allowed them to capture their sense of interconnection with their children. Nancy further described her relationship with Nemo as the intertwined roots of a tree:
The visual that comes up for me [to describe my relationship with Nemo] is simply the roots of a tree …. Every time I look at one of those beautiful visual pictures of trees with roots on them that are all intertwined, that’s how I describe Nemo.

Interviewer: So, the roots of the tree being intertwined. Of one tree or two trees?

Nancy: Just one …. And the roots are joined together. They’re not separate going out, they’re joined together.

Sue, when asked to imagine an image of her interconnection with Nala, she found that her experience of breastfeeding her child best captured her interconnection. As Sue shared, breastfeeding captured the reciprocal and active nature that she believed an interconnected relationship between two bodies implied. For Sue, interconnection was not only an ability to read Nala’s nonverbal behaviour or to know what her child needed but also a relationship of a mutual penetration of one into the other. As Sue shared,

So, the first vision, the first snapshot that comes into my mind [when thinking of an image of interconnection] is breastfeeding Nala, right? Like it … when I think of what that means, the closeness, the connection, the direct …. You know, I mean s/he is an active participant, right? It's not just me. S/he's more active than I am, like s/he's drawing from me, but there's this spiritual piece of that for me that is just so present and so you know … the eye contact, the little hand. I just—that's what comes to mind when I think of how—of my relationship with her.

*Interconnection means our boundaries are blurred.* The image of breastfeeding beautifully captured the idea of a leakiness of boundaries and experiences between two bodies; the one body informed and influenced another. A common theme that emerged among all the mothers was that of blurred boundaries between the mother and child, especially the notion of
entering one another’s experiences. When I considered that pregnancy began with the inhabiting of one body by another, I was not surprised the mothers described a blurring of boundaries with their children that began with their pregnancies. Similarly, adoptive mothers described a mother-child interconnection that began with an anticipated adoption. With typically developing children, people expect a growing sense of independence and separation from the mother. However, among this group of mothers parenting children with ongoing care needs, their sense of interconnection did not dissipate as their children grew older. In some cases, the mother’s interconnection with their children became more pronounced; for example, Sue stated, “I guess when I was pregnant with Nala I … felt a deep connection to whoever this person was”.

Ramona echoed a similar sentiment:

I think because Fawn was in me (during pregnancy), and I still feel like s/he’s right here (pointing to her body) like I literally feel so attached to Fawn all the time. I think there is some kind of very special connection there.

I noted that Fawn was almost 30 years old.

The adoptive mothers in the research study also shared a sense of connection with their anticipated children. Adoptive mother, Lucy, shared that her sense of connection with her adopted child began the minute she viewed Robin’s photograph and made the decision that Robin would be her child. Jerusha, adoptive mother of Riley, shared that her first sense of connection with her child was when she “met them”. However, an interesting addition to Lucy’s story parenting Robin was that Robin would meet their biological mother as a young adult. Lucy believed that Robin not only had a profound connection with her, the mother who raised Robin, but also had an innate sense of connection with their biological mother. When asked to describe
a moment when the sense of interconnection was most pronounced, Robin shared the following story:

I think the most profound one [experience of interconnection] was—I think it happens to some degree a lot, but the most profound one was when [my husband] and I and Robin were going to meet Robin’s biological parents, and here’s a collection of strangers, right, with this—it was like everything else disappeared. So, Robin has a really hard time meeting people and we were worried about what this reunion would look like …. So Robin had a hold of their dad’s arm, like my husband’s arm, and had a hold of my arm so tight I had bruises on my arm, but I’ll show you a photograph, s/he leaned right in—so Robin met their biological mother, (and) within seconds was kissing her cheek …. There was something about her that Robin knew that’s where s/he belonged, right. So, it was Robin wanted the support of us and needed us there, but s/he was needing her.

Although a strong sense of interconnection seemed expected during pregnancy and infancy, when the children’s bodies were embodied within their mothers, mothers in this study described blurred boundaries that extended well into adulthood. For example, Mary, mother of Blaze stated,

So, that’s how strong the connection is between and Blaze and me, and thankfully there are, [we’re] separate but connected. Separate in that I have my own voice and my own person, but I am inhabited by my [child], and s/he is inhabited by me in a very unique way.

Ramona described her relationship with her adult child as the following: “I think I am closer to [my older child], but I think Fawn is a part of me …. Like physically a part of me, still and always will be.”
Although a sense of interconnection appeared expected between mother and young infant, a handful of mothers in this study noted they received feedback suggesting that interconnection between mother and older child or adult was considered troubling. Several participants shared they had been told the blurred borders between themselves and their children was unhealthy or inappropriate, thus causing cause for concern. Nancy, mother of Nemo, stated, “We almost have what I’ve been told is an unhealthy relationship … extended family has accused me of babying her too much, but I think I do it out of survival”. Jerusha, a mother of a child in the 40s, shared that she had been told that her interconnection with Riley was problematic, and she was “still evolving in setting better boundaries”, a comment that suggested that her current boundaries were somehow inappropriate.

Regarding worrying that interconnection was troubling, Mary noted that she worried that the blurred boundaries between her and Blaze threatened her ability to retain an identity separate from her child. She worried that without outside sources to help her establish personal boundaries, she might be overwhelmed by her interconnection with Blaze. Mary found comfort in having a relationship with a typically developing child that allowed her to establish parameters to retain helpful and normalized boundaries. Mary shared, “I am so grateful for [Blaze’s sibling] because, otherwise, the lines between me and Blaze would be so completely blurred and my sense of self would have been, I think, become submerged”.

*Interconnection means that I enter my child’s experiences.* Most mothers shared that interconnection meant that they experienced their children’s worlds through their eyes, even entering their children’s experiences in an almost physical manner. Mary, mother of Blaze described entering her child’s experience of relearning skills during Blaze’s rehabilitation. Mary stated that she was not simply sharing the task of relearning life skills; rather, Mary argued that
during Blaze’s rehabilitation, she physically entered Blaze’s experience, such that she was in Blaze’s body during the movements:

[E]ach time … Blaze has to relearn how to walk, s/he had to relearn how to eat, and I have to do that with Blaze. I’m doing all those things with Blaze, and in some ways I’m in their body. I’m not just with Blaze.

Ramona shared a similar sentiment when describing Fawn’s joy upon seeing snow:

I can actually see them [Fawn’s experiences] through their eyes so, when I see Fawn dancing and so happy about the snow, now I get happy about the snow even though I used to like, not necessarily really like [snow].

Heidi shared that Willow was particularly invested in a specific television show, a television show that Heidi admitted she disliked. Heidi shared the story of Willow attending a community event where the actors of the beloved television signed autographs. Heidi admitted that even though she met famous celebrities in the past, she became overwhelmingly excited when Willow met those beloved television heroes. Heidi marvelled at how unusual that was when she considered her dislike of the television show:

Well, [watching Willow’s reaction] was exciting. It was cool. Cool. This summer meeting the [cast of Willow’s favourite TV show], like as I said, I do not like [this particular show], I’m not a fan of their show. I was literally shaking, every fibre, to see Willow so excited, to see [my child] that excited, I’m like, I’ve met all these [other] movie stars and never have I shook as shaking to see Willow’s excitement.

Like Heidi and Ramona, Pippi and Jo shared stories of entering their children’s joy. Pippi described the exhilaration of experiencing Olaf’s joy regardless of the activity:
[I]t [witnessing my child’s joy] makes you feel so happy yourself, right. Yeah, no, it does—it makes you feel great actually …. you love being in the presence of somebody else who is having so much joy—it just—it does, it warms your heart, it truly does.

Jo echoed a similar thought: “I can feel Jessie’s happiness and see the sparkle”.

Although most mothers shared stories of entering their children’s joy and excitement, a handful of mothers also shared stories of entering their children’s distress. For example, Elpheba shared that connection with Remy, an adult child who lived with serious seizures and disabilities, “takes her down”. She believed her shared sense of Remy’s pain would extend to Remy’s life:

I think I'm so connected to Remy that when I'm with him/her in my house (when s/he’s visiting from his group home) and focused on Remy, s/he's taking me down …. And I think that—and I don't want to sound like an awful person, but I really don't think it (my distress) would end (as long as) s/he remains in this world. Because it's this—I feel so bad about Remy’s quality of life.

Mary shared that she could tell Blaze was becoming ill or distressed through mounting tension in her body. At times, Mary suggested the tension took the form of a premonition; anticipating a shift in her child’s health or well-being. Additionally, Ramona described moments that she would become so overwhelmed by Fawn’s distress that she would attempt to compartmentalize those feelings as a form of self-protection. The need to do so was particularly pronounced when Fawn was ill:

[When Fawn was ill, I would feel sad, very sad. Scared because I didn’t know what was going to happen. I think almost I would say almost numb and not letting and sometimes not letting myself feel and so, I would almost—even though we had bonded—I would
almost try to sort of separate to function. I would compartmentalize things and try not to have that closeness.

*Interconnection is reciprocal.* While sharing their stories, eight mothers emphasised that their personal experiences of interconnection was bidirectional. These mothers not only told stories of experiencing their children’s experiences, they also shared stories describing moments when they were confident that their children were responding to their embodied experiences. For example, Jo stated, “I feel like sometimes Jessie knows even what I’m thinking in the moment”. Lucy noted that when she was away from Robin, neither she nor Robin could sleep: “I think Robin and I are energetically connected, so if I have to go away overnight, I cannot sleep, and neither can Robin, which is horrible”. Heidi identified that Willow would adjust their behaviour if she was upset. “If I’m upset, Willow is more loving”. Jo described her relationship with Jessie as mirror-like, with both responding to the other:

I think she picks up on what I’m going through and feeling. So, if I’m having some internal grumpiness, we do see it in her, and when I’m really happy, she’s really happy. So, it’s a mirror almost in a way.

Nancy described a time when she was diagnosed with a chronic condition. During that time, Nancy believed that Nemo understood that things were different: “I was really trying hard to pretend that everything was normal (when I was ill) and the harder I try to pretend that something is normal, the more s/he seems to pick up that it’s not normal.” Nancy noted that during that time, Nemo’s care had to be supported by a group home, and she could immediately sense when visiting Nemo that things were not going well:

It’s so strong [our connection] that I got quite ill with [a serious illness], and I ended up bedridden for a couple of months and they placed Nemo in a group home. I was back in
[names province] then, and there was no family. I had nobody. I’ve never had any help. So, they had to place Nemo in a group home. It (our connection) was so strong that I even knew that, I would call or show up at the group home on the days that I needed to, [those days] s/he was having a really, really hard time.”

Ramona told a similar story describing when she was in the hospital with a serious illness:

[O]ne time when I was very, very sick in the hospital and Fawn came to visit and s/he was the most gentlest, angelic … normally, [the hospital] would not be an environment that you know s/he’d necessarily [be calm] and so, there was that sense of, s/he knows, s/he knows that right now I have to—it’s not my time. I’m not the attention right now, mom is the attention. Same as when I came home from the hospital it was just like all of a sudden, s/he wasn’t needy, s/he wasn’t—it was just sort of oh, I’m here, and I’m content and was content with everything and I think there was that no, mom’s got enough. I don’t need, I need her, but I don’t need to be the centre of attention, she’s the one that needs to be.

Like Fawn’s or Nemo’s ability to sense their mother’s illnesses, Anne stated that when she was upset or agitated, Winnie responded accordingly: “[A]nd then, s/he’s 10 times worse [if I’m upset]. So, s/he’ll actually act out because of the emotional level of the stress”. Anne explained that Winnie often appeared to not only respond to her mother’s embodied experiences but to others’ as well:

S/he totally reads, s/he reads people, s/he feels you. S/he knows what you’re feeling.

Even if you don’t know, s/he knows. S/he can feel the tension or feel the sadness of the
anger or the happy, whatever it is, they feel and they know and they act… [S]o she feeds off of me as well, and my [other child], and my household, and her father.

**Interconnection is a mom thing.** A striking theme shared by many mothers involved in the study was that this ability to know their children were isolated to the mother. Study participants noted that even involved and loving fathers and husbands often did not share the ability to ‘read’ their child. Ten of the 12 mothers involved in the study told stories that emphasised that their interconnection with their children were isolated to the mother-child relationship. This ability to sense their children’s wants and needs was not replicated, even by involved fathers, and certainly not with people less familiar to the child.

To explain this unique maternal bond, Mary returned to the initial mother-child interconnection of pregnancy. As Mary noted, most children separate from their mothers; for Mary, the interconnection that began in-utero provided the foundation for every post-illness return to mother-child interconnection, as Blaze recovered from a significant neurological injury. This returning to a primal maternal-child interconnection translated to Mary’s increasing ability to act as the interpreter of Blaze’s experiences:

There develops between a willing mother and their baby often this incredibly nonverbal connection. You know they’re uncomfortable because, like, their diaper needs to be changed. You know that cry is that they’re really, really upset and not hungry. You learn those things because of this nonverbal relationship that you have and that when they start to learn to speak that that type of incredibly intense intuitive bond starts to become teased out, right, it’s teased out …. But for Blaze, [because of their disabilities] there were three times [following a neurological event] when s/he went back to the stage of infancy. Three times and I realized it the second time, oh, my goodness, we’re going back there
again, to that absolutely primal place of connecting and *moving in*, in an intuitive like visceral way where I can, you know, with even the slightest movement of her eye, I’m experiencing it and having a sense of what that could mean. And you know, [I’m] never totally on target, but let me tell you, [I’m] a lot closer than anybody else.

Sue similarly captured this maternal knowing as surpassing any other connection in her life, including the one she had with her life partner, Nala’s father:

> I have probably a closer physical relationship with Nala than I do with anybody else in my life including my spouse. So I … know her body so intimately and so when I hug her at night, and I can feel you know, the bulge on one side of her spine, and I can feel—I know where the tense muscles are, and I know where she likes to have a back rub. And I know as soon as I start that she’ll go oh, nice back rub, right? So, she can communicate that to me.

Many mothers shared that their interconnection with their children was not experienced in the same way by any other individual in the children’s lives, including the children’s loving and involved father. Elphaba noted, “My husband does a lot of care for Remy, and even so, Remy still has a different connection with me than s/he does with my husband”. Heidi described a similar experience: “Yeah, it’s just that …. I’ll give Willow’s dad credit …. [but] dad does not have the gut instinct”. Anne summarised the experience succinctly: “As a mum, you know”. Elphaba echoed, “A stranger who doesn't know [my child] can't really connect”.

Even in situations where the child was verbal and had some ability to communicate, more than one mother noted that their husbands could not understand their children. Lizzie discussed the experience.
Koda speaks sentences that are five words long and, you know, all these sorts of things. But, they were in very stereotyped ways, they were in very specific circumstances, and they were primarily to me, even my husband commented at the time that there was a lot of the time that he couldn’t really understand what s/he was saying.

Lizzie admitted the inability to understand his daughter caused her husband some concern:

At the time, especially when Koda was in sort of the pre-school years, he sounded very frustrating [sic] because his [inability to understand Koda] made him feel very isolated from them …. he found that very upsetting for quite a while.

Despite Koda’s more advanced verbal ability, Lizzie noted that she must do extensive work translating her child’s speech and interpreting Koda’s needs and wants, both within the family and beyond. Lizzie’s story indicated how maternal-child interconnection and the ability to read one’s child remained relevant, even when the child had some verbal ability.

[My husband] articulated to me quite a few times, I don’t know how you get what Koda’s saying, because to me, it just sounds like a big mush of words, but I had gotten very used to sort of understanding the way s/he was thinking and knowing what sort of idioms s/he used in their speech. So, I was sort of like, the translator, both within and outside of the family.

Interconnection is built upon a foundation of prolonged and committed care. Mothers of children with significant disabilities are usually the primary caregiver (Burton et al., 2008; Stabile & Allin, 2012). Although some fathers provided care, Statistics Canada (2013) indicated mothers were significantly more likely to provide care. All the mothers involved in this study were their children’s primary caregivers, with most remaining at home full-time for sustained
periods (in some cases, decades). This role of primary caregiver offered a rich environment for mothers to nurture their sense of interconnection. Ten of the 12 participants believed that their contact with and care for their children was the cornerstone of their interconnection. For the mothers in this study, the ability to enter their children’s experience required a history of living with, caring for, and learning from their children. Heidi described the constancy of caring for a special needs child as the following:

I think more of a difference being a special needs mom …. there’s very little Willow can do on their own, whereas a typical child, they’re going to run off and play in the bedroom, well Willow is going to be sitting with me the whole time. So, you kind of, you spend a lot more time with your kid then typical parents do.

Mary shared that because of her role as a constant caregiver, Blaze and Blaze’s experiences defined her:

[What people don’t understand is …. this is not Blaze this is my way of life, this is my way of life. Everything we do, every decision we make, everything, revolves around Blaze. It does not revolve around my needs, or our needs as a couple, it revolves primarily from Blaze and then it goes out from there. That’s why when her sibling said when Blaze’s in the house, Blaze is what’s happening. Well …. for me, it’s not just when Blaze’s in the house, because Blaze’s always in the house in my head.

Nancy summarised the constancy of care as the following: “We’ve been through so much and I mean we’re together all the time. She never, ever, ever leaves my side. Ever”. Jo echoed, “I stay home …. Jessie’s always been with me”. In one situation, the child’s care was sufficiently complex that the family decided to withdraw the child from the public-school system. Sue stated,
Even things like me deciding to stay home … I couldn't imagine not, but I mean that was the only way we could think of to really meet their needs which (is why) we home schooled Nala for a long time.

All mothers provided constant care for their children for a sustained number of years; it was the constancy of this care that grounded their sense of mother-child connection.

Ten mothers identified that sustained care and the resulting ability to enter their children’s lives was so ingrained that experience was taken for granted. Ongoing and attentive care for their children meant that their interconnections with their children were so normalized, they lost awareness of it until asked to describe that sense of connection. Lizzie shared,

[T]hat’s the thing, it [our interconnection] just becomes a part of your day-to-day and you don’t even think about it …. [I’m not aware of my connection] until someone says, like, “How did you know, you know, what Koda was getting at?”

Lizzie shared that her experience of interconnection was “almost unconscious”:

I was stay-at-home and working from home through the whole time [I was caring for Koda]. So, that probably has magnified to a certain extent how much interpretation I was able to do. And it’s probably also part of why a lot of it, I think, feels very sort of almost unconscious, or I don’t know why I can interpret it the way I do, ‘cause it was just, you know, I was around her so much.

For Mary, the decades of caregiving for Blaze meant that her ability to interpret Blaze’s experiences and health status, while not infallible, had evolved to be highly accurate. As she argued, her ability to read her child was not a hunch or guess but a profound *knowing* from years of shared experiences and decision-making. This knowledge derived from stressful crises when an accurate read of Blaze was essential for Blaze’s survival:
It’s [our interconnection] intuitive …. but it’s not without experience and knowledge …. And it all comes in so that when, intuitive is like a higher sense of knowledge, that comes at you so fast, but it’s built on all kinds of factors that … we think of as reasonable, experience, and it’s because it’s not a hunch …. A hunch is a lot of guessing and this is not guessing, this is knowing. Having known Blaze through all these various transitions, it’s having connected to them over and over at an extremely primal level and you do that for survival. And as a mother you know that your kid’s survival depends on you and so it’s not guessing, it’s knowing so well and so repeatedly, and so attentively, that your accuracy rate, is like, it just gets better and better. It’s never infallible but it gets better and better [emphasis added].

*Mother-child interconnection is sacred.* When describing maternal-child connection, most mothers emphasised that this bond was unique to their children. Almost half of the mothers (n = 5) went beyond identifying the bond as “special”, and they stated that their interconnected relationships with their children existed on a spiritual level. For example, Sue stated the following:

I feel like I … there’s kind of a—like the growth in my person because of my connection with Nala. Not the … you know, not the challenges of day-to-day right? But like a deep spiritual peace that’s been moved in me because of who s/he is and because s/he came into my life, like it was profound.

Jo agreed that her connection with her child was spiritual and affirmed that this connection preceded birth; she was chosen to be Jessie’s mother:
I’ve often heard that nonverbal children were, they had terrible relationships with their mothers in past lives, so they come without words for a reason but they come to women and families that can give them what they need and foster that love.

Mary, a woman of deep faith, shared that her journey of caring for Blaze reminded her of the Christian resurrection, of rebirth and rebuilding after profound changes:

[Thinking of life caring for Blaze], I just see a whole bunch of yarn in a heap, you know, and I think that people who do knit who eventually take that and find [the yarn] and put it back into a ball and then make something new out of that. You know, and for me coming from a theological point, it is the story of the resurrection. But, you always go through those incredible dark days and hopefully you get enough practice in life that when it comes to those really difficult times, you still have to go through that darkness. But, there is the sense that there is something on the other side and you have no idea what it is, but there is the other side.

Jerusha noted that her parenting journey with Riley called on her faith in Buddhist practices and mindful living, and she argued that such a spiritual connection with both life and care was counter-cultural, and thus not well-understood: “I certainly have a lot of Buddhism in me and part of it [feeling connected with Riley] is if you're mindful and present, which is not part of our culture”.

**Interconnection with my child allows me to speak their language.** Although I focused on the experiences of interconnections between mothers and children, the link between interconnection and the ability to both communicate with one’s child, as well as understand a child’s unique communication, was a theme. Regardless of their children’s verbal or intellectual ability, all mothers emphasised that their children communicated and could enter and form
relationships. For all mothers, the foundation to understanding their children’s communication was grounded in their connections with their children.

*Nonverbal children.* Five of the 12 mothers parented children who did not speak, did not consistently use augmentative communication devices, and did not employ formal sign language. One child previously communicated with a handful of unique signs when they were young but rarely used these signs as an adult. Two additional children employed a limited repertoire of self-created hand signs to communicate general ideas, such as “I want”. Mothers of nonverbal children shared that their children communicated their needs and wants through primarily nonverbal cues, sometimes only understandable to them. Mothers emphasised that their sense of interconnection with their children helped in ensuring they understood their children.

Even though their children were nonverbal, all mothers in this subgroup were clear that their children communicated and had important things to say to the world. Similarly, all five mothers shared frustration about a world that failed to “hear” their children. When describing their children’s communication, the mothers of the nonverbal children often employed terms commonly used to describe verbal language. For example, the mothers of nonverbal children would say that one needed to learn to “speak” their children’s language or “listen” to what they had to “say”.

*My nonverbal child has something to say.* Contemporary society is a language-based world with interactions often taking the form of written or verbal exchanges. Days are organized and lived out with words. Think for a moment of how a day might unfold without verbal conversation, written documents or books, radios, televisions, e-mails, texts, or the internet. For most people, such a day is beyond their imagination. Individuals who do not speak, do not use
augmentative communication, and who do not understand written or verbal language, often struggle to have their needs and wants understood by society.

Regardless of their children’s verbal abilities, all mothers emphasised that their children had a strong need to communicate and had important things to say. This theme was pronounced among the mothers of nonverbal children. A significant concern among this subgroup of mothers was that society often assumed that their children could not communicate and did not have ideas, feelings, or things that they wished to express to the world. For example, Ramona shared that it was a priority for her to demonstrate that Fawn had feelings and ideas. As captured by Ramona’s use of the word “receptive”, a significant part of amplifying Fawn’s voice and facilitating Fawn’s relationships with others was using her connection to do so:

[I]t was my mission to prove to everybody that Fawn did have feelings, s/he did care, s/he did—s/he could express. Not maybe to the extent that the rest of us can, but there is something there and so, we need to recognize what that is, but you need to be receptive. I think that’s what it was so, once I made myself receptive [to Fawn’s communication], it was … trying to help others be receptive; I made myself very receptive.

A common and vigorously expressed theme among the mothers of nonverbal children was a desire for the broader society to understand and attempt to include their nonverbal children. The mothers stated that an important part of that inclusion involved accepting their children’s form of communication, rather than trying to mould their children’s communication styles to conform to societal expectations or needs. Ramona continued by saying,

If they’re [broader society] open to having a relationship with Fawn. Yeah, I think that’s really what it comes down to. Some people tried to change Fawn’s communication system not realizing that you can’t just change someone’s communication system
because that’s how they communicate. You can’t suddenly just go oh, we’re going to teach them a whole new language, [and Fawn] needs to [conform], this is what s/he understands, this is how s/he understands so, you have to speak their, you have to speak Fawn’s language.

Jerusha echoed Ramona’s concerns:

Your behaviour will change and it's to Riley's detriment the second somebody approaches her as “an Other”. Because people will say, “Well, I don't know how to talk to Riley”. Well, you can start by listening …. a critical part of dialogue … is nonverbal with anybody.

Heidi, Pippi, and Lucy discussed the importance of having their nonverbal children’s unique communication understood. They used terms specific to verbal language (e.g., “listen”, “say”, and “hear”), even though all children in this subgroup did not speak. Pippi noted, “Olaf communicates, but not in a way that you and I probably communicate”. She later expressed concern that behavioural issues often emerged because of Olaf’s struggle:

I think they [nonverbal kids] try to communicate their needs and their wants and desires and all of that kind of stuff, and if we just think that they're being grumpy then you're constantly hitting them down, right, like not letting them express themselves.

Behavioural issues stemming from not being “heard” was experienced first-hand by Lucy: “Robin says what s/he needs to say, and most people don’t understand Robin’s sign language, then s/he goes straight to self-injury”. Heidi, like many mothers in the study, emphasised the need to “listen” to what her child had to “say”: “Willow is very communicative face wise. If … you listen s/he does tell you what s/he likes and what s/he doesn’t like, what s/he wants, but you have to listen.
Interconnection helps me speak my nonverbal child’s language. Every mother raising a nonverbal child \((n = 5)\) shared stories of learning to speak their nonverbal children’s languages. All mothers expressed that a significant part of their roles was interpreting their children’s needs and wants, as well as amplifying their children’s needs to society. For example, Lucy shared that she was the only one who could interpret her child’s unique nonverbal cues and link those cues to specific behaviours. She further shared that although the interconnection between her and Robin was unique and powerful, even intimate, it also placed significant pressure on her as the sole interpreter of her child’s voice. She worried that without her support, Robin was vulnerable:

So, if we are somewhere and s/he is about to just become beyond anxious, like, “I need to get out of here right now”, s/he’ll do this to me, s/he’ll zoom in on my eyes and then s/he’ll nod and then I’ll say, “Are you telling me you’re ready to go”, “Yes”, because if we ask Robin to use their iPad [to communicate] in those situations, s/he loses their stuff. S/he just doesn’t have enough reserve left to tell us in a way that is beyond that kind of sort of—I guess that’s very intimate, right. So, it’s something s/he doesn’t do with anybody else, so that’s the piece that worries me.

Heidi described learning to understand her child’s unique use of nonverbal cues:

Willow’s developed their own sign language. The only sign s/he does is ‘I want’ and it took us a long, long time trying to figure out why s/he was waving hello to the TV. And then it was kind of like, hold it, everything s/he seems to want, s/he’s waving at. You know, how you kind of like come here, or give me, like the hand signal for come here, s/he kind of does that either palm up or palm down, and s/he created it on his own. Like I said, it took us a little bit to figure, it was like, oh, isn’t that cute, s/he’s waving at the fridge. Oh, s/he wants something out of the fridge, okay.
Pippi also shared stories of learning to decode Olaf’s nonverbal cues:

So, you definitely know when s/he is in love with something and wants it and all of that. And the opposite, I mean if s/he doesn't want to do something, you know, s/he'll bite their hand, s/he'll yell at you basically, and if you're within arm's length, s/he'll grab you, s/he'll pull your hair, you know yeah, so there's things that s/he absolutely doesn't like as well.

Ramona described Fawn’s nuanced communication and opined that the maternal-child connection was pivotal to understanding her child’s subtle nonverbal cues. Her child’s communication style seemed so obvious to her that she struggled to understand how others failed to comprehend Fawn’s communication:

I think it [our interconnection] does [matter], just because it’s that understanding of some of the subtleties, and because with Fawn so much is body language, it’s even the way s/he’s walking on a certain day or tilting or you know, the smile, is it a straight or crooked, like there’s different, my interpretation of that is different …. And I remember [others] saying well, how do you know, and I’m like well, how do you not know?

For the mothers in this study, learning and speaking their children’s unspoken languages was a significant factor underlying their sense of mother-child connection. Mothers offered stories that showed their sense of connection with their children was strengthened as they learned to understand and decode their children’s nonverbal cues. The ability to understand their children’s unique nonverbal language then led to a stronger connection between mother and child. Ramona described learning to speak her nonverbal child’s language and its role in the mother-child connection. For Ramona, the ability to decode Fawn’s communication nurtured her growing sense of attachment to Fawn, returning her to the experience of Fawn inhabiting her body during pregnancy:
I mimicked what Fawn did and so, therefore, I think we connected, and then that made part of that understanding of the certain actions that s/he had, I was then able to just—in a way somewhat intuitively [understand what Fawn wanted] …. And I think because s/he was in me [when I was pregnant], and I still feel like s/he’s right here [pointing to her body] like, I literally feel so attached to Fawn all the time.

Finally, Jerusha emphasised that although it appeared intuitive and like a hunch, the connection with one’s child was a much stronger “knowing”: “It’s intuitive … but it’s not without experience and knowledge … A hunch is a lot of guessing and this is not guessing, this is knowing”.

Verbal children. Seven of the 12 mothers were mothers of children who had limited verbal capacity. Their verbal abilities ranged from speaking in complete sentences with concrete ideas to simple one- or two-word sentences that described immediate, concrete objects or events. For example, a child might say “bad day”, which would capture a range of ideas. The child could be commenting that s/he was disappointed that a favourite activity was cancelled, that their favourite cookies were not in the cupboard, or it could mean something as serious as the child was ill and required medical attention. Several children connected to the study spoke using idiosyncratic and complex speech. One child communicated experiences by describing events from favourite stories. For example, s/he might describe a moment when Nemo missed his father, an event from the movie Finding Nemo, to describe s/he missed a favourite support worker who relocated to a different city. Another child spoke primarily using repetitive sentences. For example, “car in garage, car in garage” could be an attempt to communicate several ideas: S/he wanted to go for drive, that their father had returned home, or even that the child was agitated or excited about an unrelated event.
Three children spoke in complete sentences; however, their mothers expressed concerns that their children’s verbal skills actually created challenges with people outside of the mother-child dyad. Mothers noted that people outside the children’s intimate circle combined the ability to speak in complete sentences with comprehension and communication abilities that the children lacked. The mothers noted that although their children spoke in complete sentences, they could not express sophisticated or abstract ideas, lacked a sense of time or location, and struggled to articulate emotions. Often, the sentence spoken had little connection to the idea the child attempted to express; for example, a verbal child might say, “Spiderman can fly between buildings”, which might mean that Spiderman was their favourite television show but could also mean that only airplanes could fly. Another child might say, “No library books today”, which meant that a year ago, the child went to the library and was not allowed to sign out a book. To illustrate, Lizzie described the challenge of understanding Koda who spoke in complete sentences:

Koda will leap from topic to topic and when you combine that with their speech being a little less clear than a child their age, people can get completely lost very quickly because five seconds ago we were talking about ponies, and all of a sudden, s/he’s telling you about a video about ants, or something like that. And there was no transition or anything to sort of guide you along the way.

As a result, Lizzie admitted that even her husband, Koda’s father, struggled to understand Koda:

[Koda speaks] in very stereotyped ways, they were in very specific circumstances, and they were primarily to me, even my husband commented at the time that there was a lot of the time that he couldn’t really understand what Koda was saying.
Another mother, Mary, noted that her child struggled to initiate ideas and express desires; therefore, Mary noted that Riley’s primary caregiver must have a strong sense of Riley’s wants and needs, as well as the ability to interpret her nonverbal cues, such as scraping her bowl following a meal, to pinpoint the correct question. Mary emphasised that her interconnection with Riley allowed her to ask focused and intentional questions, which solicited important information. Mary worried that Riley would often answer, “that would be wonderful”, not because she liked the suggestion, but because she could not find the language to express her wants and needs:

Riley [will] say, “that would be wonderful”. That’s one of their favourite lines, “that would be wonderful”. So, that if s/he wants second helpings and s/he had a really, really good appetite, s/he probably eats more than I do, and I have a good appetite, and so s/he will get to the end and s/he’ll scrape their bowl or s/he’ll do something like that, and I’ll say, and do you want more. Yes, yes, and I’d say this much? No, more, more than that. So, s/he often does not express their needs, s/he doesn’t initiate things, which is terrible because people are saying, Riley … what would you like? And so that’s a terrible question for Riley… because s/he can’t think, but if you say, Riley …. peaches or pears. [Riley will say] peaches.

Prior to participation in the study and regardless of verbal ability, all mothers were asked whether their sense of interconnection with their DD children was essential to understanding their children’s wants and needs. All mothers identified that their interconnections with their children were essential to understanding their children’s wants and needs to manage their children’s care. I assumed that verbal children could offer more cues to their wants and needs;
however, the seven mothers of verbal children identified with the idea that interconnection with their children was the foundation of understanding their children’s needs.

*Our mother-child interconnection allows me to understand my verbal child.* The role of interconnection among mothers of verbal children emerged as a particularly interesting finding. Despite that their children could speak and had options beyond nonverbal cues for communicating their wants and needs, the mothers of verbal children in this study both identified with the research question exploring interconnection and emphasised that interconnection with their children was essential for discerning their children’s needs. Like the process described by Freitag (2018) concerning extreme caregivers of largely nonverbal children, mothers involved in this study described a sophisticated yet almost unconscious process where they interpreted verbal and nonverbal cues. These, paired with their own interconnected “gut instinct”, allowed them to interpret and respond to their children with increasing accuracy.

Anne offered extensive descriptions of the ongoing process of interpreting verbal and nonverbal cues, and then combining that information with her “hunches” about Winnie:

I learned to pick up on Winnie. Okay, s/he’s going to throw themself [*sic*] down now, you know? It’s hard to, again, (to) pick up on those things. But after the first time and the second times you’re, like oh sh*t, again you’ve gone and cut your head …. It’s a learning curve.

Later in the interview, Anne described trying to put all the verbal and nonverbal cues together when her child became ill:

I’m guessing why s/he got sick, right? And then eventually I’m putting it all together. It was the look of the garbage, the look of the ketchup, the smell of the lady, the smell of the dog, the touch of anything. Butterscotch, like s/he hates butterscotch; don’t even …
can’t even bring it into my house …. Winnie’s tummy would hurt, right, and s/he’d be rubbing [their] tummy. So, it was just an, all in all, general … It was just getting through that construction jumbo in their brain, of putting it out. And as soon as … like, s/he would take my hand and show me. But then, s/he would take my hand it’ll be, like “mummy come”.

Lizzie emphasised that her sense of interconnection with Winnie, her “hunches”, and her “knowing” not only allowed her to “read” Winnie but also allowed her to advocate for Winnie’s care effectively. Without this sense of interconnection, she acknowledged that Winnie’s care and quality of life would suffer:

I knew how to deal with Winnie. So, I guess, like the best thing... figuring out where your child is, if you even have a hunch. Knowing how to deal with it, [it’s] better that way; because not knowing is the worst thing and not knowing is not going to make things easier at all. It’s just going to be really hard for the child even too, because if [others who don’t know Winnie are] frustrated, and you don’t know how to deal, then Winnie’s actually not going to learn and it’s just going to be a big rut, a big, big rut.

Similar experiences. The other mothers of verbal children described similar experiences, often using similar words. For example, Sue echoed Mary’s ability to ask focused questions based on her interconnection: “I think I have hunches around what might be going on and so I know to ask questions about those things”. Jo admitted that she drew on her knowing to care for her child, and her husband, while actively involved in Jessie’s care, lacked this knowing:

So, Jessie can point or sometimes s/he pulls me and drags me, and s/he’ll scream or, you know, [aaach noise]. S/he’s just recently learned “more”, which she uses for everything. So, if s/he needs help, or wants something or wants more—more is for everything. But
really, I find for me a lot of it, which my husband has trouble with, is kind of knowing how their face is looking, how their eyes might be looking, or their body language.

Sue described the interconnected experience of caring for Nala as the following:

It's complex and it's combined, but … the role feeds the relationship and the relationship feeds the role … I can't trust that Nala’s going to say it in a way that other people will understand … and there it's drawing on that depth of our connection.

Lizzie summarised the sophisticated process of interpreting her child’s communication cues: “The word I want to use is seamlessly, but intuitively we just do it [communicate].

**Maternal-child interconnection: Professionally speaking.** I asked the mothers to describe times when they had to interpret their children’s experiences to outsiders, such as educators, physicians, or therapists. Several themes emerged from these stories, including times when the mothers had predicted when their children were ill and had to communicate their concerns to physicians. This question elicited stories from several mothers about experiencing premonitions of their children’s illnesses or disabilities, including during their pregnancies. All mothers shared stories of interacting with professionals, many noting that when their connections with their children’s bodies were honoured, good care ensued. When their “hunches” were ignored by professionals, mothers shared that both their children and their children’s care suffered.

*I often know when something is wrong.* Mothers often described their sense of interconnection as “knowing”. The mothers explained incorporating verbal and nonverbal cues, as well as their “hunches”, to show why they drew specific conclusions about their children’s health, wants, and needs. Several mothers told stories where they “just knew” something about their children.
The mothers linked “knowing” to their profound connections with their children. For several mothers, “knowing” took on a predictive quality. More than half of the mothers \((n = 7)\) told stories of knowing in a manner that accurately predicted a concerning outcome. Several moms told stories of knowing when their children were becoming ill or of being able to predict a seizure. Some mothers told stories of simply knowing something was “wrong” and seeking necessary medical attention without knowing exactly why. Several of the biological mothers \((n = 4)\) described premonitions during pregnancy, predicting that their children would be born with disabilities, or something was “wrong” with their developing baby. Mothers attributed this maternal-knowledge to their profound sense of mother-child interconnection.

*Premonitions while pregnant.* Of the 10 biological mothers, four shared stories of experiencing premonitions during pregnancy or at birth about their children’s health. For all these mothers, these premonitions existed despite a typical pregnancy and childbirth, and in the absence of formal assessments. For example, Jo admitted that she knew “since the day Jessie was born something was a little off”. Despite this worry that something was amiss from the moment of birth, Jessie did not receive a diagnosis of DD subsequent to a chromosomal deletion until the age of 4.

Sue discussed dreaming that her unborn child would have complex disabilities. Nala was diagnosed at birth with Down syndrome. As Nala grew s/he would also be diagnosed with autism, as well as a rare and serious cardiovascular condition that caused strokes and subsequent physical disabilities. Sue had not participated in prenatal screening and Nala’s diagnosis was a surprise. For Sue, this premonition was a great gift, preparing her for life as a mother of a child with significant challenges:
Yeah, so the dream …. it happened during the week that our midwife had said okay, so now you need to decide if you want to have amniocentesis and we … were kind of grappling with that. I went to bed one night and had a really profound dream where I dreamt that a baby… had been born, that I birthed this baby… and at the hospital they said to me their needs are so profound, and s/he has so many layers of disability, that we would like you to leave the hospital and just pretend that this never happened …. So, I have often felt that there was a message in that. I mean that was the most beautiful gift I think I’ve ever received. So, the morning that s/he was born, because we didn’t know, s/he was a total surprise package. The morning s/he was born, s/he was born at home. She popped out and I took a look at her and went what is that? Like is that a human being? Because s/he was tiny. S/he was under 5 pounds. S/he was skinny; their head was this weird shape. S/he looked scary and … and I looked at [my baby] and said—I remember thinking it was like this long, stretching piece of time where I had looked at [my baby] and said the baby has [a particular] syndrome I said to myself, like in my head. That baby has [a particular] syndrome and I looked at the midwife and she was just doing her thing, and I couldn't see Dad because he was sitting behind me, and he was just going, s/he's so beautiful. S/he's so beautiful, and I thought, are you fucking kidding me? That is not a beautiful baby …. That is one funny looking kid. So, like at that point I said …. that baby [needs medical attention].

Like Sue, Elpheba admitted that she worried for much of her pregnancy that her unborn child was not healthy or would be born with a disability. For Elphaba, this premonition existed beyond reason and language, an experience that described many mothers’ experiences with interconnection:
When Remy was born and came out and [my husband’s] holding [the baby] and he said, “See all that worry [that something was wrong] for nothing”. And I still thought—I didn't say anything, but I still thought something's—something's wrong. Couldn't put my finger on it—couldn't make anyone understand—it was like above the realm of [explaining] …

So then, when Remy, at 6 weeks, was diagnosed with this [neurological issue], I sort of was saying things like, “I knew it, I knew it”… I can't put my finger on why I knew it—I just seemed to know it.

Knowing. More than half of the mothers described knowing in a predictive way when something was wrong with their children or that their children were becoming ill. Sue described when Nala experienced a stroke at the age of 10. Nala had some verbal ability and even her ability to speak did not provide cues to the impending health crisis. Sue simply stated that she knew something “awful” was brewing, though admitted she could not discern what the concern might be: “I had an awful feeling that something wasn't right [just before my child’s cardiac event]”.

Nancy summarised that the ability to “read” her child and know that something was wrong took the form of a gut feeling that happened beyond even nonverbal cues. Nancy described a moment when Nemo was ill:

I knew that there was something brewing. *I just sensed it*. It’s not even Nemo’s look because s/he doesn’t even have really expressive facial features. S/he smiles, and s/he laughs. But people can read me like a book because it’s all over my face, but s/he doesn’t tend to do that. It’s more nonverbal and non-gesture stuff. It’s so hard to explain.

Heidi shared that her ability to read Willow and predict Willow’s health issues had been ubiquitous. She could not remember a time when she could not interpret Willow’s health and
behavioural shifts. Heidi shared that when Willow became ill, behaviours and changes missed by others were easily readable to Heidi, even though she could not explain why: “I don’t know. I can’t even explain how, just, you know, whenever s/he has been sick or s/he didn’t want to be somewhere Willow’s behaviours are readable to me.” She explained how her ability to interpret Willow assisted with Willow’s diagnosis of seizure disorder:

I can’t remember a time where it [the ability to read my child] wasn’t [there] …, even with the diagnosis, it was like something’s wrong with this child … I’m like, no, something’s wrong, something is wrong with this child and that’s when we ended up getting the diagnosis [of seizure disorder]. There was a time, it’s like something’s wrong, I can’t place my finger on it, something is wrong. And we happen to have an appointment at Children’s Hospital, and I’m like I need an EEG ‘cause something is going on with this kid. And s/he was having a number of absence seizures, which you really don’t notice absence seizures unless you’re literally staring at somebody.

Anne discussed “knowing” something was amiss with Winnie’s development and the challenges of obtaining a diagnosis for her child. Anne shared that she had emerging concerns about Winnie’s development, health, and behaviour as an infant but did not receive a diagnosis of autism until her child was 3, and only because Anne initiated a self-referral to a children’s treatment centre. For 2 years, Anne attempted to communicate her concerns to physicians who offered alternate explanations for her child’s developmental delays:

I knew for a long time [that my child had a developmental delay], and I fought them [health professionals] tooth and nail. They were trying to tell me it was … it’s just Winnie’s hearing, it’s just the [ear] tubes. Oh, give it until 2 … they’re not worried. I went through probably about, like nine, ten months of being very persistent. I self-
referred myself to children’s treatment centre, because I knew something was not right [with Winnie’s development] …. I didn’t take no for an answer. I knew something was wrong ….. It was like all these light bulbs started, check marks started going off. It was, like okay, everything’s making sense. Then I just went from there and I sought help for my [child] because no one was listening …. So, essentially, like I knew around 18 months [that my child likely had autism], but s/he never got diagnosed on paper until 3, 3 and a half.

_When our interconnection is ignored, my child’s care suffers._ Many mothers shared stories of the challenges of communicating their hunches or knowing about their children’s health with health professionals. Mothers shared stories of having their concerns dismissed, often with concerning results. Mary described a time when Blaze was in the hospital. For a time, Blaze had a shunt in the skull to drain cerebral spinal fluid and reduce pressure on the brain. If the fluid was not drained, pressure would build within the skull and cause a brain injury. To determine if the shunt was still needed or could be removed, the medical team decided to attempt clamping the shunt closed. If fluid was no longer collected, then Blaze could have the shunt removed. During this time, Blaze who normally had some verbal ability was so ill s/he could not communicate. Even in the absence of clear indications of pain and discomfort, Mary could “read” her child and insist the shunt be unclipped, relieving pressure on the child’s brain and preventing a serious health crisis:

[O]ne time a nurse came in, and they’re trying to see whether s/he could do without a shunt …. Blaze wasn’t responding as though s/he were in terrible pain, although I knew s/he was, and I said you’ve got to unclip that [shunt]. I said this will kill Blaze. I said you’ve got to unclip that, and that nurse did not want to do it because the doctor had not
said it was time to unclip this tube coming out of Blaze’s head. And I was so angry because Blaze had no voice … I don’t know if she was fully unconscious, but s/he was not going to scream and cry, s/he was not going to thrash around, but we were losing Blaze. And I said take (my child’s) vitals right now. I’ve never spoken to people like that, but I was my child’s voice. I was Blaze’s voice, and she [the nurse] did, and she went, “Oh, I should go check with [the doctor]”—I said, “No, you’re not checking with anybody, you’re unclipping that [shunt]”.

Blaze’s situation was interesting and concerning. Prior to this hospitalization, Blaze was a typically developing child; in the months leading to this health crisis, Mary observed some concerning health shifts and “knew” Blaze required medical attention. Mary attempted to discuss her concerns with several physicians, including specialists, but they dismissed her concerns. Only when a family friend intervened on the family’s behalf was Blaze’s serious neurological condition diagnosed:

So, when Blaze was 9, s/he was diagnosed with a (neurological condition) and we had already, we knew something was wrong …. by that time, I knew something was terribly wrong, took Blaze to all these places, doctors missed it and a [physician I knew], a friend of mine, knew something was very wrong and that it was neurological. We had dinner there. She [our family friend] paged a paediatrician and said we just had dinner with friends, this is their child, these are the symptoms, something is very wrong. And he said it sounds like [neurological condition] to me. We had seen five doctors up to that point who had all missed it.

Similarly, Sue expressed concerns to a physician, only to be ignored. She requested a meeting to discuss her growing concerns about Nala’s health with the family physician; this
meeting led to Nala being discharged from the physician’s practice. Sue struggled to pinpoint why she felt concerned about Nala’s health and focused on the risk of leukemia among children with Down syndrome. Although Nala did not have leukemia, s/he did have a serious cardiovascular condition that remained undiagnosed until when, a few months later, s/he had a significant cardiac event. Sue expressed frustration that the physician could not hear her underlying concern about her child’s health and discuss ways to address her concerns:

I remember talking to the family doctor about it, and he was tired of me. [Laughs] He was tired of me, and he was tired of me asking questions, and he was tired of me asking for confirmation of this or that. I was concerned about leukemia because s/he has [a particular] syndrome. There’s that much higher risk of Nala developing leukemia …. So, I went in and asked for a [specific blood test] and left without a family doctor because when I asked for the [blood test], he said … I think you might be happier if you found a different family doctor. And I said are you firing me? He said, well, I think your needs are too complex for our practice, and I was furious. Absolutely furious. So, that was in I don’t know, maybe March or April, and then … by October s/he had [the] brain bleed …. Clearly, s/he didn’t have leukemia, but s/he had this whole mess of weird blood vessels in her brain …. but at the same time, the physician had no interest in my read as a parent …. And so, rather than that being the beginning of a conversation, and an exploration [of my concerns about Nala’s health], it was the end of the conversation, and the relationship.

The theme of expressing concerns about their children’s health and remaining unheard was common among the mothers in the study. Six mothers described seeking medical attention for their children and having their “read” of their children’s health status disregarded. In all situations, the children were known to be at high risk for serious medical issues.
Ramona described an episode when she presented to the emergency room because she “knew” something was “wrong”. The physicians in the emergency room were unfamiliar with Ramona’s ability to understand Fawn, and they sent the two home because Fawn did not meet objective criteria. A few hours later, Ramona returned with Fawn to the hospital, seriously ill by this time. Ramona noted that when the emergency room physicians treated Fawn during this subsequent admission, Ramona’s voice was heard and her concerns were respected, but her credibility had required an unfortunate episode before that happened:

I remember taking Fawn to hospital a couple of times, and I knew s/he was getting sick and got there, and I remember some new doctors who were like no, there’s nothing wrong with Fawn, the tests are coming back. And I’m like no, I know there’s something wrong and they’d say no, we can’t do anything because there’s nothing here …. and sure enough, we would go home and within 6 to 12 hours we were back again, and the signs were then very obvious. And then there was the, oh, so, sorry and then the next time [we went to the emergency room], it was no, what would you like to do [mom]?

Even in a situation when the mother was a trained emergency room nurse, the emergency room team ignored the mother’s experience. Nancy described taking Nemo to the emergency room and being told that she was overreacting and a “nervous mother”:

[C]onvincing the doctors that there was something wrong was my biggest hurdle. I kept getting patted on the back even as a nurse. I was an emergency room nurse. They’d pat me on the back, “Oh you’re a nervous mom. Just go away and do as best you can”.

Nemo was later diagnosed with a serious gastrointestinal issue.

Nancy’s case indicated the concerns that many health care professionals have when parents speak for a child, even when that child could not speak for themselves. In Nancy’s
situation, Nemo had some verbal ability but could not discuss health and symptoms with the health care team, including Nemo’s pediatrician:

Those [episodes in the emergency room] are pretty concrete examples [of talking to a health professional] because Nemo started to have episodes of gastrointestinal bleeding which were really significant, and trying to talk to the paediatrician and tell him what was happening like, “I’m really scared here”, it was a nightmare. He just wasn’t hearing me and of course we’ve got Nemo … not being able to tell him that s/he has abdominal pain, not being able to tell him that s/he had diarrhea with it, or anything. Everything that I had to tell them was coming through me.

Lizzie emphasised the challenge of speaking for a child with a severe communication challenge:

[O]n sort of the medical side, because, of course, they increasingly want Koda to articulate things for themselves. And, s/he’s not always able to do that. So, I usually try to be, sort of, let Koda say something, but I feel like a lot of the time, I have to sort of talk over it, almost …. I’m trying to do it in a way that makes it clear that I’m prompting and not just kind of trying to steamroll Koda, because I know that there is, you know, there’ve been a couple doctors who are like, “Well, you know, I really want to hear it from Koda”, and you know, I just sort of try and be upfront and say, like, “Without the prompting, you might not hear it from Koda, s/he might not articulate it.”

Lucy described many of the challenges that she believed physicians had hearing a mother’s voice on behalf of her child, even when that child was nonverbal like Robin. Lucy believed that health care providers would prefer objective evidence, such as with video. Additionally, Lucy suggested that challenges emerged because Robin was no longer a child and
was developmentally beyond the stage of life when it was typical for a mother to speak and advocate for her child. Lucy believed that physicians preferred to conduct Robin’s appointments with someone less connected than the mother, such as a support worker. This request was a source of concern for Lucy. She was unprepared to allow an individual who did not know Robin to take an advocacy role on behalf of her nonverbal child:

So, yes, it’s a little bit harder [to work with] the medical field because they want to see Robin functioning …. they would welcome video [to allow them to directly see a behaviour]. They do not want to take my word for the amount of anxiety Robin might experience, or they really don’t want to take our word for anything now that Robin’s an adult, right. So they would much rather Robin go to the psychiatrist’s visits with the support [worker], but [my husband] and I are not willing to hand over that piece yet, and [having workers provide Robin with] support is all within the last three years, so nobody holds their history except us, right. Yeah, so it’s very challenging.

Mary identified that an important factor when working with health professionals was the need to communicate the extent of her expertise. As she noted, she and Blaze lived with the consequences when her wisdom was dismissed:

I’m actually in charge, and I am responsible. Whatever we discuss here, the decision is mine with Blaze and Blaze’s dad. This is our decision; we live with the consequences, and that was a very hard learning for me because you take somebody’s word that this surgery is going to be fine and in fact it devastates things. And I realize then, I need to be the expert as much as I can be, but always, ultimately, it is our decision, and we are the ones who are responsible.
My child benefits when providers trust my knowing. Although having their hunches ignored often translated to less than optimal care, several mothers shared optimistic stories acknowledging that when their interconnections were honoured, timely and effective care occurred. Many mothers noted that their knowing was respected only after a previous negative experience demonstrated their expertise to health care providers, or they had been previously dismissed by numerous health care providers. For example, Anne told of her relief when a specialist finally validated her concerns about Winnie’s development:

And he [the specialist] was, like well, have you been voicing your opinion, and I said, “Damn right I have”. I’ve been at my family doctor for the last year and a half saying something, and they said it’s a watch and wait thing, and he then said, I don’t think it is. I think you might be on to something. And this was around 2, 2 and a half.

Mary told a similar story of having her concerns about Blaze’s health ignored by five physicians and her relief when working with a responsive physician. Mary’s story showed two components integral to a collaborative mother-professional relationship. First, she, Blaze, and the physician had a history of working together that allowed them to respect one another’s contributions. As Mary emphasised, this history allowed the physicians to develop an understanding of Mary’s ability to know Blaze and to trust her maternal wisdom. Second, Mary identified that Blaze’s physician understood the valued role of parents when working with children and adults with disabilities:

They [Blaze’s current physicians] trust me to be Blaze’s voice after numerous, you know, appointments, and meetings, and/or situations. Like Blaze’s neurosurgeon at [Specialized Hospital]. If I phoned up with anything, he had me in there, Blaze, right like, right away …. He absolutely trusted my opinion, one, because that’s who he is as a
person. He’s a remarkable person. He also really believed in the role of the importance of parents for him.

Summary of Findings

Twelve mothers shared detailed stories of their lived experiences of interconnections with their children with DDs. Three overarching themes emerged. First, maternal-child interconnection was difficult for mothers to describe but encompassed a sacred, mutual, and unique interpenetration of experiences between mother and child. Next, all 12 mothers shared that their interconnections were essential for understanding their children’s needs and “speaking” their children’s unique languages, regardless of verbal abilities. Finally, all mothers shared stories of advocating to health professionals based on their interconnections with their children. When maternal-child interconnection was respected, the children’s care was enhanced. When their interconnected sense of their children was ignored, their children’s care suffered.
Chapter 5: Discussion

Extreme parental caregivers provide ongoing care for complex children of all ages. This study explored maternal-child interconnections among mothers parenting children with both a developmental delay and a communication challenge. I explored how mothers experienced their children in an embodied way and how this embodied connection influenced their parenting and care of their children. This study addressed mothers’ answers to the following research question:

What are the intercorporeal experiences of mother raising developmentally delayed children?

Three key themes emerged in response to the mothers’ responses to the research question. The themes are summarised as the following:

1. Maternal-child interconnection was difficult for mothers to describe but encompassed a sacred, mutual, and unique interpenetration of experiences between mother and child.

2. Maternal-child interconnection allowed mothers to “speak” their children’s languages, regardless of verbal or communication abilities.

3. Maternal-child interconnection yielded a unique and predictive form of “knowing” that was often poorly understood beyond the mother-child relationship, particularly by health professionals.

These three themes are explored regarding the available literature. I consider the three themes as informing the following four areas of inquiry.

1. Caregiving, mothers, and the postmodern body.

2. Maternal knowledge and the consequent epistemological challenges.

3. Pastoral care for caregiving mothers.
4. A theological reflection exploring the *imago Dei* in relationship with interconnected mothers.

**Caregiving, Mothers, and the Postmodern Body**

In her postmodern feminist analysis of the body, Shildrick (1997) outlined the following four key assumptions inherent to a postmodern critique of the body: (a) A coherent understanding of truth associated with the enlightenment had passed and was replaced by a fragmented approach to knowledge where multiple, and indeed competing, discourses offer insight; (b) because this unified understanding of the world had passed, the grand narratives of key disciplines, including medical science’s understanding of the body, must be abandoned; (c) because of this fragmented approach to knowledge universal knowledge claims and subjectivity became problematized; and (d) boundaries between discrete bodies of knowledge were eroded, challenging the organization and hierarchy of knowledge, and the distinction between pure theory and the practical/lived experience. Regarding the body, these assertions indicated an abandonment of the reductionist embodiment of traditional Western medicine (Cregan, 2012), in favour of a problematized and critical view of the body.

For this research project I included only mothers and focused on their experiences of embodied interconnection. The mothers’ narratives echoed a contemporary feminist understanding of the body. Feminism entered discussions of the body in the early 1970s, and feminists asserted that gender differences were based on social constructs and oppression, rather than biological determinants (de Beauvoir, trans. 2011; Schiebinger, 2000). Like the social model of disability that indicated limitations placed on disabled bodies originated within the environment and minimised the role of bodies (Hughes & Paterson, 1997), early feminists
neglected the distinctions between male and female embodiment (Cregan, 2012; Shildrick, 1997).

Current feminists have explored female bodies as subject to societal stereotypes, oppression, overt medicalization within the patriarchal medical model (Findlay & Miller, 1997; Lorentzen, 2008; Schiebinger, 2000), and the foundation of distinct sex-based differences (Bolaria & Bolaria, 1994; Schiebinger, 2000). For example, women’s health care has been based on the archetypical male body. The assumption that the male body was generalizable to women’s bodies led to disparities in care (Adigan, Boler, & Mankad, 2018; Mann, 1995). Similarly, researchers exploring intersectionality asserted that “woman” was not a universal descriptor, and variables like poverty, sexuality, culture, or ethnicity remained significant contributors to health (Bolaria & Bolaria, 1994; Kronenfeld, 2017). Further, current feminist discourse challenged the dualism of male/female in favour of a more fluid spectrum (Butler, 2004). Taken together, a feminist critique of the body deconstructed the patriarchal boundaries of Cartesian dualism in favour of a multifaceted, relational body.

The results of this study aligned with a feminist, postmodern deconstruction of the body. In particular, the mothers described complex, porous, and deeply interconnected relationships with their children who lived with DDs. Mothers shared that their experiences of parenting their children with disabilities involved a sense of embodied enmeshment that allowed for an interpenetration of experiences. In extreme cases, mothers admitted that they struggled to discern their experiences as unique from their children’s experiences. For example, Mary shared, “I’m doing all those things with them and in some ways I’m in Blaze’s body. I’m not just with Blaze”.
In this study, mothers shared stories that indicated their children’s joy became their joy; the children’s suffering manifested as the mothers’ suffering. Further, because their children could not effectively communicate their wants and needs, mothers relied on this embodied intermingling of experiences to discern their children’s needs and tell their children’s stories. Interconnection allowed mothers to not only determine necessary care needs but to also understand their children’s experiences of the world and, by extension, amplify their children’s voices and narrative to society. Affirming their children’s voices and personhoods, particularly among mothers parenting nonverbal children, emerged as a significant theme during interviews.

Within this overarching theme of a porous body, four further interrelated subthemes are considered. First, the postmodern view of the body as both complex, and porous is discussed. Porous boundaries between bodies led to an intermingling of experiences between mother and child. Two more subthemes are discussed: identities and mingled voices. Finally, the ethical challenges posed by the mingling of the voices and bodies of the care provider with the care recipient are considered.

A complex, porous body. The results of this study aligned with the postmodern notion of a complex, extended body, porous body that permitted the intermingling of embodied experiences between bodies. Researchers defined the postmodern body as embracing a fluid relationship where embodied beings experienced fractures and dislocations that connected bodies with other equally leaky bodies (Grosz, 1994; Shildrick, 1997, 2002). Hence, embodied experiences could transfer between bodies. Like Merleau-Ponty’s (trans. 2010) suggestion of a white cane becoming a sensory extension of the body, postmodernists argued that bodies were not bound by skin but expanded to include technological and living extensions, such as wheelchairs, mobility, and other communication devices, as well as caregiving bodies and/or
service animals (Churchill, 2012; Fritsch, 2010; Nishida, 2017; Trigg, 2013); all these assertions were echoed by the stories of the mothers in this study.

Few researchers explored the lived experiences of intersubjectivity among caregivers, particularly maternal caregivers. Those few researchers described stories of caregivers and their charges entering relationships that included exchanges of embodied experiences (Churchill, 2012; Fritsch, 2010; Nishida, 2017), particularly when caregivers provided toileting, bathing, or facilitating sexual expression (Fritsch, 2010).

Related qualitative studies, although not explicitly studying intersubjectivity, also provided insight into maternal-child interconnection. For example, Holt-Woehl (2018) conducted a qualitative study of parents of children with DDs and shared the narrative of a mother relying on her “sense” (p. 14) of her child to guide care. Another mother stated that she knew in her gut that something was wrong. Holt-Woehl’s (2018) maternal descriptions of relying on embodied cues to discern the state of a child’s body echoed the themes of the 12 mothers participating in this study.

All participating mothers identified with the theme of interconnection and described their maternal-child interconnections. Mothers used language that conveyed a sense of shared experiences. Nancy shared, “I have to look at Nemo’s face and realize, and just sense, that something’s not right”. Jo shared that she and Jessie shared energy; therefore, she could sense her child’s joy and “feel the sparkle”. Jo shared that Jessie was her “mirror”, suggesting reciprocity of experiences between mother and child. Ramona emphasised an embodied connection with her child: “I think Fawn is a part of me …. Like physically a part of me”. Mary noted that her ability to identify when Blaze was becoming ill was experienced through her own, embodied tension.
**Mingled bodies, mingled identities.** When embodied experiences are closely connected, even interconnected, the distinction between mother and child can become blurred. Kelly (2005) conducted a qualitative study of parents raising children with disabilities and offered insight into the experience of blended identities. Kelly suggested parent and child identities leaked into one another, thereby overlapping to form a blended narrative. Kelly suggested that parents of children with impairments internalized discriminatory and oppressive views regarding their children with disabilities, thereby incorporating these views into their personal identities. The children’s stigmatised identities as “disabled” would influence parents’ identities, thereby resulting in a coconstitution of parent/child identities as “disabled”.

Although other qualitative researchers did not study maternal/child intersubjectivity or blurred identities, similar themes of overlapping identities in response to the societal stigma of disability and parenting a disabled child were evident in qualitative studies exploring mothering and disability. Landsman (2009) argued that mothers of children with disabilities were viewed through a societal lens of diminished motherhood. Children viewed as “diminished” by society’s ableist attitudes led to mothers viewing their experience of motherhood through a similar lens (Landsman, 2009). Scott (2010) studied labour force involvement among mothers of children with disabilities and found that the societal limitations for people with disabilities extended to mothers. Scott interviewed mothers of children with disabilities who described an erosion of their sense of self that was deeply intertwined with their children’s disabilities and societal stigmatization. Holt-Woehl (2018) suggested that mothers absorbed the blame and societal stigma of having children with disabilities. Although none of these researchers explored intersubjectivity, the results indicated similarities to the themes of interconnection that emerged from this study.
This study of mothers supported the assertion that maternal narratives and identities not only blended with their children’s identity as “disabled”, but mothers’ identities and personal narratives extended to include their disabled children’s embodied experiences as well. For example, when asked to describe her relationship with her child using an image, Nancy described a single tree with profoundly intertwined roots. If Cartesian dualism had informed Nancy’s image of two bodies, then Nancy’s image would have included two bodies represented by two trees and intermingled roots. Ramona believed Fawn was “physically” a part of her. Mary viewed her relationship with Blaze as so interconnected that it threatened her sense of self: “The lines between me and [my special needs child are so] completely blurred [that] my sense of self would have been, I think …. submerged”. Mothers were often aware that their enmeshment with their children was poorly understood. For example, Sue shared, “In our highly … individualistic society this idea that people can exist as a unit that's almost indivisible is something we have a hard time [understanding]”.

Kelly’s (2005) study with parents, as well as Landsman’s (2009) work with mothers (2009), indicated that parents often experienced the discriminatory attitudes directed at their children, leading to a merging of experiences. Parents used their sense of interconnection with their children to construct narratives that challenged troubling societal views regarding disability. In particular, Landsman (2009) conducted an ethnographic work with mothers to argue that maternal narratives reframed their children as a “gift” to counter more troubling societal views of diminished motherhood and mothering a child with a disability.

Like Landsman’s (2009) and Kelly’s (2005) studies, mothers in this study worried about concerning societal views of their children with disabilities. Several mothers believed their embodied interconnections allowed them to express their children’s voices and needs within a
society that failed to value or hear their children. Their children with communication challenges had much to “say” if society was willing to “listen”. For example, Jerusha emphatically stated the following:

It's to [my nonverbal child’s] detriment the second somebody approaches them as “an Other”. Because people will say, “well, I don't know how to talk to them”. Well, you can start by listening, and listening which is part of dialogue, a critical part of dialogue. A lot of it is nonverbal with anybody.

Elpheba was emphatic that Remy’s echolalia was a meaningful form of story telling and communication. When Remy repeatedly said, “Car in garage”, Elpheba believed, “Everyone who knows Remy knows very, very well that you're having a real conversation with them if you partake in the repetitive talk”. Ramona emphasised, “It was my mission to prove to everybody that Fawn did have feelings, s/he did care, s/he did—s/he could express”. Having their children heard by society was imperative for these mothers.

Mothers involved in this study used words that described verbal language, even though interconnected maternal-child communication took the form of a nonverbal, intuitive exchange. Even the mothers of nonverbal children suggested their children “spoke” if one “listened”. For example, Heidi shared, “Willow is very communicative face wise. If … you listen s/he does tell you what s/he likes and what s/he doesn’t like, what s/he wants, but you have to listen” (emphasis added).

**Mingled voices.** The enmeshed embodiment between mother and child combined with increasingly blurred identities and voices meant that authorship of stories could be unclear, again echoing themes in the existing literature. Kelly (2005) studied families parenting children with disabilities and suggested that overlapping identities and stories were common. Swinton, Mowat,
and Baines (2011) argued all personal stories were told within a complex matrix of narratives and people with profound intellectual disabilities are often wholly reliant on other voices telling their stories. Drawing on Tronto’s (1993) description of responsiveness, Freitag (2018) explored the way that maternal knowing, a common word used by mothers in this study to describe embodied interconnection, assisted mothers in developing both identities and life narratives for their children. For Tronto (1993), responsiveness required the care provider to enter the experience of the care-recipient.

Freitag (2018) expanded Tronto’s (1993) thinking to explore how extreme maternal caregiving facilitated an embodied understanding of one’s child. Freitag (2018) cited the autobiography of Rapp (2013), the mother of Ronan who lived with significant neurological impairment, which suggested that mothers used their knowing to become the primary narrators of their children’s life stories. As Rapp (2013) expressed, “My other task beyond physical care, I began to realize, was to find Ronan’s quiet, gap-ridden myth, his idiosyncratic narrative, to interpret it, to share it, and learn from it” (p. 48, emphasis added).

Like Rapp (2013), mothers in this study employed their interconnections with their children to interpret their children’s stories and amplify their children’s voices within a world that often viewed their children as voiceless, without story, and unable to enter meaningful relationships. For example, Ramona argued that her child had a rich personal narrative and strong opinions, despite society not hearing Fawn’s story. Similarly, Ramona asserted that Fawn could enter meaningful relationships; therefore, Ramona believed that a significant part of her role as Fawn’s mother was to draw on her interconnected understanding of Fawn to interpret their stories to society, as well as forge relationships on behalf of her child:
I think the reason I listened more was because I felt I had to be there for Fawn to advocate for (my child) to make sure other people understood how s/he was communicating and how s/he could connect with other people.

**Ethical implications.** Although the mothers in this study used their interconnections to give voice to their children’s stories and affirm their personhood, blurred voices, stories, and identities could still raise concerns about power, agency, and autonomy. Swinton et al. (2011) noted that the mingling of voices, identities, and stories raised concerns that people with DDs might become “victims of constructions of their stories that they do not own” (p. 6). Medical researchers have identified the challenges of working with parents who speak for their children with complex care needs regarding accurately assessing voice and agency (Woodgate, Zurba, Edwards, Ripat, & Rempel, 2017). When mothers speak on behalf of their children with profound intellectual disabilities, it can be challenging to discern authorship of the story.

Historically, society has denied people with disabilities autonomy, voice, and power. Self-advocates living with disabilities discussed these attitudes. Denying authorship of their stories meant that their voices, rights, needs, power, and desires were ignored and dismissed (Charlton, 1988). The importance of discerning whose voice and needs, as well as the location of power, in a caregiving relationship is crucial and remains an ethical challenge, particularly for health care providers who often work with the primary caregiver.

Currently, people with disabilities can use improved augmentative technology and assistive devices to express their wants and needs. Improved education regarding the skills and abilities of people with DDs, combined with appropriate supports and inclusive communities, mean that many who live with intellectual impairments can engage in some form of self-advocacy. However, like most of the children in this study, there will always be a small cohort
of children and adults who live with the most severe forms of intellectual disability; therefore, they will be reliant on their caregivers to tell their stories and voice their needs. In these situations, many outside the intimate circle of immediate care may struggle to discern whose voice is being expressed or whose needs are being met. Society’s reluctance to embrace a notion of embodied experiences, as described by the mothers in this study, contributes to the challenge of advocating for a child with significant communication challenges and the continuing stigma of the hypervigilant mother. Navigating the ethical issues of honouring a mother’s voice when she speaks on behalf of her vulnerable child, who cannot express needs, while ensuring her child is as autonomous as possible, remains an ethical and practical challenge for many professionals. Therefore, future research is essential.

Maternal-child interconnection is poorly understood. A society that embraces a Cartesian model of the body often struggles to understand how bodies can be interconnected and how that interconnection can inform caregivers. The mothers in this study shared that describing this interconnection to health professionals caused challenges. Although numerous researchers explored caregiving burdens and the lives of mothers caring for complex children, few studied the relationships between mothers and health care providers, and none explored the challenges of describing an intercorporeal relationship to professionals. Researchers noted that parents, especially mothers, found navigating relationships with professionals stressful (Ryan & Quinlan, 2017; Todd & Jones, 2003; Woodgate et al., 2017).

Ryan and Quinlan (2017) conducted a qualitative study and noted that parents often struggled to be heard by health professionals, and rather than experiencing collaborative relationships with health care providers, they reported a lack of child and family centredness and an “us vs. them” approach. Similarly, Mattingly (2010) studied African American mothers’
mothering children with disabilities and significant illnesses and highlighted the challenges that many poor mothers of ethnic and cultural minorities experienced navigating relationships with health care providers who occupied different cultural, educational, and socioeconomic locations in society. The power differential associated with an us-them relationship between health providers and mothers added the challenge of a discerning voice when considering enmeshed parent-child experiences in relationships with professionals. Were mothers’ voices, regardless of their stories of interconnection, minimised to favour the more powerful physician’s voice? Further study of these themes is imperative.

My findings indicated support for the limited research available describing relationships between mothers and health care providers. Most mothers in this study told stories of having their concerns ignored by health professionals. Mothers stated that physicians often failed to honour their abilities to read their children who could not speak or express their needs. As Elpheba succinctly stated, “I had to battle it out with the doctors”. Nancy summarised, “Convincing the doctors that there was something wrong was my biggest hurdle”. Anne described her struggle obtaining a diagnosis for her child: “I was more upset, I think, that my concerns weren’t actually being …. validated”.

Several mothers shared that once trust with a health professional had been established, their abilities to speak to their children’s experiences were honoured, thereby leading to better health care outcomes. Anne described the relief of finally finding a physician who honoured her interpretation of her child: “So I walked in [to the physician’s office], and they were very … just amazed that I was … [so] aware of her”. Mary shared that although it took many encounters with her child’s health care team, they learned to trust her ability to speak on behalf of her child’s experiences: “They [physicians] trust me to be Blaze’s voice after numerous, you know,
appointments, and meetings, and or situations”. Heidi shared that her physician was willing to accept her voice on behalf of her child’s: “We’re very lucky our family doctor knows to listen to me”.

**Maternal Knowing: Epistemological Challenges**

Most mothers in this study described situations when health professionals either dismissed maternal concerns or struggled to accept their intuitive knowledge of their children. The leaks and flows between interconnected bodies often meant that mothers experienced their children’s bodies through their own embodied experiences, something that was difficult for mothers to describe and equally difficult for professionals to understand. However, the embodied interconnection between mother and child often provided valuable information to mothers regarding their children’s health and allowed them to “read” emergent situations. Jerusha’s “tension in the body” suggested Blaze was ill. Heidi could assess Willow’s seizure activity by her “gut”. Sue “knew” to be concerned about Nala’s health during the weeks before a cardiovascular event. Ramona took Fawn to the emergency room and was sent home, only to return a few hours later after Fawn was measurably ill. These mothers’ embodied experiences often informed them of their children’s health concerns before assessable symptoms appeared.

The *Stanford Encyclopedia of Philosophy* defines epistemology as the study of knowledge and beliefs. In particular, epistemology is concerned with questions related to the acquisition and verification of knowledge versus opinion (Steup, 2018). Contemporary medical practice is based on the belief that medical knowledge is supported through evidence-based study (Branson, 1998; Solomon, 2015). Solomon (2015) argued, “Evidence-based medicine de-emphasises intuition, unsystematic clinical experience and pathophysiological rationale as sufficient grounds for clinical decision-making and stresses the examination of evidence from
clinical research” (p. 106). Clinical researchers ground themselves in the scientific method to argue data are valid, reliable, replicable, and value-free or unbiased (Lincoln & Guba, 1995).

Maternal knowledge of their children’s body that emerges from an intuitive interconnection between mother and child is poorly understood, difficult to describe, often impossible to measure, and lacking empirical study. The mothers in this study struggled to articulate and describe the source of their embodied, intuitive knowledge of their children. Often, the mothers simply knew to be concerned about their children’s health or development. Each mothers’ knowledge of their children was unique. Mothers noted that even actively involved and concerned fathers did not have the same connections or abilities to understand their children.

Maternal knowledge was not based on the scientific method. Often, mothers’ knowledge could not easily be replicated or assessed; for example, despite knowing her child was becoming ill, Ramona was sent home from the emergency room because Fawn did not have measurable symptoms, only to return later that day when her child’s condition became obvious to others. Mothers shared stories of being told they were hypervigilant or needlessly anxious, despite accurately knowing their children were unwell. Several mothers predicted their children’s diagnoses or health problems (i.e., seizures), even when physicians minimised their concerns. Although mothers could interpret their children’s body and diagnose a health status with considerable accuracy, that ability was beyond the verifiable realm of the traditional scientific method; therefore, physicians were often uncomfortable and unwilling to consider maternal knowledge as valid, thereby leading to stressful situations for both mother and child. Kittay (1999) noted, “Dealings with medical authorities are among the most frequent complaints one hears when listening to the mothers of disabled children” (p. 164).
The reluctance by medical professionals to utilize maternal knowledge, for whatever reason, when making health care decisions, at times translated to delayed diagnoses or less than optimal health care. In some cases, such as Sue’s attempts to pinpoint growing concerns about Nala’s health, unwillingness to consider a mother’s concerns led to serious consequences. Nala’s physician not only did not hear Sue’s growing concerns about her child’s health but discharged Nala and Sue from their practice as well. Thus, a serious cardiovascular condition was not diagnosed until after Nala had been hospitalized following a significant event. Anne sought advice from multiple physicians who dismissed her concerns about Winnie. Winnie was diagnosed with autism because of Anne’s tireless advocacy but only after she self-referred to a specialist clinic after her general practitioner refused. Jo knew her child had an intellectual disability years before a chromosomal deletion was discovered. Mary voiced concerns to her family physician about Blaze and was only taken seriously when a family friend, who was also a medical doctor, intervened on her behalf. Heidi diagnosed Willow’s seizures and demanded an EEG for confirmation. All these mothers told stories of having their maternal knowledge ignored by the medical establishment.

Shildrick (2009) asserted that Cartesian dualism, along with the erasure of the body and retreat from embodiment, derived from a patriarchal worldview. This worldview, like the medical model, largely concerned the neutral body as masculine, heterosexual, and able. Similarly, sexes were viewed as binary, male, and feminine/not-male. However, Shildrick (2009) asserted that a return to embodiment was not necessarily a feminist project but was relevant to all “differently excluded others” (p. 2) that included not only women but also people with disabilities, diverse sexual identities, and orientations. The goal of a feminist analysis of the body was to align with the postmodern assertion that knowledge was complex, subjectivity was
problematized, and “knowing” could not fall into bounded, measurable categories, nor conform to tidy agendas (Shildrick, 1997). The problem for the mothers in this study was that the medical system in which they voiced their interconnected experiences did not endorse their form of postmodern knowing, and those physicians had the power to dictate what constituted knowledge.

Titchkosky (2011) discussed power and voice through the idea of positionality by employing the metaphor of seating at a table. Titchkosky (2011) defined positionality as an inquirer’s position regarding “the act of inquiry and subsequent knowledge production” (p. 111). An individual’s identity often positioned them within social hierarchies, which in turn influenced the value, or not, of their knowledge and contribution to the conversation. Titchkosky (2011) used the concept of the table, as well as seats at the table, to describe the role of power and voice. Those with power control the table; who may be invited to sit at the table, who may speak, and whose voices and knowledge carry authority. Those in power tightly control access to the table, and even being invited to sit at the table does not necessarily mean one may speak or have their voice and knowledge honoured. Often, one’s presence at the table is tolerated only insofar as the invited member conforms to the status quo.

Although health care is moving toward a multidisciplinary approach to practice, in many settings the medical model as well as its valuation of evidence-based, reproducible, knowledge continues to dominate all conversations at the table to the exclusion of all other forms of knowing. Mothers may be invited to sit at the table when discussing their children’s health, but unless their knowing conforms to the norms of medical knowledge, including the acquisition of knowledge, mothers may not be permitted to speak or have their voices heard. Because mothers’ knowing often failed to meet medical norms regarding knowledge, significant challenges occurred for the participants of this study.
Freitag’s (2018) argued the following:

Mothers of chronically ill children often know when their children are seriously ill before it becomes obvious to medical providers. Sometimes even parents whose understanding of medicine is incomplete have an intimate and accurate knowledge of their children’s symptoms and reactions, and should not be ignored. (p. 127)

Others supported Freitag’s (2018) assertion that mothers were uniquely qualified to assess their children’s health status and could predict health concerns before physicians or medical teams (Landsman, 2009; Mattingly, 2010, 2014). In one troubling article, a mother predicted that her child with autism and significant behavioural challenges would seriously injure her (Simplican, 2015). Sky killed his mother, Trudy Steurnagel, in February, 2006 (Connors, 2009). Trudy left a note indicating that she expected she might be “seriously injured or killed” (Simplican, 2015, p. 217) and did not fault her child. The medical establishment’s failure to recognize Trudy’s intimate knowledge of her child’s disability and its threat to her safety had disastrous consequences.

Landsman’s (2009) ethnographic work with mothers of disabled children provided numerous examples of mothers who, like the mothers in this study, accurately predicted their children’s emerging health problems and “butted heads” (p. 100) with physicians who failed to value the mothers’ expertise. Like the mothers in this study, the mothers in Landsman’s (2009) study noted that their continued care of their children provided unique opportunities to learn to interpret their children’s health and body that evolved regardless of educational background or training. The mothers were “not challenging the position of biomedical knowledge as authoritative knowledge. Rather they are denying exclusivity in whatever area such knowledge can reside” (Landsman, 2009, p. 103, emphasis added). Like the mothers in this study, mothers
in Landsman’s (2009) study acknowledged and valued the physicians’ medical knowledge, while learning to trust and value their own instincts regarding their children. Mothers argued that health professionals should equally value their often accurate, yet ‘unorthodox’, instincts. Mothers of children with disabilities wanted a renegotiation of the power dynamics between physician and mother to ensure not only a place at the table, but an opportunity to have their expertise regarding their children respected as equal to that of the physicians’ expertise.

**Pastoral Care for Caregiving Mothers**

**Spiritual care.** Christians believe that offering care for those who are ill and vulnerable is synonymous to offering care to Christ. The Christian call to provide care is rooted in Christ’s commandment to offer generosity to people who are sick and vulnerable as written in Matthew’s Gospel:

> For I was hungry and you gave me food, I was thirsty and you gave me something to drink, I was a stranger and you welcomed me, I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me.’  
> Then the righteous will answer him, ‘Lord, when was it that we saw you hungry and gave you food, or thirsty and gave you something to drink? And when was it that we saw you a stranger and welcomed you, or naked and gave you clothing? And when was it that we saw you sick or in prison and visited you?’  
> And the king will answer them, ‘Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me. (Matthew 25: 35-40, NRSV)

O’Connor and Meakes (2005) noted that in the early Christian church, illness and disability were often linked to sin. As a result, historically, spiritual care focussed on conversion as well as the cleansing of the spirit and soul in anticipation of meeting the Divine upon death.
As noted by O’Conner and Meakes (2005), this approach to spiritual care often bordered on preaching and assumed a judgemental tone with an emphasis on the alleviation of sin rather than on care.

Koenig, McCullough, and Larson (2001) differentiated spirituality and religion. Koenig et al. (2001) defined religion as “an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent” (p. 19). Religious practices included adherence to specific rituals and traditions, loyalty to a specific code of ethics, maintenance of specific beliefs, and an emphasis on the responsibilities of living in community. Religion was often associated with belonging to a community of like-minded believers, was behaviour oriented, authoritarian, and aligned with specific beliefs around the nature of good and evil.

In contrast, Koenig et al. (2001) defined spirituality as a nebulous term. Koenig et al. associated spirituality with personal characteristics and practices and defined spirituality as the following:

the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community. (Koenig, 2001, p. 19)

Spirituality and spiritual practices were less visible to others, as well as being less formal, orthodox, or systematic. Spiritual practices tended to be more emotionally oriented and subjective, and unlike religious practices had little, to no, accountability to formal faith structures.
Drawing on these themes, VanKatwyk (2003) asserted that spiritual care was care offered to an individual rooted in the Judeo-Christian tradition of *cura animarum*; Latin for cure of the soul. Spiritual care supported an individual in the context of their life, and with respect to their spiritual meanings and existential questions. Spiritual care was holistic and rejected the body/soul duality often encountered in traditional Western medicine. Spiritual care was not oriented toward, or around, a faith tradition such as Christianity, but rather acknowledged the plurality of faith and faith traditions in the contemporary context. Spiritual care, at its core, was focused on the meaning-making journey of the person within the context of their personal life, as well as their world and relationships more broadly, which may or may not include religious practices and faith. In summary, VanKatwyk (2003) defined spiritual care as the following:

A pluralistic and inclusive practice that reflects on the such intrinsic qualities of the human spirit as the yearnings to give and receive love, to find and fulfil one’s vocation and potential in the world, and to be grasped by transcendent beauty and transforming values. (p. 4)

**Pastoral care.** Although authors combined the terms spiritual and pastoral care, VanKatwyk (2003) differentiated the two terms. While spiritual care was care focused on the holistic existential journey of an individual, VanKatwyk asserted pastoral care was specifically focused on care that aligned with, and drew upon, the Jewish-Christian religious traditions, beliefs, and practices, and connected individuals to care providers within their particular faith communities. Authors defined pastoral care as a specific form of supportive care rooted with the specific traditions and communities of the Judeo-Christian tradition (Campbell, 1987; Couture & Hester, 1995; Doerhing, 2006; Hoeft, Shannon Jung, & Marshall, 2013; Hunter, 1995; Pattison, 1988).
Pastoral care emerged from the ministry of the Christian church concerned with the well-being of both individual members, as well as the faith community (Campbell, 1987). Care is provided by both ordained and lay care providers within the context of a community of faith (Hoeft et al., 2013). Pastoral care differs from other forms of psychosocial care with respect to its faith-based, rather than secular focus (Doerhing, 2006; Hunter, 1995). Pastoral care acknowledges that individuals do not exist in isolation, but rather live, work, worship, and play, within deeply interconnected and relational networks (Hoeft et al., 2013). Sources of authority for pastoral care, for Christian providers, include the Hebrew Scriptures and New Testament, as well as liturgy, doctrines, and religious traditions and practices (Doerhing, 2006). However, pastoral care providers also draw upon resources in the social sciences, especially from sociology, psychology, and cultural studies (Couture & Hester, 1995; Doerhing, 2006). The overall aim of pastoral care is to offer, through a faithful community of believers, the comfort and support of a loving God and when possible to further the cause of justice for all who may suffer or are oppressed (Campbell, 1987). Pattison (1994) opined that pastoral care and the emancipatory goals of liberation theology were interconnected.

**Spiritual and pastoral care with caregiving mothers.** Pastoral care emphasises care grounded within a particular Judeo-Christian tradition and community, while spiritual care encompasses meaning-making more broadly. For the purposes of this discussion the pastoral and spiritual care of mothers will be considered together with respect to mother-child interconnected dyads who live and worship within mainline, Canadian Christian communities. Although researchers acknowledged that mothers who experience their children’s experiences in an embodied manner shared both their children’s joy and suffering, many explored providing support for those who suffered. This emphasis was continued with this discussion, regarding
supporting maternal caregivers who, because of an embodied interconnection, might enter their children’s pain.

**Maternal-child interconnection and the pastoral care of Christian friendship.** As modeled by Jesus and embodied by a community of believers, Swinton (2000b) proposed that radical friendship could be an effective form of pastoral care for people living with the chaos of mental illness. Swinton (2000a, 2000b) claimed that Christlike friendships embraced a practice of unconditional acceptance as well as communal solidarity that offered comfort and reassurance to those who may be living amid challenging situations. Swinton’s (2000a, 2000b) model of pastoral friendship provided a helpful model for conceptualizing how pastoral care might be embodied by communities of faith by offering unconditional acceptance to those who might be living chaotic lives.

As shared throughout this project, the research exploring the lives of mothers caring for children with significant disabilities indicated that mothers experienced numerous challenges. This study of mothers found similar results to several qualitative studies that indicated mothers entered their children’s embodied experiences, and correspondingly experienced their children’s challenges and suffering. Mothers caring for children with multiple, significant, and complex disabilities may experience their children’s complicated journeys. In the case of children who might be suffering, the results of this study indicated that the mother might be vicariously suffering. Christian friendship could be a resource for isolated and overwhelmed caregiving mothers.

Pastoral care can be offered by ordained and trained personnel (Campbell, 1985), but may also be provided by lay members of faithful communities (Kornfeld, 1998; Swinton, 2000a, 2000b), including those with diverse abilities and/or intellectual impairments (Shurley, 2017).
Hence, all members of communities of faith, if embracing the unconditional friendship and support encouraged by the model of Christian friendship described by Swinton (2000a, 2000b), and echoed by Wadell (2002), Vanier (2008), and Nouwen (1997, 2011), can offer rare, safe spaces for maternal caregivers where their embodied interconnection with their children is honoured, and their challenging journeys are supported. For mothers who inhabit a world that often fails to understand their interconnected relationships with their children, the opportunity to give voice to this experience within a community of loving friends offering unconditional acceptance was a rare gift and could have therapeutic value.

**Maternal-child interconnection and the Christian practice of lamentation.** An important aspect of the Christian tradition of providing care to those who suffer is offered through the communal practice of lamentation. For Swinton (2000a, 2000b), Christian friendship amid chaos was not a passive form of accompaniment, but rather an active engagement in another’s story absent theodicy or any other “fix-it” strategies. This active form of friendship could include the active, communal, and Christian practice of lamentation.

Lamentation is a contemporary liturgical practice that can offer a meaningful opportunity to those living in chaos, such as mothers who may share their children’s suffering, to voice anger and frustration with the Divine and to do so with the support of a faithful community who share the lament. Echoing the themes of interconnection, the traditional Christian lament is intended as a communal activity combining the voice of one who suffers with the voices of their community (Soelle, 1975). Thus, as in embodied interconnection, during a lament voices and experiences become mingled.

Soelle (1975) argued that lamentation facilitated the initial step away from the pain of suffering toward solidarity because the communal lament assisted a sufferer with articulating
their narrative of chaos. Once again echoing the spirit of embodied interconnection, lamentation bonded the sufferer with their community who shared in the lament. The lament offered a practical and active form to Swinton’s (2000a, 2000b) notion of Christian friendship. With a lament, the sufferer was actively supported by the loving friendship of their community as their story of pain and anger was articulated and communally shared by many bodies and mingled voices.

**Pastoral care in the form of advocacy for caregiving mothers.** Pastoral care offered to people who suffer can take many forms. Pattison (1994) argued that effective pastoral care not only provided support to individuals who suffer but also engaged in advocacy to create a more just and supportive world for their friends who suffered. Advocacy as a form of pastoral care provided an interesting lens to consider how faith communities might support caregiving mothers. Virtually all mothers participating in this study shared stories of oppression in the form of having their voices and advocacy on behalf of their children dismissed, particularly within formal structures such as health care and education. Communities of faith who advocate for mothers, and others who live with disabilities, might provide pastoral care in the form of both solidarity with the mother, but also in their efforts to create a more just and equitable world for caregivers.

Soelle (1975) defined lamentation as the first step of faith that communities offered in their journeys of advocacy to create the impetus to create societal change. Lamentation created the space for a sufferer to voice their pain and disillusionment with God. A lament allowed the sufferer to move beyond the overwhelming pain of mute suffering to find the voice with which to articulate their narrative of chaos. “By giving voice to lament one can intercept and work on his suffering within the framework of communication” (Soelle, 1975, p. 74). Although lamentation
gives voice to suffering, Soelle (1975) argued that a lament gives rise to new tension for the sufferer as their pain is drawn into sharper focus. Lamentation may lift the veil of injustice to reveal new sources of pain and hopelessness. For mothers who share their children’s suffering and social isolation in an interconnected and embodied way, communities of faith may have an important role in the form of pastoral care as demonstrated through advocacy and solidarity with an overwhelmed mother and child dyad by challenging formal and informal structures that fail to support mothers and children living with disabilities.

Theological Reflection

Whitehead and Whitehead (1995) noted that theological reflection attempted to integrate Christian tradition, personal experience, and cultural context together to make sense of events. It is an attempt to align Christian faith with the practical realities of the world in which we live. Whitehead and Whitehead (1995) defined Christian theological reflection as a person responding to key questions, such as the following: (a) What is my experience, (b) how does this experience impact our Christian community, and (c) how does or how might our Christian tradition respond to the issues at hand?

**Mothering and the imago Dei.** Whitehead and Whitehead (1995) offered a model for theological reflection incorporating the three conversation partners of (a) Christian tradition, (b) personal experience, and (c) culture, into a three step method of (a) attending, (b) asserting, and (c) pastorally responding to the issue. Attending, included seeking information about a pastoral concern via the three key points of tradition, experience, and culture. Assertion involved “bringing the perspectives gathered from these three sources into a lively dialogue of multiple clarification to expand and enrich religious insight” (Whitehead & Whitehead, 1995, p. 13). Finally, pastoral response explored how the discussion could translate to pastoral action. Using
Whitehead and Whitehead’s (1995) three-step method of theological reflection, I explored the theme of maternal-child interconnection within Canadian, Christian communities, particularly regarding the understanding of the imago Dei.

**Pronouns and gender.** Because this section of my research engages my personal experience, along with the Christian faith, I will honour my preferred method of referring to the Divine. I employ gender-neutral identifiers for God. I prefer to identify God using gender-neutral terms such as Creator, Sacred, or Divine; therefore, I employ those terms throughout my discussion. Further, because I explored interconnection through the experiences of mothers, there might be moments during the discussion when identifying God as “Mother” provided helpful insight.

**Attending.** Whitehead and Whitehead (1995) identified that the practice of attending began with the practice of deep listening to a theological question or concern, absent judgement, or presuppositions.

To focus the theological reflection, my personal narrative formed the impetus of this research project regarding the themes and stories that emerged following deep conversations with the 12 mothers. This study of interconnection between a mother and her child with significant disabilities emerged from my own personal experience caring for my son. Matthew lives with both significant physical and intellectual disabilities. He is nonverbal and cannot communicate his wants and needs with speech or augmentative communication strategies. His communication is limited to nonverbal cues, such as crying, laughing, or irritability.

Several years ago, a physician reluctantly wrote a prescription to manage Matthew’s pain. He did not want to write this prescription, and it was only my insistence that an inability to diagnose Matthew’s pain should not lead to my child’s suffering that led him to do so. The
Physician admitted as he was leaving the room that he was only writing the prescription to quiet a difficult mother. He admitted he was treating what he saw as my anxiety, through the conduit of my son’s body. It worked. We both felt better. I will add that several months later, the source of Matthew’s pain was diagnosed and effectively treated. There was a clear and measurable cause for my child’s distress.

As a mother, I knew my child was in pain. Like the mothers in this study, I knew it in my gut. My body was telling me that there was something that required attention happening within my son’s body. This embodied interconnection led to my advocacy with the physician. Although the physician struggled to understand the embodied interconnection between Matthew and me because it challenged all he had been trained to value as knowledge, he honoured our interconnection and treated both our bodies by treating my son’s body.

The results of this study echoed my experience and added to the narrative of maternal-child interconnection. Mothers told stories of meaningful interconnection with their child. Mother described sharing their children’s joy, pain, and anxiety. Similarly, mothers told stories suggesting that their children seemed to correspondingly respond to their mother’s experiences or emotional state. Mothers described embodied relationships between themselves and their children that felt porous and blurred. As a result of these porous boundaries between bodies, communication not readily apparent to others happened seamlessly between mother and child. And like my story, mothers also noted that this interconnection was poorly understood within formal structures. As I reflected on the theological themes of this research project, I found myself wondering how a study of maternal-child interconnection would inform a theological anthropology regarding how mothers’ experiences of interconnection provided new ways of considering the imago Dei.
**Asserting: Imago Dei, perichoresis, and interconnected mothering.** Historically, God was portrayed as masculine, and Christian theology oriented to a patriarchal worldview. Feminist theologians have argued that a feminist theological anthropology provided rich opportunities for a re-imaging of the *imago Dei* (Coakley, 2013; Daly, 1973; M. A. Gonzalez, 2007; McClintock-Fulkerson, 2001; Radford Ruether, 1983, 1985). As M. A. Gonzalez (2007) asserted,

> to transform the *imago Dei* into an egalitarian vision for all humans, we must do away with patriarchal constructions of God. The image of God must be grounded in our understanding of God as God has been revealed to us within human history. (p. 149)

As feminist and other liberationist theologians have entered theological discourse, greater opportunities for the marginalised other to enter the *imago Dei* have emerged.

Feminist theologians argue that the lived experience is a core ingredient of faith (Gonzalez, 2007; McClintock-Fulkerson, 2001). The challenge for feminist theology is to mine the experiences of women to enrich our understanding of God without resorting to essentialist, universalist, or socially constructed notions of womanhood or motherhood (Gonzalez, 2007). For many women, mothering is a profound life journey and an experience that provides rich opportunity for theological reflection. However, the journey of motherhood has also been fertile ground for traditional and patriarchal theological narratives that limit women to a God-given destiny of care and mothering to the exclusion of other roles forms of leadership. For example, Prokes (2009) explored Pope John Paul II’s *Mulieris Dictatum* and womanhood, especially mothering, through the exclusive lens of Mary’s mothering of Christ, rather than exploring a more inclusive and liberative *imago Dei*. A feminist theological reflection must honour the journey of mothering in such a way that women’s experiences, including the experience of mothering, inform a holistic understanding of the Divine and *imago Dei* without isolating the
role of women to a romanticized version of the caring, holy mother that honours care over and
above other forms of leadership, or worse limits women to kenotic mothering that encourages
self-abnegation.

Motherhood is almost always viewed synonymously with caring. Feminist theologians,
while not explicitly exploring the lived experience of motherhood, have offered helpful insight
into the valorization of caregiving within theological discourse. Often the patriarchal view of the
caring mother is portrayed using the model of kenosis; Christ’s voluntary and sacrificial, self-
emptying as an offering of care for the world. Feminist theologians stridently critique this
understanding of care, arguing that valorizing selfless care in such a way is dangerous for
women, and I would argue, particularly destructive for extreme caregiving mothers such as the
ones in this study (Coakley, 1996).

Feminist Goldstein (1960) defined the sin of women not as pride, or a desire for power,
which she viewed as male attributes, but as a tendency to self-abnegation. Coakley (1996)
argued that kenosis was an unhelpful theological ideal for women who might already struggle
with self-abnegation. Similarly, Nakashima Brock and Parker (2001) offered a compelling
narrative unpacking the dangers for sacrificial, caring women through the lens of domestic
violence. A caregiving mother who idealizes kenotic self-abnegation may avoid establishing
protective boundaries and risk self-harm. For mothers of children with significant disabilities,
such as those participating in this study, and for whom research indicated the ubiquity of
overwhelming caregiving demands, a theological model of kenosis may be particularly
destructive.

I returned to my original question for theological reflection: How do we explore
interconnected motherhood with respect to the imago Dei without resorting to essentialist or
destructive theological views of women, caring, or mothering? The answer might be found in a meeting of contemporary and ancient theology. Turning to the Christian understanding of Trinity, and in particular perichoresis, offers helpful opportunity to imagine the Divine in a way that honours motherhood without valorizing caregiving or kenotic self-sacrifice (A. Jorgenson, personal communication, June 7, 2019).

Perichoresis is the term used to describe the unique interpenetration of the three persons in the Trinity. Liberation theologians such as Leonardo Boff have argued that perichoresis provides a helpful model for both human relationships and communities (McGrath, 2007). Oliver Crisp (2007) argued that perichoresis exists in two ways. Nature-perichoresis describes the hypostatic union of both the divine and human in the person of Jesus Christ, while person-perichoresis is the interpenetration of the three persons of the Trinity. Person-perichoresis provides a helpful reflective model for maternal-child interconnection.

In the 4th Century of the Common Era, Athanasius wrote of the concept of homoousis in On the Incarnation (McGrath, 2007). Briefly, in On the Incarnation Athananius argued that Jesus Christ was homoousios. Homoousios means that Jesus was simultaneously Divine and human, and provided the foundation for the Christian belief for the indwelling of the Divine Parent in the human Child. Jesus, like the mothers in the study, was the embodiment of the porous experiences of two distinct beings: Divine Parent and Human Child. Theologically speaking, interconnected human motherhood, when viewed through the lens of the Divine Mother intertwined with her Child and infused with the mystery of the Holy Spirit, offers refreshing possibilities for a feminist imago Dei.

Pastoral response: Honouring maternal interconnection According to Whitehead and Whitehead (1995), the final response of theological reflection is the translation of reflection into
action in the form of a pastoral response. Indeed, insightful reflection is only meaningful if it offers insight into constructive pastoral response (Whitehead & Whitehead, 1995). So we must consider how a theological anthropology of an interconnected Mother and Child might offer comfort or guidance to maternal caregivers, as well as the faith communities within which they live, work, play, and worship.

One source of frustration among the mothers participating in this study was the fact that their knowledge of their child was often dismissed by a world that still embraced a dualistic understanding of the body. Mothers of children with significant disabilities spend the majority of their time engaging with formal structures that endorse a Cartesian understanding of the body, and an evidence-based approach to knowledge. As a result their embodied knowledge of their child was often minimised.

The cornerstone of the Christian tradition is built upon a belief in interconnected bodies. Person-perichoresis, or the mutual indwelling of Divine Mother and Child, offers a helpful narrative with which to explore what it means to enter into another’s experiences. Communities that accept the possibility that Jesus could simultaneously embody the Divine Mother and Self, offer powerful opportunities for isolated, caregiving mothers to voice their personal experiences and receive affirmation of their embodied, enmeshed experiences of mother and child. Similarly, the Christian belief in the ubiquitous mystery of the Holy Spirit that infuses and informs life and faith with personal meaning provides a helpful muse with which to consider interconnected human relationships. The Spirit that remains with us all and moves between and among bodies offers a helpful illustration of how human embodied interconnection can be experienced while still remaining elusive and difficult to articulate. Faith communities who embrace the Christian narrative of a Holy interconnection as demonstrated by the Trinity offer great promise as a safe
space for mothers to have their personal stories of human interconnection accepted, even celebrated.

I withdrew from my church community several years ago. The reasons for my withdrawal are many, and include concrete challenges such as inaccessible church buildings, to troubling theology that embraced theodicies that bordered on offensive at times. Faith communities often reinterpreted my journey of mothering my son to suit their own theological agenda. Church stopped being a safe space for me. The offering of a safe space where my story and knowledge of my child could be heard and valued would have been healing, particularly during a period of my life characterized by pain, confusion, and disempowerment by formal structures.

Swinton (2000a, 2000b, 2007) argued that one of the most powerful forms of pastoral care was to be with another and enter into their story. Soelle (1975) reminded faith communities that honouring the voices and experiences of those with difficult lives could be one of the most powerful forms of solidarity. Faith communities that value narratives of an interconnected Mother and Son offer unique opportunities for mothers to share stories of interconnection and porous, embodied knowledge. Similarly, by exploring a maternal God who knows Her Child in an embodied way provides a helpful muse to consider the imago Dei that may be particularly liberating for all mothers, and in particular mothers who are extreme caregivers.

Summary of Discussion

Maternal-child interconnection, as described by the twelve mothers participating in this study, echoed the themes of postmodern feminist literature describing a complex, leaky, and porous body that encompassed human and non-human appendages. Mothers’ interconnected knowing provided the foundation for much of the mothers’ care. As a result, mothers struggled
to navigate formal patriarchal structures that remained embedded in empiricism. Knowledge emerging from maternal-child interconnection created epistemological challenges for mothers navigating formal systems, such as medicine, that valued measurable, validated knowledge. This study aligned with the postmodern view that knowledge is subjective and highly contextual. Finally, pastoral and spiritual care, and in particular the Trinity as person-perichoresis, was explored with respect to caregiving mothers.
Chapter 6: Conclusion

This phenomenological study explored the research question, what are the intercorporeal experiences of mothers of developmentally delayed children? The results suggested the following: (a) Maternal-child interconnection was difficult for mothers to describe, but encompassed a sacred, mutual, and unique interpenetration of experiences between mother and child that was nurtured and sustained by ongoing togetherness. (b) Maternal-child interconnection allowed mothers to “speak” their children’s language regardless of verbal, or communication, abilities. (c) Maternal-child interconnection yielded a unique, and at times predictive, form of knowing that was often poorly understood beyond the mother-child relationship, particularly by health professionals.

The results of this study indicated similar findings to existing literature describing a complex, leaky, postmodern body that incorporated human, animal, and technological appendages. Similarly, the results of this project challenged a traditional, patriarchal understanding of knowledge and aligned with the postmodern, feminist assertion that knowledge was subjective, intersectional, and contextual. The narratives of the mothers in this project further supported the suggestion that embodied knowledge had a place in conversations about health and quality of life.

Theologically speaking, the results of this study supported calls for pastoral and spiritual care within communities that endorsed a supportive, non-anxious form of authentic friendship offered to caregiving mothers during chaos, as well as solidarity expressed by faith communities in the form of communal lament and advocacy within the broader social context. A theological anthropology expressed by imago Dei as relationship between mother and son was explored, regarding the simultaneous indwelling of the Divine Mother within the human child. The role of
such an understanding of the *imago Dei* was considered regarding its possibility for empowering caregiving mothers in terms of voice as well as embodied knowledge.

**Concluding Thoughts and Directions**

Engaging in a study is an empowering journey. The opportunity to ask questions and explore their answers is an exciting and valuable experience. The privilege of engaging in research that emerged from personal experience, and for which the results have personal meaning, was deeply meaningful for the primary investigator who was also a mother of a child with significant disabilities. Added to that privilege was the opportunity to contribute to the conversation exploring caregiving broadly, and more specifically the lives of caregiving mothers. As part of the journey of research, I discuss my journey and identify the challenges, personal growth, strengths, and limitations of the research experience, as well as its conclusions.

Research studies bring forth results that show insight about a specific research question. I explored the lived, interconnected experiences of a particular group of caregiving mothers; therefore, I offered tentative suggestions to practical questions, clinical scenarios, and future research. Similarly, this research project was limited in its scope; therefore, I must explore both the strengths of the project, as well as the limitations of both the project itself, and its conclusions.

**Strengths and Limitations**

The results of this study supported a postmodern feminist understanding of both the body, as well as embodied knowledge. The qualitative nature of this study offered both methodological strengths, as well as limitations. Quantitative researchers aim to generate conclusions that generalize to a representative sample (DePoy & Gitlin, 1998; Hulley & Cummings, 1988). Within the scientific paradigm, knowledge is defined as quantifiable, and
reality is believed to be tangible and measurable. Quantitative researchers aim to be value-free, valid, reliable, and replicable (Lincoln & Guba, 1985). Alternatively, the qualitative paradigm argues for an interpretative approach that emphasises both reality and knowledge as subjective and constructed, and argues that as such, objectivity is impossible, and generalizability impossible (Lincoln & Guba, 1985; Swinton & Mowat, 2006). A qualitative research design has considerable strengths, as well as limitations.

**Design of study.** Phenomenological researchers aim to explore the essence of a shared experience among informants (Van Manen, 1990); therefore, a strength of the study was that the qualitative design offered a unique glimpse, in a rich and detailed fashion, into the lived experiences of the interconnection among caregiving mothers. The lived experiences of mothers caring for children with significant disabilities are often invisible and their voices are often diminished, or absent, in clinical research and decision-making. There is considerable research exploring the lives of mothers of children with disabilities but limited research exploring how interconnection with their children informs their care. Thus, a strength of this study was its emphasis on the exploring the lived experience of a small population of mothers whose experiences have received little attention in the research and who have the potential to positively influence care. By listening deeply to the voices of mothers, communities of friends and professionals who support mothers and children with disabilities may have a richer understanding of the way that interconnection informs, and benefits, the care of children with intellectual impairments.

Although the qualitative design offered an opportunity to explore the stories of mothers, the method also had limitations. Qualitative studies are not generalizable to a population at large (Lincoln & Guba, 1985). Phenomenological researchers do not attempt to generate data that are
universally applicable to a population but strive to study experiences and phenomenon in a
detailed manner to provide a rich description of the essence of an experience (Creswell, 2013).
As a result, the results of this study do not represent the universal lived experiences of caregiving
mothers of children with developmental disabilities. One cannot interpret the results of this
study beyond the group of mothers participating in the study.

This does not mean that the results of this study do not offer insight into the lived
experiences of mothers caring for children with significant disabilities. Indeed, the results of this
study, while not universally applicable, do suggest that health professionals may wish to explore
maternal-child interconnection when working with mothers and children. This study indicated
that mothers often had deep insight into their children’s experiences, and respect for maternal
knowledge and intuition might allow health care professionals to support and care for children
with disabilities better, particularly those with communication challenges.

I explored the lived experience of a small group of mothers parenting children with a
range of significant developmental disabilities, and communication impairments. However, both
mothering and disability are not universal constructs or experiences. Continued study of the
interconnected experiences of mothers of children with diverse abilities, as well as those
parenting typically developing children, would provide additional insight into the experience of
maternal interconnection. Along that vein, additional research exploring the experiences of
fathers of children with both disabilities, as well as those parenting typically developing children,
would further illuminate the experience of parent-child interconnection.

No claims to objectivity can be made within the qualitative paradigm. The researcher,
herself, is a caregiver mother. Considerable efforts were made to ensure the trustworthiness of
the study, such as the maintenance of a reflexive journal, member checking, and peer-debriefing
(Lincoln & Guba, 1985); however, my lived experience as a mother of a nonverbal child with a profound intellectual impairment might have influenced engagement with the data. As Gadamer (2013) reminded, a person cannot step away from his or her experience and completely enter another’s experience. We always bring our experiences, or our personal horizons, with us to create a fusion of horizons. As a result, the researcher’s personal horizon as a caregiver inevitably engaged the stories of the participants. It is possible that the interviews or analysis were impacted by the researcher's personal experiences in ways that are not immediately identifiable.

Similarly, the primary investigator was an active member of the local, small, and often tightly knit community of mothers raising children with intellectual disabilities. Being a member of the community of interest offered the researcher the advantage of access to informants through personal connections. As well, being transparent about the fact that the primary investigator was also a mother of a child with profound disabilities offered the advantage of creating rapport between researcher and informant. Informants felt comfortable talking to someone who “got it”.

I was a member of the researched community, which was associated with limitations for the research study. First, there was the risk that mothers who wished to share their stories might decline to participate because they did not wish to share private details about their lives with a peer. Similarly, participants might have offered a certain narrative that affirmed the experience of interconnection because it was known among the community of mothers that a self-identified peer had a declared interest in the topic. Ongoing study of the experience of interconnection among mothers, as well as among other caregivers such as fathers or paid care providers, is essential and will provide helpful insight into the experience of embodied interconnection and its
role when providing care for people with intellectual disabilities and communication impairments.

In addition to the limitation of a qualitative research design, three additional limitations of this research project are important to discuss.

1. The study’s reliance upon a homogenous sample of mothers.
2. The research project’s emphasis on a Western understanding of the body.
3. The research study’s emphasis on a Christian interpretation of interconnection.

**Homogenous sample.** I employed a small, snowball sample of convenience. Twelve mothers were interviewed. All mothers, to the best of the researcher’s understanding, were cis-gendered. Nine mothers were in a heterosexual marriage, and three were either divorced or separated. None of the 12 mothers identified to the researcher as members of the LGBTQ+ community. Similarly, no mothers identified as being members of a racial, cultural, or religious minority. Most mothers had some form of post-secondary education, with only one mother sharing that she had not pursued studies beyond high school. Four mothers had a graduate degree. All but three mothers lived within the region of Kitchener-Waterloo, or surrounding areas. All mothers spoke fluent English. Hence, they were a relatively homogenous group of straight women, living in traditional family structures, who were well educated, articulate, and identified with the dominant, European ancestry often encountered in Kitchener-Waterloo, Ontario. Further study exploring the experiences of a more diverse sample of mothers is necessary to provide insight into the experience of maternal-child interconnection.

**Western emphasis on the body.** Cartesian dualism has permeated Western philosophical thought, as well as the medical model. All mothers involved in this study identified with European ancestry and were caring for their children with disabilities amid the traditional
medical and health care systems of Ontario; a system with long history of embracing a dualistic view of the body. As a result, traditional, Cartesian dualism and a Western understanding of the body heavily influenced the study. It is acknowledged that globally, as well as historically, there are numerous rich traditions that offer divergent, porous, and interrelated views of the body. Future studies of interconnection would benefit from the incorporation of diverse philosophies of the body and the inclusion of expertise that can speak to those understandings.

**Christian emphasis.** In addition to an emphasis on Cartesian dualism and Western philosophical thought, I acknowledged that the study was primarily viewed through the lens of a Christian researcher, studying at a Christian institution, within a secular, Canadian university. Theological and personal reflections engaged the Christian tradition, and this naturally led to conclusions ground within a Christian tradition and faith. Further, even among Christians, interpretations of Scripture and tradition could vary widely, and I approached the Christian faith through a progressive lens. Future studies, as well as the results of this study, would benefit from engagement by researchers and members of faiths outside of progressive, mainstream Christianity.

**Implications for Caregiving Mothers**

The work and voices of maternal caregivers often go unnoticed. Similarly, professionals working with children and adults with disabilities and communication challenges often struggle to understand the experiences of people who cannot effectively communicate their experiences. Although one should emphasise that both disability and parenting are not universal experiences, the inclusion of the voices of stakeholders, including maternal caregivers, in conversations considering clinical practice, research, and policies about caring for people with profound disabilities may improve care overall.
Similarly, research exploring the lives of caregiving mothers, including the results of this study, emphasised that mothers often experience a significant power differential when advocating for their children within the formal structures of education and medicine. The value and voices of caregiving mothers are often dismissed resulting in less optimal care for their children who cannot self-advocate. Continued research exploring and emphasizing the unique and valuable knowledge of caregiving mothers might serve to empower, and amplify, the voices of a vulnerable group of caregivers whose voice and knowledge has the potential to inform care yet remains underutilized.

Although I did not directly address the issue of boundaries and interconnection, it is important to note that maternal interconnection likely exists upon a spectrum. The results of this study would suggest that many caregiving mothers of a child with significant disabilities experience a healthy form of interconnection that allows them access their children’s experiences through their unique sense of blurred boundaries but do it in such a way that maintains healthy and safe boundaries for both individuals. Further studies must explore the extremes of the spectrum: caregiving mothers who are disconnected from their children, or mothers who are overly interconnected. Both extremes of interconnection are cause for concern. Ongoing study is necessary to further flesh out the contours of this spectrum of interconnection.

**Future Directions for Research**

This research project pointed to many future possibilities for research. Future research projects may include studies that explore the following:

- Maternal interconnection among women of diverse ethnic, cultural, and religious backgrounds.
• Interconnection as experienced amid family structures beyond the “traditional” family structure of mother/father, such as within families where children are being raised by two mothers, two fathers, or families that rely upon multigenerational parenting (i.e., grandparents, etc.).

• Experiences of interconnection among adoptive or foster mothers.

• Experiences of interconnection among mothers of children with diverse abilities, including typically developing children.

• Experiences of interconnection among fathers and other male care providers.

• Experiences of interconnection among other caregivers, including paid and professional care providers.

• The way that interconnection might be employed within medical and educational decision-making, in particular studies exploring the generation and “validity” of intuitive, interconnected knowledge and its impact on clinical scenarios.

• Larger scale, quantitative work exploring the predictive value of maternal/interconnected knowledge.

• Experiences of interconnection beyond parent-child.

Personal Reflection: A Final First-Person Story

The study emerged from an encounter with a physician struggling to assess and understand my son’s pain, and who was hesitant to treat pain he could not objectively diagnose. During the clinical encounter, I asked him to treat pain that I knew existed in my son’s body, but he could not measure. Based on his departing comment, he responded to this request by prescribing pain medication for my son, not to treat my son’s pain, but to address what he viewed as my anxiety about my son’s distress. In other words, he offered to treat my body by
medicating my son’s body. His proclaimed worldview and clinical practice might be entrenched in evidence-based knowledge and the medical model, but his ultimate approach to treating my son’s body, albeit reluctantly and perhaps even unwittingly, was linked to his acceptance of maternal-child interconnection.

Before concluding this paper, I would like to share one final, personal story that illuminates how care might be impacted when maternal-child interconnection is honoured, rather than dismissed. I must also share, that like the mothers in this study, this story has been the exception rather than the rule. However, I believe it is a powerful example of how a mother’s “gut” can inform and improve care when her voice, and her “gut” is heard.

Four years ago, Matthew, my son with profound disabilities who is also nonverbal, returned from his day program with a note saying he had had an “off” day. The nurse on duty that day could not find anything “objective” to note. Matthew did not have a fever, nor had he experienced a seizure. His feeding tube was running, his water flushes were updated, he had not missed any medications, his oxygen saturation levels were reassuring, and he did not seem particularly ill or distressed. In other words, there was no evident reason that any of us could pinpoint for him to be “off”. Yet, I agreed with the nurse. Within a few hours my “gut” was screaming, and I felt an impending sense of concern.

After a few hours of my gut telling me to be concerned with no obvious signs of illness, I packed Matthew into our van and drove an hour to our regional children’s hospital. Matthew was well known in the emergency room because of his medical history. I told the triage nurse that I was not entirely sure why I had brought Matthew to the hospital, but I was concerned and believed he needed to be there. At this point, Matthew still did not demonstrate any measurable symptoms. Yet, the nurse listened to my concerns, told me she trusted my judgment, and
brought Matthew to an observation room. To this day, I am grateful for her faith in my gut. An hour later, Matthew was in the intensive care unit (ICU) in respiratory distress, and a social worker pulled me into the hall to clarify our expectations surrounding intrusive and life-saving measures for Matthew.

To this day, we do not know why Matthew deteriorated so quickly, the cause of his rapid decline, or why my “gut” knew to be concerned. The medical team struggled to pinpoint the specific cause of his medical decline, and no formal diagnosis was ever confirmed to my knowledge. We were left with more questions than answers upon Matthew’s discharge from the ICU. Because I trusted my gut and a nurse honoured my knowing, Matthew received timely and appropriate care that likely saved his life. As I have engaged in this research project, I have often found myself reflecting on this experience. How did I know to be concerned about Matthew’s health? Why did my body respond to Matthew’s deteriorating health? Why did my ‘gut’ speak before measurable, clinical evidence? What if I hadn’t listened to my ‘gut’, or if the nurse hadn’t been willing to trust my knowledge in the absence of clear clinical evidence? Did other mothers have similar experiences? Does this sense of interconnection extend to Matthew? Does it extend to others? And perhaps most often, how do we better understand mothers’ ‘guts’ to improve the care and support for children with significant disabilities by creating environments that value, and hear, maternal knowledge?

The opportunity to listen to the stories of other mothers, who like me, have experienced the porous and blurred boundaries between their body and the body of their child, has been a rich, rewarding, empowering, and affirming experience. I had the rare privilege of reflecting on a personal experience to explore a similar journey with mothers navigating similar paths. I will be forever grateful to the mothers who entrusted me with their stories.
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Appendix A: Research Ethics Boards Approval

June 15, 2016

Dear Laura MacGregor

REB # 5750
REB Clearance issued: June 10, 2016
REB Expiry / End Date: December 31, 2019

The Research Ethics Board of Wilfrid Laurier University has reviewed the above proposal and determined that the proposal is ethically sound. If the research plan and methods should change in a way that may bring into question the project’s adherence to acceptable ethical norms, please submit a "Request for Ethics Clearance of a Revision or Modification" form for approval before the changes are put into place. This form can also be used to extend protocols past their expiry date, except in cases where the project is more than four years old. These projects require a new REB application.

Please note that you are responsible for obtaining any further approvals that might be required to complete your project.

Laurier REB approval will automatically expire when one's employment ends at Laurier.

If any participants in your research project have a negative experience (either physical, psychological or emotional) you are required to submit an "Adverse Events Form" within 24 hours of the event.

You must complete the online "Annual/Final Progress Report on Human Research Projects" form annually and upon completion of the project. ROMEO will automatically keep track of these annual reports for you. When you have a report due within 30 days (and/or an overdue report) it will be listed under the My Reminders' quick link on your ROMEO home screen; the number in brackets next to 'My Reminders' will tell you how many reports need to be submitted. Protocols with overdue annual reports will be marked as expired. Further the REB has been requested to notify Research Finance when an REB protocol, tied to a funding account has been marked as expired. In such cases Research Finance will immediately freeze funding tied to this account.

All the best for the successful completion of your project.

(Useful links: ROMEO Login Screen | REB Students Webpage | REB Connect Webpage)
Yours sincerely,

Jayne Kalmar, PhD  
Vice-Chair, University Research Ethics Board  
Wilfrid Laurier University

OR

Robert Basso, PhD  
Chair, University Research Ethics Board  
Wilfrid Laurier University

OR

Rosemary A. McGowan, PhD  
Vice-Chair, University Research Ethics Board  
Wilfrid Laurier University

Please do not reply directly to this e-mail. Please direct all replies to reb@wlu.ca
Modification to REB#5750 Clearance Notification

Thu, Sep 20, 2018 at 1:19 PM

do-not-reply-laurier@researchservicesoffice.com <do-not-reply-
laurier@researchservicesoffice.com>
To: "MacGregor Laura(Principal Investigator)" <macg4706@mylaurier.ca>
Cc: "Lund Kristine(Co-Investigator)" <klund@wlu.ca>, reb@wlu.ca, do-not-reply-laurier@researchservicesoffice.com

September 20, 2018

Dear Laura,

REB # 5750
REB Clearance Issued: June 19, 2018
Expiry / End Date: December 31, 2019

I have reviewed the changes (add option for interviews to be digitally recorded telephone interviews completed via a secure telephone line; revised recruitment poster) to the above proposal and determined that they are ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please contact me as soon as possible and before the changes are put in place.

(This letter has been issued on behalf of Dr. J. Kaimar, by Courtney Lund, Research Compliance Officer)

(Useful links: ROMEO Login Screen ; REB Students Webpage; REB Connect Webpage)

Yours sincerely,

Jayne Kaimar, PhD
Chair, University Research Ethics Board
Wilfrid Laurier University

Please do not reply directly to this e-mail. Please direct all replies to reb@wlu.ca
Modification to REB#5750 Clearance Notification

To: "MacGregor Laura(Principal Investigator)" <lauram4706@mylaurier.ca>
Cc: "Lund Kristine(Principal Investigator)" <klund@wlu.ca>, reb@wlu.ca, do-not-reply-laurier@researchservicesoffice.com

November 29, 2018

Dear Laura,

REB # 5750
REB Clearance Issued: June 15, 2016
Expiration / End Date: December 31, 2019

I have reviewed the changes (Recruitment expanded to include participants with whom the PI has a pre-existing social relationship; potential informants where there is an existing formal relationship will not be recruited) to the above proposal and determined that they are ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please contact me as soon as possible and before the changes are put in place.

(This letter has been issued on behalf of Dr. J. Kalmar, by Courtney Lunt, Research Compliance Officer.)

(Useful links: ROMEO Login Screen; REB Students Webpage; REB Connect Webpage)

Yours sincerely,

Jayne Kalmar, PhD
Chair, University Research Ethics Board
Wilfrid Laurier University

Please do not reply directly to this e-mail. Please direct all replies to reb@wlu.ca
Appendix B: Letter of Information

Laura MacGregor, PhD Candidate
Martin Luther University College/Wilfrid Laurier University

75 University Avenue West
Waterloo, Ontario, Canada
macg4706@mylaurier.ca
N2L 3C5
REB #:5750

Date:

Dear:

My name is Laura MacGregor and I am a doctoral student at Wilfrid Laurier University. I am completing a study of mothers who have a child with a developmental disability. My study focuses on how mothers experience interconnection with their children and how they describe this interconnection to others, particularly health professionals. A better understanding of how mothers experience this interconnection may assist people in the community who work with, and support, mothers and children.

I am asking mothers of a child of any age who has a developmental disability as well as a concurrent communication challenge to consider participating in my study. This letter will provide an overview of my research to assist you in deciding whether you would be willing to be involved. Participation in the study is completely voluntary.

This study involves participating in an interview that will take approximately 90 minutes. We can meet wherever you feel most comfortable. During the interview I will use a digital
recorder to record our conversation. Afterwards I will transcribe our conversation word-for-
word. Later I will study the interview in detail to learn more about how mothers experience a
deep connection with their children with a developmental disability. I have attached a copy of
the interview questions to this letter so you can have a chance to review the questions I would
ask.

Participation in this study is totally voluntary. You can decide to stop participating in the
study at any time, including during our interview, or even during the weeks following our
interview. If this happens your personal information and data will be removed and not used in
the research project. Prior to beginning the interview, I will review the study with you, including
the goals of the study as well as the risks and benefits of participating in my study. Before we
begin the interview, I will ask you to sign a consent form that indicates that you are willing to
participate. Again, even if you sign this form you can choose to withdraw from the study, or
stop participating in the study, at any time.

Your privacy is very important to me. The only place your name will be noted is on the
signed consent form that will be stored in a locked filing cabinet. Every other document will be
identified by a pseudonym. Any information that might identify you will be changed when I
transcribe the interviews. For example, when transcribing your interview I will change the name
of your child, the city you live in, or even the sex of your child, to ensure your information and
identity remains anonymous. All paper information will be stored in a locked filing cabinet. All
computer documents will be password protected.

It is possible that to manage my workload I may use a transcription service to assist with
typing interviews. The transcription service employs only individuals who have signed a non-
disclosure agreement. Audio files are destroyed immediately after transcription and transcribed
interviews are destroyed two weeks later. All computers are double password protected. I will only use a transcription service if you consent.

I hope to publish my work and share the results with the community, including people who provide support for families who care for children with disabilities. Part of sharing my work means that I might use details of your interview, including word-for-word quotes, in a paper or when speaking at a conference. All information gained from your interview, including quotes, will be identified by a pseudonym. Any part of your story that might identify you will have been changed.

The risks associated with this study are minimal. There is a risk that while participating in the interview you may re-visit a painful or difficult memory. I am a trained occupational therapist with experience working in mental health. I am also a trained support parent who has worked with parents caring for children with a range of complex disabilities, so I have experience working with parents during difficult moments.

I am hoping that knowing your information may improve our understanding of how mothers experience deep connection with their children who have developmental disabilities may be a benefit to you. Your participation in this study will assist in understanding this relationship and may help those who support mothers and work with children with disabilities.

This study has been reviewed and received ethics clearance through a Wilfrid Laurier University Research Ethics Committee, however the final decision about participation is yours. If you have any questions about this study or would like more information, please contact me at 519-885-3467 or by email at macg4706@mylaurier.ca. You may also contact my supervisor, Dr. Kristine Lund at 519-884-0710 ext. 2246, or by email klund@wlu.ca. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research
have been violated during the course of this project, you may contact Robert Basso, PhD, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

Yours sincerely,

Laura MacGregor
Ph.D. Candidate, Human Relations
Martin Luther University College
Wilfrid Laurier University

Dr. Kristine Lund
Professor
Martin Luther University College
Wilfrid Laurier University
Appendix C: Informed Consent

Wilfrid Laurier University Informed Consent Statement


Laura MacGregor, PhD Candidate

Dr. Kristine Lund, Professor, Wilfrid Laurier University

REB#: 5750

You are invited to participate in a research study. The purpose of this study is to explore the embodied interconnection between a mother and their children with a development disability. The researcher is a Wilfrid Laurier PhD Candidate in Human Relationships working under the supervision of Dr. Kristine Lund.

Information

Participants will be asked to participate in an interview. The study will take about 90 minutes to complete. Data from approximately 10-15 research participants who are mothers of a child with a developmental disability will be collected for this study.

- As a part of this study your interview will be audio recorded and transcribed verbatim for research purposes. Your consent to participate in the audio-recorded interview can be withdrawn at any time during the study. Laura MacGregor, and Dr. Lund, and with your permission transcription services, will have access to these recordings and information will be kept confidential at all times. The interview will be transcribed within 6 weeks.
- All recordings will be deleted following transcription. All transcribed interviews will be stored on a password-protected computer located in the researcher’s home. All paper documents will be stored in a locked filing cabinet. During the transcription process all
identifying information will be altered. Pseudonyms will be used to protect the confidentiality of research participants.

**Risks**

As a result of your participation in this study you may relive moments of sadness and difficulty you may have experienced during your parenting journey. While the provision of counseling services is beyond the scope of a research interview, the primary researcher trained as an occupational therapist and has experience supporting parents of children with complex disabilities. If appropriate a list of supportive counseling services will be provided to you if you to feel a need to explore further counseling as a result of any feelings raised during the research interview.

You are free to discontinue the study at any time and to choose not to respond to any question.

**Benefits**

Participants may benefit from the participation in this research project by knowing that their contribution to the study may assist people who support parents and their children with developmental disabilities, including health professionals, with enhanced understanding of how mothers experience deep embodied interconnection with their child. The research will contribute to the body of literature/knowledge on embodied interconnection and client-centred care.

**Confidentiality**

Maintaining all information in a locked cabinet will ensure the confidentiality of your data. All computer files related to this study will be stored on password-protected computer located in the primary researcher’s home office. Audio recording devices containing data not yet transcribed will be stored in a locked cabinet drawer.
The researcher may use transcription services to transcribe your interview. Transcribers have signed non-disclosure agreements, files are deleted after transcription, and computers are double password protected. Transcription services will only be employed with your consent.

The primary researcher is also a parent of a child with disabilities. As such it is possible that researcher and research participant may meet one another again after this research project. If this happens the researcher will not refer to the research project. If the participant choses to engage the researcher in conversation about the project only information shared publicly (i.e., published documents) will be discussed.

Please note the following limits to confidentiality:

- In any cases involving suspected abuse of a vulnerable child or adult.
- Any situations where the informant expresses suicidal ideation or intent.
- Identifying information such as consent forms will be stored separately from the data and will be kept for three years beyond the completion of the study, at which time they will be destroyed by the principal investigator. De-identified data such as transcribed interviews will be stored indefinitely and may be reanalysed in the future as part of a separate project (i.e., secondary data analysis).
- If you consent, quotations will be used in write-ups/presentations and will/will not contain information that allows you to be identified.

Contact

If you have questions at any time about the study or the procedures or you experience adverse effects as a result of participating in this study you may contact the researcher, Laura MacGregor, at lmacg4706@mylaurier.ca or (519) 885-3467.
This project has been reviewed and approved by the University Research Ethics Board (REB#: 5750), which receives funding from the Research Support Fund. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Robert Basso, PhD, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

**Participation**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty. You have the right to refuse to answer any question or participate in any activity you choose.

If you withdraw from the study, you can request to have your data removed/destroyed by contacting the primary investigator within 8 weeks of the completion of your interview.

**Feedback and Publication**

The results of this research might be published/presented in a thesis, course project report, book, journal article or conference presentation. If you wish to receive an executive summary of the research findings, please provide an email contact to the primary researcher and a review of the research results will be forwarded following analysis of the data. If you do not wish to provide an email contact, you are welcome to email the primary researcher by December 2018 to receive a summary of research results.
Consent

I have read and understand the above information. I have received a copy of this form as well as a copy of the letter of information. I have had the opportunity to ask questions and I agree to participate in this study.

Participant's signature ___________________________________
Date __________________

Investigator's signature ___________________________________
Date __________________

Email address of participant (optional) ___________________________________

Consent for Using Verbatim Quotes

I understand that verbatim quotes from my interview may be used in published documents or shared during conference proceedings. I understand that all confidential information will be altered, and a pseudonym will be used. I consent to the use of verbatim quotes.

Participant's signature ___________________________________
Date __________________

Investigator's signature ___________________________________
Date __________________

Consent for Using Transcription Services

I consent to the use of transcription services to transcribe my interview.

Participant's signature ___________________________________
Date __________________

Investigator's signature ___________________________________
Date _________________

Summary of Results

I wish to receive a summary of results following the completion of data analysis.

Participant's signature ____________________________

Date _____________

Email and/or address___________________________________________________
Appendix D: Recruitment Poster

Wilfrid Laurier University

Research Participants Needed

Are you the mother of a child with a developmental disability?

Photograph by Adrien Taylor downloaded with permission from unsplash.com

We are looking for volunteers to take part in a study examining mothers’ interconnection with their child.

As a participant in this study you would be asked to complete a semistructured interview exploring how you experience an embodied interconnection with your child, as well as how you describe that experience to others.

Your participation would involve one audio-recorded interview taking approximately 90 minutes. We can meet wherever you feel most comfortable.

For more information about this study, or to volunteer for this study, please contact:

Laura MacGregor, PhD Candidate

Martin Luther University College/Wilfrid Laurier University
This study has been reviewed by and received ethics clearance through a Wilfrid Laurier Research Ethics Committee. (REB #5750)
Appendix E: Semi-structured Interview Guide

Interview questions:

1) Can you tell me about your child? Your family?

2) How does your child communicate? With you? With others?

3) Can you tell me about a moment (or moments) when you experienced the world through your body? (examples: exercise, music, meditation, prayer).

4) How do you know what your child is feeling or experiencing?

5) Can you tell me how your awareness of your child’s feelings/experience/sensations has changed over time? Is it still evolving? How so?

6) How would you describe the connection between you and your child? Can you describe a moment when you felt deeply connected with your child?
7) Can you describe a situation when you believe your experiences/feelings impacted your child?

8) If you were to describe an image/metaphor/piece of music that captures the connection between you and your child, what would that be?

9) Can you describe a situation when you were required to share your child’s experiences with another such as health professional?

10) Is there anything further you would like to share?
Appendix F: Member Check Summary

Following transcription of the interviews, textual data was reviewed to determine emerging themes. When studied together the 12 interviews tell a “big picture story” that sounds something like the following:

1. Mother-child interconnection:
   a. Can be difficult to describe with words.

      The interconnection I feel with my child is real and takes many forms that can be difficult to fully capture with words—intuition, gut-feeling, shared energy, a dance, joy within the same activity.

   b. Means our boundaries are blurred.

      Most mothers at some point told a story that described overlapping boundaries between their children and themselves. Mothers talked about their children being “a part” of them, of blurred boundaries, of having interconnected roots, of being a single unit, and so on.

   c. Means we share experiences.

      Mothers offered numerous experiences of shared joy, but also shared distress. Mothers described seeing something as if for the first time through their children’s eyes, or of sharing intense excitement. As well mothers described feeling shared pain, cold, and so on. Similarly, mothers noted these feelings
appeared reciprocal. Many mothers shared that their children responded to their behaviour/energy as well. When the mother was upset, frantic, or ill, the child responded with changed behaviour.

d. Is a mom thing.

_Mothers described that this sense of interconnection is often unique to the mother-child relationship._ Even very involved, active, caring fathers often did not have the same ability to enter their children’s world or understand their unique communication. Maternal knowledge was a unique and powerful tool in understanding their child.

e. Is built upon a close, ongoing togetherness.

_Mothers noted that their sense of interconnection and ability to read their children emerged as a result of a prolonged and intimate history with their child._ For many mothers this meant that their “read” of their children were not a “hunch” but actually an interpretation based on an extensive and sophisticated journey of interpreting nonverbal behaviour and shared experiences.

f. Is sacred.

_Several mothers described their interconnection with their children as a spiritual, unique, and profoundly meaningful relationship._
2. Mother-child interconnection means that I understand my nonverbal child’s communication.

   Mothers of nonverbal children provided numerous stories of how their sense of interconnection allowed them to develop a sophisticated ability to understand and translate their children’s behaviour and experiences. Mothers of nonverbal children were very clear that despite the fact that their children do not speak s/he communicates in a meaningful way to those who are attentive and willing to enter their children’s world.

3. Even though my child speaks our interconnection is what allows me to understand his/her wants/needs.

   This was a particularly interesting finding. One would assume that children who have some verbal ability might be more skilled at communicating their wants and needs. However, most mothers noted that even though their children were able to speak they often struggled to communicate sophisticated or abstract ideas (feelings, pain, distress, etc.). Several children had very limited verbal skills. As a result, mothers of verbal children with developmental disabilities relied extensively on their ability to “read” their children—both to understand their wants and needs, but also as a tool to translate verbal speech to outsiders. Verbal skills did not seem to suggest that a mother relied less on their interconnection with their children as a tool to interpret their children’s needs/wants.

4. Maternal-child interconnection: Professionally speaking
a. I often know when something is wrong.

   This was a fascinating theme. Initially I organized quotes that talked about “mothers’ knowing”. However, it quickly became obvious that many mothers had stories where they “knew” in a predictive way. Mothers predicted diagnoses and health issues before health professionals. Mothers often “knew” something was “wrong” before others.

b. When I am heard my child’s care is enhanced.

   Mothers shared stories that when their “sixth sense” was honoured effective and timely cared ensued.

c. When I am ignored the outcome is often unfortunate.

   Similarly, and unfortunately more often, mothers also shared stories that when their “gut” or “sense of interconnection” was ignored their children’s care was compromised.