

***“I seemed to understand”:***  
**Mothers’ Experiences of the Schooling of their Children**  
**with Multiple Disabilities**

A thesis presented to the Faculty of Education and the Department of Women’s Studies  
University of Ottawa

In partial fulfillment of the requirements for the degree of  
Master of Arts in Education (Specialization: Women’s Studies)

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## ABSTRACT

Mothers of children with multiple disabilities have unique and important things to tell us about their children's schooling. In this work, the overarching question asks: *How do the mothers of children with multiple disabilities narrate their experiences with their children's schooling, and what insights can their stories provide?* Within a feminist framework that acknowledges participating mothers as "expert witnesses" (Traustadottir, 1991, p. 216) with important insights, this study employs a hermeneutic-phenomenological approach to develop the themes that, taken together, can be said to describe these participants' experiences. Four mothers of children with multiple disabilities were interviewed in an open-ended qualitative manner, and their experiences are thematized in this thesis. It is my hope that the stories so generously offered by the participants, and the themes which arise from them, can play a part in guiding those involved in the education of students with multiple disabilities, in changing our practice and policies in order to truly include children with disabilities and their caregivers in our schools.

## ACKNOWLEDGEMENTS

I want to thank my supervisor, Dr. Cynthia Morawski, for her encouragement, guidance and patient support over the course of this project; without Cynthia by me at the helm, this project would have seemed overwhelming and untenable. I would also like to acknowledge my appreciation for the rich readings and suggestions made by my committee members, Dr. Patricia Palulis and Dr. Raymond Leblanc. And, although she was not directly involved in my thesis experience, Dr. Jessica Whitley was a fundamental element in my development as a researcher and student – I want to extend my appreciation to her for including me in her important projects and for guiding by example.

I also need to thank my family for their strong support and encouragement in this project, as well as my other educational and professional undertakings. Although I don't thank them nearly enough, it should be noted that I appreciate all of their love and support.

My partner, Martin, of course, was a key ingredient in this project. Reading draft upon draft, and bringing tea-cup upon tea-cup, he propped me up and encouraged me in tireless and important ways. I hope that I can manage at least a fraction of what he's done for me as he works towards his doctorate. His love and his cheerleading were extraordinary.

Last, but certainly not least, I need to acknowledge the mothers who made this project come to light. The four participants who carved out space in their busy lives for our conversations, generously shared some extremely vulnerable and touching stories about themselves and their children. I hope that this work does their words some justice, and that their knowledge can be used to inform and improve schooling practices for students with disabilities. I should also acknowledge the mothers who led me to this project – who with their advocacy, love and determination – showed me that the status quo was grossly insufficient. This project took its roots in their comments and their hopes.

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## Push

*You were pulled away,  
told to sit down,  
taught to use picture symbols,  
to kiss the baby doll.  
That would satisfy them –  
plastic affection,  
obedience  
and oh,  
to communicate.*

*Kindergarten –  
a quieter place  
little shoes lined up in the hall.  
You learned your routine,  
to cleanup,  
put in your chair,  
sit with kids.  
Those kids –  
fast talking, moving, sharing tea cups, Lego,  
dolls  
like the blur of the ceiling fan.  
They didn't come over.  
I ached for you,  
for me  
they didn't see.  
The fan above  
kept you company  
and you waved hello.*

*You made things  
you showed me your love of animals and  
dinosaurs  
you made drawings with details  
that your peers couldn't draw.  
Their voices were louder,  
their hands stronger,  
thicker lines on paper –  
typical lines.  
So people praised them  
while you circled the room  
trying not to be seen.*

*You see things  
you know things  
you can't say things  
very often.  
Wordless  
yet full of hums, clicks and whoops,  
you uttered many  
like jazz  
I seemed to understand.*

From *Push* by Estée Klar

## INTRODUCTION

### Talking with Mothers

*I'm a mum who doesn't sit.* (Kristine)

Over the course of this research, I met four mothers who do not sit. Their days are filled with appointments, phone calls, therapies, love, planning, feeding, bathing, toileting, brainstorming, wondering and advocating for their children with multiple disabilities. They squeezed me into their schedules, welcomed me into their homes, and showed me a glimpse of their days – phones rang, children entered and exited, doorbells rang, pets demanded attention, a didgeridoo was played, and the cooking of dinner was postponed. As they described their experiences with their children's schools, stories sprang forth as if they had happened only yesterday. Not a single interview was less than the hour I had asked participants to put aside, and most of the participants voluntarily doubled (even tripled) the amount of time asked for. These mothers, who don't typically allow themselves time to sit, sat with me for hours and told me about their experiences.

### The Guiding Question

The experiences of mothers of children with disabilities are wide-ranging and include countless professionals, institutions, late nights, early mornings, advocacy, arguments, and celebrations. All of these elements emerged as I sat with participants, re/living their experiences. In an effort to focus this research, while still allowing participants to guide our conversations to what they found most salient, I developed the following research question:

- *How do the mothers of children with multiple disabilities narrate their experiences with their children's schooling, and what insights can their stories provide?*

The participants in this study narrated many stories, weaving the joyful with the infuriating, those experiences that kept them “*lying awake at night, angry*” with those that filled them with “*gratefulness*” and brought tears to their eyes. This thesis introduces the stories of each participant, and then weaves some of their significant statements into wider themes.

### **Framing the Problem**

*What might be learned if we heard parents’ stories of their children’s schooling experiences and their stories of their own experiences as parents in relation to the school landscape? (Pushor, 2007a, p. 9)*

Canadian schools and school boards are increasingly developing policies that are oriented towards the inclusion of parents and parental knowledge. Additionally, research has begun to explore some of the issues around families with children with disabilities (Edelson, 2005; McKeever and Miller, 2004; Read, 2000), as well as the experiences of these children and their families with schooling (Malacrida, 2003; Watson, 2008; Murray, 2000; Hess, Molina & Kozleski, 2006; Todd and Jones, 2003). Nevertheless, Ryan and Runswick-Cole (2008) discovered that parents often cite their relationships with professionals as one of the central struggles that they encounter in the raising of their child. Read (2000) makes a similar observation, writing: “[I]t was ironical that contact with the services that were ostensibly there to help them and their children had proved to be some of the most stressful and difficult experiences that they had had” (p. 34). The intent of this study is to develop insight into the experiences that mothers of children with profound, severe, or multiple disabilities (hereafter referred to as “multiple”) have with their children’s schooling.<sup>1</sup>

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<sup>1</sup> This study included the mothers of students with a variety of disabilities, including developmental disabilities, physical disabilities, visual impairments, ASD, and many others. Each student had more than one disability and so, for the purposes of space, I have chosen to use the umbrella term of “multiple” to describe the children’s disabilities. Concerns about labelling and “disability” are further considered in the section “Negotiating Disability.”

In order to best develop an understanding of these relationships, we must turn to parents themselves. As Ware (2002) reminds us: “the knowledge parents possess can remake what we know about living with a disability” (p. 148). Like others (including Kingston, 2007; Read, 2000; Traustadottir, 1991), I believe that it is essential to pay specific attention to mothers, who are the primary (although not the sole) caregivers and advocates of children with disabilities.<sup>2</sup> As such, my research focuses on the experiences of *mothers* of children with disabilities. Without an account of mothers’ experiences with their children’s schools, we fail to acknowledge an element that is central to the success of students with disabilities.

Thus, the guiding question of this study asks: How do the mothers of children with multiple disabilities narrate their experiences with their children’s schooling, and what insights can their stories provide? By learning about the experiences of these mothers, we (a) learn how the “partnership” between schools and parents is actually being manifested in their lives, (b) consider whether students’ needs and potential are being fully addressed, and (c) recognize and incorporate the oft-overlooked voices and stories of mothers. If mothers’ experiences are not considered, then schools risk inadequately serving their students (see Murray, 2000; Reay, 2005; Ware, 2002), while devaluing the knowledge and beliefs of mothers.

### **Two Key Terms: Disability & Mothers**

*You must sharpen your ear, you must realize that when you take a word up in your mouth, you have not taken up some arbitrary tool which can be thrown in a corner if it doesn’t do the job, but you are committed to a line of thought that comes from afar and reaches beyond you (Gadamer, 2003, p. 548).*

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<sup>2</sup> The Roeher Institute (2000) reported that mothers are the primary caregivers of children with disabilities in Canada, reporting that they spend “between 50-60 hours per week ... in addition to other workforce or domestic responsibilities” (p. 20). My research focus on mothers will be explored further later in this introduction, as well as in the literature review.

## Negotiating “Disability”

Disability is not a simple, monolithic entity. As numerous disability activists and theorists (e.g., Corker and Shakespeare, 2006; Wendell, 1996) have pointed out, such an overarching sense of disability (and thus, what it is to live with a disability) fails to do justice to the detail and personal intricacies of each life. Corker and Shakespeare (2006) challenge the totalizing claims that abound in the discourses around disability:

We believe that existing theories of disability – both radical and mainstream – are not longer adequate. Both the medical model and the social model seek to explain disability universally, and end up creating totalizing meta-historical narratives that exclude important dimensions of disabled people’s lives and of their knowledge. The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas (p. 15).

This diversity is an important reality in the educational realm as well. For example, the distinct academic needs and abilities of a young Deaf woman and a boy with severe developmental and physical disabilities are significant and can not be ignored. Erevelles (2005) makes the importance of this distinction clear, when she challenges the totalizing discourses that dominate both education and special education by introducing a student named Peter, who has multiple and severe disabilities:

... A radical transformation would require that educational theorists begin to dismantle the ‘normalizing’ ideologies that serve as the cornerstone of even radical theories of difference and explore the implications of such changes ... Only then will it be possible to really ‘see’ Peter (p. 436).

I appreciate this insistence on “seeing” Peter in all of his complexity. Employing an overarching and dualistic concept of “disabled” student versus “non-disabled” student allows for neither detailed, nor honest, research and practice.

I want to move away from generalizations about parenting a child with “a disability.” Following Ryan and Runswick-Cole (2008), I believe that “the lumping together of such diverse

experiences [in research] is, in itself, a form of disablism, because it fails to engage with very different life experiences” (p. 207). Individuals with disabilities have extremely different experiences and understandings of living with disability, as do their parents and caregivers, and these extremely different experiences deserve acknowledgement. As McDermott and Varenne (1995) powerfully ask, “On what grounds could experts have assumed that the complex worlds of individuals in multiple relationships with each other could stand still long enough to be characterized by simplified accounts...?” (p. 337). Simplified accounts do no justice for children with disabilities. To best support these students and their families, we need to recognize all the spaces and variation that lie within the term “disability” and begin to excavate them.

As such, the focus of this study is shaved down to mothers of students with multiple disabilities. I believe that focusing on a subsection of the broad category of “mothers of children with disabilities,” will provide a more textured account of the particular experiences of a particular group of mothers. There is not a great deal of research or theorizing done regarding the experiences of students with more severe disabilities (as discussed in Erevelles, 2000; Feder Kittay, 1999; Gottlieb, 2002). Erevelles suggests that one reason for this dearth is the lack of clear voices coming from this population. Referring to the research challenge of unclear voices, Ryan (2005) suggests that a “focus on mothers ... [can] provide rich insights into the position of a group of children who may not be able to conform” (p. 291). She thus confirms the usefulness of turning to voices and experiences of the mothers who care and advocate for their children with multiple disabilities. In foregrounding mothers’ voices, we will hear stories and explore experiences that are not always readily available, and which provide important perspectives on the schooling of students with disabilities.

## Negotiating “Mothers”

At this point, it should be mentioned that my focus on mothers was not done without consideration.<sup>3</sup> There are two concerns that must be addressed before continuing. First: why not turn to the voices of the students with disabilities themselves? Certainly, these voices have been long overlooked in educational settings; and these voices are important for us to develop an understanding of the school experiences of children with disabilities. Second: why focus on mothers to the exclusion of fathers? Does this not simply reflect long-held gender stereotypes about who does (and should do) the parenting?

In addressing the first question, it must be acknowledged that students with disabilities have long had their voices denied an arena (French and Swain, 2004; Morris, 2003; Watson, Abbot, and Townsley, 2006). Indeed, there remains a significant lack in this regard – a lack which needs to be addressed. Nonetheless, I align myself with McLaughlin’s (2006) claim that

Disability studies is enhanced by exploring the experiences of parents who care for disabled children ... By capturing the difficulties parents, in particular mothers, face in the refusal by others to care for them as well as their children, what is being captured is the social exclusion of people (parents and children) who experience disability (no pagination, section 9.4).

In turning to mothers, I do not intend to minimize the importance of the voices of people with disabilities. Rather, like Panitch (2006), it has been my goal to frame this paper with an eye towards “mothers’ disability activism” (p. 307).

Much like people with disabilities, mothers of children with disabilities have also had a frequently silent, and occasionally demonized<sup>4</sup>, role in the realm of special education; they too have voices that need to be heard, and a critique of special education. Harmonizing the voices of people with disabilities and those of their caregivers will ultimately result in a fuller

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<sup>3</sup> This focus is further explored in the literature review

<sup>4</sup> Consider the term “refrigerator mothers,” that was used as a popular explanation for their children’s autism.

understanding of disability and education in today's society. Further, as pointed out in the introduction, when dealing with students who have very 'uncertain' voices, we can turn to mothers to provide "rich insights into the position of a group of children who may not be able to conform" and join in the dialogue around their educations (Ryan, 2005, p. 291).

Let us turn to the second question: why discuss mothers to the exclusion of fathers? Popular educational discourse indeed refers to *parents*. Numerous provincial documents emphasize parental involvement and support, as we explore in the Literature Review. Similarly, textbooks designed for teacher-candidates also focus on engagement with parents.<sup>5</sup> Much of the research done in this area of home-school relationships has similarly avoided making distinctions according to gender. While it would be easy to follow this trend, I believe that assuming a gender blind approach obscures an important element of raising a child with a disability. Without an honest recognition of who it is that does the lion's share of raising, caring and advocating for a child with a disability, we miss an element that is central both to the lives of these mothers, and to the lives and educations of their children.<sup>6</sup> The Roeher Institute (2000) found that, in Canada, mothers caring for children with disability had significantly poorer health than mothers of children without one (p. 22-23); they also reported that these mothers spent an average of 50-60 hours a week, caring and advocating for their children (p. 20). Similar findings from Brehaut et al. (2004) indicate that, compared to other Canadian parents, care-givers<sup>7</sup> of children with cerebral palsy reported lower incomes, poorer psychological health, and poorer

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<sup>5</sup> As the Canadian textbook by Smith et al. (2005), used when I was a pre-service teacher at the University of Ottawa, claims: "teachers, parents, and other family members all should gain from co-operative relationships that truly flow in both directions" (Smith et al. 2005, p. 410).

<sup>6</sup> I imagine it would be clear to anyone after spending a day or two in a classroom with children with disabilities that mothers are the parents having the most consistent contact with the schools of their children – educators and other professionals don't need a research study or text book to "reveal" that fact. Nonetheless, there exists some very revealing research on the lives of mothers of children with disabilities.

<sup>7</sup> Given the emphasis on gender-neutral language in the literature, we are left to add words where there are none. We know, through research and experience, that most primary caregivers are still women, so when I read "most caregivers" or "most parents" I'm really reading "most mothers."

physical health. I follow the work of Traustadottir (1991), Greenspan (1998), Kingston (2007), and Read (2000), among others, in asserting that specific attention needs to be paid to the mothers of children with disabilities.

I would like to emphasize that my focus on women's experiences of parenting is by no means prescriptive. *Recognizing* the gendered dimension of care-giving is not *condoning* it.<sup>8</sup> Nor does recognizing mothers' roles as primary caregivers exclude the fact that there are instances of others, such as fathers or grandparents, providing this care. Nonetheless, it is the case, in Canada today, that mothers continue to be the overwhelming majority as the primary caregivers and advocates for children with disabilities. Because, in caring for children with disabilities, women are the de facto majority, I assume a gendered and feminist focus for my research into the experiences of mothers with their children's schools.

In this study, the stories of mothers are relied on to describe schooling experiences, and to share what they consider most meaningful of their experiences. Like Traustadottir (1991), I consider mothers to be positioned as "expert witnesses" (p. 216). I accept Phillips' (2005) description of the "argument from local knowledge" which calls for parental involvement in schooling. "Parents," she asserts, "are better placed than distant policy makers or administrators to identify the strengths and weaknesses of a child's school" (p. 86). This knowledge should be central to educational policies and practices. It is only when mothers have opportunities to share their experiences and ideas that we can truly work towards the call for home-school partnerships.

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<sup>8</sup> There is some fascinating research done by Fox (2001) and Ranson (2010) about the gendered (and gendering) dimensions of raising a child. Both note that the introduction of parenthood to Canadian couples often and significantly changes the division of labour within the home. As Ranson puts it: "The bottom line, in Canada as in many other industrialized countries, is the responsibilities of parenthood continue to be 'gendered and privatized' (Fox 2001:388) – with mothers continuing to face greater demands than fathers" (p. 17).

## Methodology

This research, which recognizes the gendered dimension of care-giving and views the experiences of mothers *specifically* as central and insightful, thus frames its goals and analysis with a feminist lens. It is my hope that the lived experiences of participating mothers, understood in their specific contexts, will show us some of the cleaves and corners of the relationships between schools and the mothers of students with multiple disabilities.

In order to develop an account of the experiences of these mothers, this study takes the form of a hermeneutic phenomenology. Relying on the stories that mothers share, I draw upon significant statements and stories in my effort to describe a set of themes which they hold in common<sup>9</sup>. As Dr. Morawski suggested, the “patterns of meaning” that this study developed are both thematic, repetitive patterns, and also include some “patterns of chaos,” emerging from the stories of women who have pushed forward, through sometimes seemingly impenetrable institutions and professionals, in an effort to care and advocate for their children.

The four mothers who graciously agreed to spend time with me all had children over the age of 18 with more than one disability. Between the four, they lived in or around two cities, in two different provinces (Quebec and Ontario); yet, despite the different ministries and school boards, a significant amount of experiences stretched across municipalities and provinces. Three of the four children had completed their schooling and were involved in various activities in their communities. Three mothers were no longer living with their children’s fathers, the fourth was married and living with her husband. Three of the four mothers were still living with their children with disabilities, the fourth mother’s child had, within the past few years, moved into a

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<sup>9</sup> It is not my intention to minimize the differences between women’s experiences. As I discuss in further depth in the section entitled *Immersing Myself in Stories*, it is important to note the commonalities as well as the distinctions that characterize individuals’ experiences. In sections 4.1 – 4.4, I introduce the participants independently, noting the strong themes that emerged from each mother’s experiences, in 5, I offer some of the themes that have emerged from their four lived experiences, taken together.

group home in the same neighbourhood, and they saw each other regularly. All of the mothers were loving and passionate about their children and their children's best interests. Although several were initially afraid they would have trouble remembering their experiences with their children's schooling, stories – some wonderful, some infuriating – nonetheless quickly spilled forward. It was a privilege to hear their reflections and ideas.

### **Positioning Myself in the Research: What Brought me Here & Where do I Stand?**

Following the approaches of both feminist theory and hermeneutical phenomenology, it is essential to remain cognizant of my personal relation to the subject matter. As outlined below, this area of research came to me out of my personal experiences of simultaneously working as an educational assistant and home support worker. It is further complicated by the happy reality that I have recently become a special education teacher. Peshkin (1989) suggests that a researcher is responsible for staying alert to the “warm and cool spots” (p.18) that arise during research, noting that these show us our various biases; with my new overwhelming entry into teaching, these “warm” spots are blisteringly hot and the “cool” ones are frigid. I do my best to acknowledge and consider these biases, remembering always that a student's best interests are served if parents and teacher are dancing to the same beat. This dance is another of my responsibilities. But what brought me here in the first place?

### **What Brought me Here?**

I was brought to this project by mothers' stories. Through my work in students' homes, I regularly heard claims like: “She understands all these different words! Why don't they use them at school?” or “I'm sure he's started having seizures, but they keep telling me I'm seeing things.” Mothers in the kitchen, their child's bedroom, or over the phone from work, telling me

that they didn't feel heard – reporting, often with a desperate undertone, a disjuncture between themselves and the professionals working with their children with disabilities.

My concern about the relationship between mothers and professionals in special education was emerging slowly, sharpening over time. During my BA, and for a few years afterwards, I was working as both an educational assistant and a home-support worker. I was seeing the same children in remarkably different circumstances, and I was often struck by a gap between these two worlds. I noted that children behaved differently in these worlds, and had to meet different expectations, that they thrived and struggled with things that were uniquely apparent only in these environments. Of course, the fact that school and home have different expectations is true (and typical) for any child, but I found the distinction to be striking. Given that these students had, at best, emergent language, they were not able even to begin bridging the gap between school and home. I was working within and across the gap between students home and school experiences, and seeing how these two worlds impact the lives of students. For this reason, it was becoming clear that regular and respectful communication between schools and homes needed to be all the more central.

My position of straddling two worlds gave me the awkward privilege of watching very different scenes pan out. On Saturday evening, exhausted parents would ask me how to convince the speech therapist at school that their child needed support, and on Monday morning I'd be warned before the IEP meeting that the mother who was coming in was pushy or demanding.

My intention is not to imply that professionals and parents were not making efforts to address this challenge. Certainly, I never encountered anyone who was trying to do harm or purposefully exacerbating the situation. Nonetheless, conflicts and miscommunications did

emerge regularly. Many parents – many mothers – felt unheard and unsupported by the school. Many professionals in the schools felt undermined and negative about students' home-lives. A significant amount of tension, disagreement, and outright conflict characterized relationships between these stakeholders. In particular, I was struck by the level of disdain some mothers received from schooling professionals – they advocated too hard or too little, were crippling their child's progress or expecting too much; there were many, many ways that mothers deemed to be harming, but few ways considered to be helping. Indeed, I was not immune from these tense relations; I can not honestly assert that I was always above the fray. Working in homes and in schools, I developed relations with mothers that had moments of extreme cooperation and support, as well as moments of disagreement and frustration. My dual role, although sometimes awkward, placed me in a privileged position to observe some of these gaps.

When I entered the Bachelor of Education, I began to read about policies of parental involvement. Here, I was able to step back and reflect on the educational policies of parental inclusion and support. *'What would the mothers I've worked with have to say about that?'* I wondered. With this question in mind, my past work experiences came to be illuminated, and I began to understand that my experiences took place within a broader and more complicated backdrop. Once I realized this, and stepped back, I saw that there was something bigger there, something to unpack. These personal stories had a place in a bigger story, a structure that was not quite apparent or effable.

### **Where do I Stand?**

As I've already mentioned, my positioning in this bigger story is further complicated by my current employment as a special education teacher. I sometimes see myself grimacing when I hear the phone ringing, knowing it to be a parent with a concern, question, suggestion, or

occasional accusation. I *force* myself to write in communication books – knowing that these are an essential tool for parents of non-verbal children, but I certainly can't find the time in the day to write everything that I would like. Possible conversations are cut short, students' days aren't fully captured in the daily communication. My role as researcher has come to be a spectre in my new role of teacher<sup>10</sup> – I am always trying to navigate with it and around it, remembering that despite all the frustrations and challenges of being a new teacher, I *know* that mothers have important and illuminating knowledge to share. My latest challenge is making a space in my pedagogy to share them. As Van Manen (1990) phrases it: “When we raise questions, gather data, describe a phenomenon and construct textual interpretations, *we do so as researchers who stand in the world in a pedagogic way*” (p. 1, my italics). I stand in my pedagogic way, trying to incorporate the knowledge and experiences of mothers into our already hectic school days.

I recognize that, although I am articulating my research in terms of a feminist project, aligned with the subjugated knowledge of mothers, there is no guarantee that I am being perceived (or even presenting myself) according to this understanding. Indeed, I am fundamentally an ‘educational professional’: a teacher in a specialized school, who is currently working on a project related to improving special education services. Given what research tells us about mothers' experiences of being negatively framed by the professionals working with their children, was I sometimes categorized according to this experience? Did my status as professional hinder discussions? Did participants feel that “their self-esteem and identity were under constant threat” from me, the professional? (Kingston, 2007) How much of my identity is actually aligned with my professional status? Might I be guilty of mother-blaming or shutting down conversations? How might these elements have been manifested in my interviews and data analysis?

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<sup>10</sup> I would further assert that my role as teacher has come to be a spectre in my research.

There are no easy or ready answers to these questions. I suppose that the starting point should be the awareness that Ettinger (2005) calls for:

[researchers] ...whether insiders, or outsiders, or both, need to reflect critically on their own personal histories as well as how their insider/outsider status has affected the creation of oral history. That self-knowledge helps oral historians to understand the ways they identify and do not identify with their interviewees, and more generally what they bring to the interview exchange as well as how they affect and respond to it (p. 112).

I am dancing on the line of insider and outsider. I am an insider to the educational institution, and an invited insider to several homes, but an outsider to mothers' experiences. I have worked in the homes of children with disabilities, alongside mothers, but have no access to the lived experience of mothering a child with multiple disabilities. Furthermore, given that I am conscientious (to a degree) of the power-relations and struggles between mothers and professionals, I am painfully aware that I (have) often pose(d) a challenge to mothers, even in my efforts to be supportive. It is so easy to focus on a "mother" when what is at fault is systemic oppression and lack of support. My uneasy position demands that I make efforts to remain reflective, un/balancing my knowledge as teacher, and un/balancing my knowledge as researcher.

When I ask my research question, "How do the mothers of children with multiple disabilities narrate their experiences with their children's schooling, and what insights can their stories provide?" I am looking to develop themes that characterize this experience. The stories and perspectives of mothers point to a cleave between the policy and the practice, where I'm currently uncomfortably positioned, and where the experiences of mothers and their children with disabilities take shape.

## **The Chapters**

This work is divided into six chapters, circling and deviating, but ultimately culminating in the development of five shared themes. In developing this set of themes that tie together the experiences of participating mothers, the concluding description of this study is not meant to be objectively ‘right’ for all time and in all circumstances, but it will (hopefully) resonate as true to some mothers’ experiences.

The literature review in the second chapter considers a number of areas that come together in the experience of mothers dealing with schooling of their children with disabilities. Included in this section is a consideration of the literature around parenting and mothering children with disabilities, the institution of special education and its professionals, various policies of parental involvement, and some of what research shows as parents’ experiences with the schooling of their children with disabilities.

Chapter Three provides the framework from which this study was undertaken. It fleshes out the feminist and phenomenological elements of this study, situating the work within two fascinating and complementary academic realms. It also provides more of the details of this particular undertaking, introducing the participants, revealing the structure that was underlying our conversational interviews, and outlining how the data analysis process took place.

Chapter Four takes up the experiences of the participants. In an effort to remain faithful and to reflect their stories, this chapter is divided into four parts, so as to explore some of the tales and themes that emerged from my conversations with each woman.

Chapter Five takes these four separate stories, and finds what they held in common, offering up a “composite description” (Creswell, 2007, p. 58) of their experience(s). Despite the uniqueness of each woman’s experiences, there was significant overlap and echoes between the participants.

Chapter Six is my reflection on what this study explored. I share some of my personal struggles and thoughts, and then turn to a consideration of the potential spaces and connections that this study has to our practice, policy and pedagogy.

### **“I Seemed to Understand”**

Estée Klar’s (2010) powerful poem, *Push*, gives us a glimpse into her perspective as the mother of a child with Autism. I have included an excerpt of her poem at the beginning of this document because I believe that it captures something fundamental about a mother’s experiences and knowledge, as well as some of her views about schooling. Significantly, both of these issues arose in this research and are reflected in the themes explored in Chapters Five and Six. Klar’s poetic presentation allows for a different point of access to these themes. It offers us a new way to empathize and consider the experiences of being the mother of a child with a disability and how she might conceptualizing his/her schooling. Klar “seems to understand” something about her son – something which the educators, in their efforts to make him “kiss the baby doll” and draw “thicker lines,” have profoundly missed.

I used “I Seemed to Understand” as this document’s title because, in addition placing prominence on a mother’s own words, it highlights the hermeneutic phenomenological method with which I approached this study. I appreciate how the phrase emphasizes *seeming* to understand; I view this as a recognition that, as Van Manen (2002) writes, “no interpretation is ever complete ... no insight is beyond challenge” (p. 7). The participants in this study understood certain elements and shared various insights, and I think that I *seemed* to understand them. The themes in Chapters 4 and 5 offer what is at least a tentative understanding of their stories. It is my hope that this work has done their experiences a bit of justice. Let’s now turn to what I seemed to understand from these mothers, and the process by which we got t/here.

## CHAPTER 2: LITERATURE REVIEW

In order to contextualize my research focus on the experience of mothers of children with disabilities, it is necessary to first look to the research that has come before, noting both the previous findings as well as the gaps in our knowledge about both the experiences of mothers of children with disabilities and the institution of special education.

As such, I begin this review with a quick overview of some of the research done about parental experiences in its broadest sense, remarking on health, employment and other factors that characterize it. I then take a step away from the gender-neutral language that abounds in the literature and revisit the reasons for this paper's emphasis on mothers. I shift our focus to a consideration of various elements of the system of special education, pointing to some discussions about special education as a problematic discourse. I briefly provide an overview of some current pedagogical policy that is oriented towards parental involvement and knowledge. I describe the research that has been done thus far, and note the disjunction that has been discovered between current policies and the practical implementation of such policies. In looking to past research and theoretical work, this study is situated within a growing body of work central to the successful implementation of a major tenet in special educational policy, the inclusion of parents and their knowledge.

### **Parenting Children with Disabilities**

*Stresses and strains – faced by all Canadian children and families – are exponentially felt by children with disabilities and their families (Hanvey, 2002, p.3)*

*Dealing with the disability per se was not the greatest problem. Consistent with the social model of disability, it was lack of support from family, community and professionals that was the most challenging ... (Home, 2002, no pagination)*

The social model of disability emphasizes the structural challenges that work to disable individuals with disabilities (see Oliver, 2004, 2009; Thomas, C, 2004, among others). These systemic and structural impediments also work to disable and isolate the parents and families of these children.<sup>11</sup> Research shows that families of children with disabilities face a series of unique challenges and barriers. These challenges include both quantifiable ones (e.g., extra expenses, reduced time for paid work or leisure activities), as well as ineffable ones related to the stigma and ableism that impacts people with disabilities and their families. These stresses compound and put strain on families in need of a support system to assist them and their children.

Research repeatedly notes the stressors and consequences in the lives of parents who have children with disabilities. There are concerns about the physical and mental health of caregivers (Brehaut et al, 2004; Raina et al, 2004; Roeher Institute, 2000). Brehaut et al. (2004) found that “the demands of their children’s disabilities ... explain differences in the health status of parents...” (p.182). Furthermore, financial pressures are a real concern for many families with children with disabilities (Roeher Institute, 2000; Home, 2002) These issues are compounded by a lack of personal time (Statistics Canada, 2008) and sometimes marital friction (Statistics Canada, 2008, found that 30.9% of respondents reported that their child’s disability caused problems within the marriage).

The stigma that surrounds disability is a powerful and perhaps overarching factor in the lives of individuals with disabilities and their families (Green, 2003, 2007; Kediye et al., 2009; McKeever and Miller, 2004). Because of the (often visible, sometimes invisible) ‘difference’

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<sup>11</sup> For example, Woodcock and Tregaskis (2008) frame parents’ struggles to access appropriate services for their children within the paradigm of the social model of disability: “[Parents’] narratives often revealed what a social model of disability would call systemic barriers. These barriers occur when services are developed primarily to meet the normative needs of the provider, and take insufficient account of the diverse needs of client groups” (p. 63).

tied up with various disabilities, as well as the reality/reminder that all people are vulnerable to disability, people and families with disabilities often experience exclusion and isolation.

Coleman (2006) notes that two of the most common methods of stigmatization are social isolation and lowered expectations (p. 47) – notably, both are elements with which parents of children with disabilities struggle. Parents often experience isolation and self-doubt as they struggle to deal with their children on their own. Participants in Kediye et al.’s (2009) research reported that they felt obliged to stay home “out of the public eye” rather than face the embarrassment of people judging and misunderstanding their children and parenting (p. 218).

Although the literature is often focused on the gaps and more negative elements of parenting children with disabilities, it is important to also note the positive, life-enhancing elements of this experience (see, for example: Green, 2007; Magill-Evans et al, 2010) . The mothers interviewed by the Roeher Institute (2000) identified multiple qualities that they connected directly to their parenting a child with a disability, including a greater acceptance and sensitivity to difference.<sup>12</sup> In the section on “Parent voices and Professionals,” we look at how some mothers narrate the new strengths that they have developed because of their advocacy roles.

### **“Mothering at the Margins” – Mothering Children with Disabilities**

*If, as the saying goes, it takes a village to raise a child, then special-needs children need the village even more than others do. The absence of that village – of community support and of honest, balanced, informed and communal understanding of the joys, challenges and difficulties of raising a child with disabilities – not only contributes to what’s disabling about disability, but is at the core of what perpetuates a sense of mothering at the margins (Greenspan, 1998, 42-3).*

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<sup>12</sup> Eva Feder Kittay reiterates these lessons, but places them on a grander theoretical scale, to challenge concepts of what it is to be *human*: “She [Sesha, her profoundly disabled daughter] is a most gentle tutor. She instructs us in the beauty of life itself. Her right to be in the world is not earned by her rationality but by her example that reason is not what defines what is human ... What we learn in Sesha is that our humanity sits at our very core – that it is not vested in this skill or that, that a skill less does not mean less a human being, worthy of less care and dignity. Maybe there is no more important lesson for us to learn” (2000, p.68-69).

While much of the literature available about parenting children with disabilities uses gender-neutral terms (“parents” and “families”), research consistently reveals that women are the most likely to primary care-givers (Morris, 2004; Roeher Institute, 2000; Statistics Canada, 2008; Hanvey, 2002 are just some of the countless examples). Participant groups in studies are often largely (and sometimes exclusively) mothers; this is often mentioned in passing, but without regard to the significant impacts that gender roles can have on the experience of “parenting” (Baines et al, 1991; Home, 2002; Morris, 2004).<sup>13</sup>

Morris (2004) tells us that “the purpose of gender-based analysis is to develop good *evidence-based* policy based on a complete picture of how women and men are affected” (p.110) Gender-based research into parenting acknowledges the significant differences between mothers and fathers. If we know, for instance, the mother is most likely to leave the workforce to take on the primary caring role, does that change the experiences of being a mother or a father to a child with a disability? Home (2002) accuses the majority of research into “parenting” children with disabilities of “hid[ing] the role of gender in [mothers’] oppression” (no pagination, section 3.3). Much of the research discussed in the previous section, for instance, largely reflects the experiences of *women* participants – but their experience is then conflated within the umbrella term “parent” or “caregiver,” removing the gendered element of their experience from the literature.

There is nonetheless some research that points to mothers’ experiences. The Roeher Institute (2000) found that, in Canada, mothers caring for children with disabilities had

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<sup>13</sup> Panitch (2006) notes that mothers of children with disabilities were at the forefront of significant movements in Canada, a reality which is only now coming to the fore. She writes, “While their activities and influence have frequently led to the formation of social movements and organizations which have influenced Canadian society, women’s contributions often were ‘hidden from history.’ Very few mothers’ struggles in particular have been documented in the outpouring of literature recently that has tried to address this. There is virtually no scholarly work on the significant struggles for social justice and equality waged by activist mothers of disabled children” (p. 5).

significantly poorer health than mothers of children without them (p. 22-23); they also reported that these mothers spent an average of 50-60 hours a week, caring and advocating for their children (p. 20). Similar findings from Brehaut et al. (2004) indicate that, compared to other Canadian parents, care-givers of children with cerebral palsy reported lower incomes, poorer psychological health, and poorer physical health. Single mothers report high stress, but some research has suggested that once questions of age, education level and income are controlled, this difference fades – pointing to the stress of finances as a central factor (Home, 2002). Indeed, financial pressures are a real concern for many families with children with disabilities (Roehrer, 2000; Home, 2002). Mothers are the most likely parent to decrease or stop their participation in the paid workforce<sup>14</sup> (Roehrer Institute, 2000; Statistics Canada, 2008; Home, 2000), thus exacerbating the problems of finances and isolation. Compared to mothers of typically-developing children, mothers of children with disabilities spend more time caring, and less time pursuing recreational activities, and this gap increases as children age (Crowe and Florez, 2006).

An honest appraisal of who is doing what types of caring will give us a better sense of many lives: those of women with children with disabilities, individuals with disabilities, family members, and wider networks. Who does what, and what repercussions might this have? As Armstrong and Armstrong (2004) remind us:

Care costs. Some of the costs are financial. Some are in time, in emotional and social resources, or in lost opportunities. The costs may be borne mainly by individuals, families, community organizations, or governments. Sometimes all share in the costs, although they seldom do in equal portions or in similar ways. Whatever the distribution, the ways in which costs are borne and shared have significant consequences for women (p. 28).

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<sup>14</sup> The chances of leaving the paid workforce correlate with the severity of a child's disability. This is reflected in my study, where all of the mothers either stopped working entirely (for several years or permanently) or switched to part-time work with flexible hours.

### **Looking Critically at Special Education & Its Professionals:**

*My work describes what fields like special education ... hold themselves to be, and then confronts them with what they in effect have become (Skrtic, 2005, p. 155).*

*... Educators have to interrupt the scripted story of schools as protectorates and start looking inward at themselves – at what they do and why they do it (Pushor, 2007a, p. 6).*

Challenges such as those of Skrtic and Pushar provide a powerful test to special education and the schooling services provided to students with disabilities. Special Education is a realm replete with assumptions and “truths” that must be unpacked in order to move forward. Theorists interrogating the processes and paradigms of special education have found a rich, and rarely discussed, area. Initial work has probed the existence of ableism in schooling (Ware, 2002; Hehir, 2002), the construction of a “special education student” (Erevelles, 2005; Ware, 2002; Skrtic, 2005) and the role of professionals (Tomlinson, 1982, 1996; Ware, 1994, 2002; Skrtic, 1991, 2005) among other elements.

This latter consideration is particularly relevant to this study. The role of professionals (medical, educational, therapeutic, etc.) in the lives of students with disabilities is indisputable. But under what frameworks, with what presuppositions and understandings, are professionals working? Research has indicated that professionals are not always perceived as helpful, and are sometimes an added stress (Hess, Molina and Kozleski, 2006; Home, 2002; Kingston, 2007; Malacrida, 2003; Read, 2000; Todd and Jones, 2003). Although Mehan (1993) points out the power-distinctions between different types of educational professionals, the vast majority of research notes that parents frequently experience conflict or struggles with educational professionals. The recognition of this experience has led to a closer look into the types of knowledge held, and consequent discourses used, by professionals.

Because of their training and consequent status, professionals automatically have access to specialized information and knowledge (Murray, 2000). Professional knowledge garners much of its authority from its popular characterization as objective and scientific. Wendell (1996) discusses the ‘cognitive authority’ that medical professionals hold in describing and in/validating a person’s perception of their body. Professional knowledge can “undermine our belief in ourselves as knowers, since it can cast authoritative doubt on some of our most powerful, immediate experiences” (p. 122). The knowledge of educational professionals also holds the authoritative power to in/validate experiences; Neirstheimer (2000) describes “feeling quite vulnerable and at the mercy of those making decisions about and for our child— those who did not know him, no matter how many tests they performed” (p. 2). Walker and MacLure (2005) describe the use of ‘institutional talk’ by educators that is used to “exert a greater degree of control over the direction and content of the [conversation/meeting]” (p. 101). Pushor (2007a) describes the “badge of difference” which educators use as “a rationale for their claimed positions as decision-makers in the school” (p. 2). Professionals, and their knowledge, hold a great degree of power to frame and marginalize the knowledge of others (Sheehan, 2000; Neirstheimer, 2000; Read, 2000; Ware, 2002; McDonnell, 1998; Kingston, 2007; Malacrida, 2003; Hodge & Runswick-Cole, 2008).

Tomlinson (1996) observes some of the positions in which educational professionals find/create themselves. Educational professionals inhabit a powerful discursive space, from which their words and decisions have a very real effect on the students whom they serve. Like the authorizing “institutional talk” discussed by Walker and MacLure (2005), Tomlinson describes the use of “treatment language,” borrowed from the medical model. From the space of “benevolent humanitarianism” (1982, 1996) or “benevolent expertise” (1982), educational

professionals are equipped with the power to “persuade clients to accept certain judgements without recourse to actual coercion” (1996, p. 179). “Benevolent humanitarianism” insists that “a child’s welfare should rightly be a matter for capable experts,” and has become “such a natural assumption that questioning it becomes very difficult, professional knowledge has developed a singular authority” (1982, p. 107). Pushor (2007a), in emphasizing the necessity for reciprocity and partnership between parents and members of the school community, challenges education professionals to step outside of their traditional role of benevolent decision-makers and into the realm of “reciprocity”:

Rather than with the mindset of charity, privilege or expert knowing, acting in reciprocity reflects a relational and caring engagement in initiatives deemed important by and for parents and families (p. 9).

As we turn to a consideration of current Canadian educational policy, let us remember, the power that a professional brings into the school-home partnership. Let us also keep in mind Ware’s claim: “the knowledge parents possess can remake what we know about living with a disability” (2002, p. 148). Both of these types of knowledge are addressed by current special educational policies; as we explore these policies, let’s prepare to consider how parents are addressed according to both these policies and the practices in schools.

### **Policies of Parental Involvement & Partnership**

The potential roles for parents within the schools of their children with disabilities are numerous. These roles have shifted over time, leading us to our current policies of inclusion and partnership. Let us first briefly consider, following Turnbull et al. (2006), different ways that parents’ roles have been configured, then turn our attention to current educational policy and its implementation.

Turnbull et al. discuss the variety of roles that parents of children with special needs have had, traditionally and currently, available to them. These roles include parents being perceived or addressed as (1) the cause of their child's disability; (2) members of advocacy and service-oriented organizations; (3) the developers of services that they deem necessary for their children; (4) the recipients of professional decisions; (5) teachers and therapists within the home, who implement educational goals and practices; (6) political advocates, struggling for change; (7) potential educational decision makers; and (8) true partners in a family-centred approach to educating students with disabilities. Ideally, the eighth role outlined by Turnbull et al. would be the aim of any special education team. This relationship is frequently cited in literature as "best practice" (e.g.: Benson et al., 2008; Dardig, 2008). Indeed, this model guides much of current policy, which we now turn to.

Recognition of the important roles of parents as partners in their children's educations is widespread. Parental involvement has been repeatedly found to have positive and quantifiable effects on children's educational success (Dardig, 2008). Pushor (2007a, 2007b) emphasizes the distinction between parental "involvement" and parental "engagement," noting that "parental engagement" involves welcoming parents and "providing a meaningful place for them on a school landscape and in the processes of schooling" (2007b, p. 6). Fine and Gardner (1994) point out that a collaborative model "implies a relationship characterized by trust and a sense of mutuality in which the involved persons see each other as partners" (p. 299), and note that this notion of partnership is center stage in current "educational and philosophical shifts in services to children with special needs" (p. 286).

Educational policies in Canada today reflect such findings. The Ministry of Education in Ontario recognizes, on its website, that "parents play a vital role in the development and

education of their children and in the success of schools.” In a similar vein, the Ontario Ministry of Education’s guide to *Individualized Educational Programs* (2004) emphasizes the importance of consulting with and supporting parents of students with disabilities. The Alberta Ministry of Education posits in *The Learning Team* (2003) that “As parents, you know your child best... and as a result you can be your child’s greatest supporters” (p. 1). The Quebec document, *Adapting our Schools to the Needs of All Students* (1999), notes “the essential role of the parents” and insists that schools “support them in the task of making their children’s needs known” (p. 23). With policy thus encouraging the inclusion and support parental knowledge, the question we are left with is whether these policies are being implemented to the satisfaction of parents. Unfortunately, as we see in the next section,<sup>15</sup> research indicates that parents are frequently unsatisfied with the roles allotted to them in the schooling of their children with disabilities. Let us now turn to a discussion of what some of the research has uncovered thus far.

### **Parental Perspectives & Experiences with Schooling and Related Service Provision**

With the above consideration of the policies surrounding parental involvement in special education, we can now focus on the research done to understand the dynamic from parents’ perspectives. As The Roeher Institute (2000) reports, more than 50% of mothers expressed dissatisfaction with their children’s education, and that “most mothers (85%) were engaged in advocacy with the education system on their child’s behalf” (p. 24). Research conducted by the Ottawa chapter of Autism Ontario (2007) discovered that, while parents were typically satisfied that the staff members involved with their children were working hard and in the children’s best interest, many felt “their children [were] not being educated to their full potential” (p. 5), and had significant concerns about safety, appropriate education, staff training and the availability of

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<sup>15</sup> And is reflected in this study’s participants’ stories.

adequate resources. Notably, in a study involved Somali-Canadian mothers of children with ASD, Kediye et al. (2009) notes: “*Several key professionals and institutions were named by mothers ... as causing considerable stress and anxiety.* First among these institutions are the schools” (p. 216, italics in original).

In this section, we consider the research conducted around parents’ experiences with the educational professionals and the themes that have emerged. Research has revealed that parents have experienced difficulties *accessing* services, and struggles around *diagnoses and labels*. After considering these elements, we will look both at the themes of *hearing parents’ voices* and some *positive results*. Looking through the research of parental perspectives and struggles sets up the terrain from which I will plan and conduct this study.

### **(A) Accessing Services**

Services are not always readily available for children with disabilities. Edelson (2005) writes that Canada’s current structures for obtaining services are overly bureaucratic, and act as hurdles for already overwhelmed parents; in fact, she considers “this lack of organization and coordination ... [to be] neither cost-effective nor humane” (p. 45). Whitley et al.’s research (2010) echoed this experience, noting that Ontario families feel that there is a lack of available services and supports for their children; one key informant emphasized how the basic human needs of children are not met:

When I speak of human needs, [I mean that] the types of supports needed – financial, health, counselling, respite, educational supports, etc – should be offered based on needs. *The processes can seem to be set up to limit accessibility to service which is a real frustration for families. [Families] feel as if they have to fight and advocate for their children and their children’s needs* (Participant in Whitley et al., 2010, p. 128, italics added).

Statistics Canada, in its 2006 report, *Participation and Activity Limitation Survey 2006: A Profile of Education for Children with Disabilities in Canada*, also reported that parents report a significant amount of trouble accessing resources. The report notes that:

Nearly half of parents reported difficulty getting special education for their child. Among children who required special education or who attended a special school, nearly half (49.0%) had parents who reported experiencing difficulty obtaining special education services. This level was consistent across all types of education; that is, regardless of whether the child was currently enrolled in full-time (53.0%) or part-time (49.3%) special education or in regular classes (46.2%). Parents of children with very severe disabilities were the most likely to report challenges in obtaining special education for their child (64.0%), but this proportion decreased as the severity of disability lessened from severe (54.1%) to moderate (41.8%) (p.15).

These results indicate a significant concern; the report speculates that the reason for such high rates of dissatisfaction amongst parents of children with “very severe” disabilities is due to the number of teacher’s aids and attendants needed to assist these students. An Ottawa-based study (Autism Ontario, 2007), revealed that 1 in 5 families had switched their child’s school board within the previous five years in an effort to access better services for their child; almost half (47%) of participants expressed doubts that (a) school staff was providing adequate support, and (b) staff had enough knowledge of autism to appropriately teach their children, with many parents expressing doubts about the training and resources provided to educators and assistants (p. 3). The Canadian Roehrer Institute (2000) reports similar results, noting that even parents who reported being satisfied with their child’s schooling, frequently had to “fight to get educational supports” (p. 25).

### **(B) Diagnoses and Labels**

Tied up in parents’ “fight” for resources, is the issue of receiving diagnoses and labels. This process figures prominently in the literature around parenting a child with disabilities.

Watson (2008) reported that parents seek diagnoses for a variety of reasons, including desires to: have a label, alleviate guilt, plan for the future, understand causes, know about proper interventions and therapies, and to have access to services for their child. Hodge and Runswick-Cole (2008) report that labels proved to be an essential part of gaining access to services that their children needed, and some parents considered receiving a diagnosis to be a “trade-off” (p. 642).

The research of Malacrida (2003) into Canadian mothers of children diagnosed with ADHD describes the diagnosis as a “lengthy, complex ruling-out process”, which involved a great deal of contradiction between professionals, and indicated that responses to diagnoses ranged from relief to disbelief in both the diagnosis and the infallibility of medical discourses (p. 16). Furthermore, some parents report initial resistance from professionals towards diagnosing students with disabilities or special needs (Neirstheimer, 2000; Sheehan & Sheehan, 2000), while others find that the diagnosis takes on a life of its own, eclipsing the actual child (Esquivel, Ryan, and Bonner, 2008). McKeever and Miller (2004) discuss how mothers struggle to have their child viewed as a “fully loved ‘child’, rather than the ‘data’” (p. 1189). McLaughlin (2006) describes parents talking about “the need to get away from medical care ... and professionals ... in order to regain their child and develop new templates for their family life” (no page, paragraph 6.1).

### **(C) Communication: Parents’ Voices, Professional Services & Advocacy**

*What parents seemed to be looking for were active partnerships based on mutual recognition of expertise (Woodcock and Tregaskis, 2008, p. 65)*

*Activist is not something I would have chosen as a label for myself ... But we’ve fallen into this mode because of having to defend what we treasure most (Participant in Panitch, 2006, p. 283)*

As outlined in above sections, research repeatedly reveals that parents have concerns about the education and related services that their children with disabilities are receiving. Furthermore, despite parents' close knowledge of their children, there remains a significant disjunction between parents and the professionals involved in the lives of their children. For example, research conducted by a branch of Autism Ontario (2007) revealed that, despite a modest level of satisfaction (67%) with parent-school communication, 57% indicated that they had encountered significant challenges in resolving concerns that they brought forward (p. 4). Parents often feel that their knowledge is marginalized or discredited by educational professionals; participants in Kingston's (2007) study "felt that they had both knowledge and skills in dealing with their children, and professionals should be aware of this 'maternal knowledge'" (p. 85). Hillyer (1993) powerfully describes herself as a "discredited appendage" to her daughter (p. 105). And Ware (2002) remarks, regarding the knowledge she holds about her son, that "over time, my knowing would have little impact on how [my son] came to be known – so much was narrated before him" (p. 148).

Reay (2005) discusses three conceptualizations of mothers' roles with regard to the schooling of their children. First, a mother can assume a *complementary* role, wherein she accepts the school's authority and knowledge, and works as teacher-support. Such a role has also been identified by others (Turnbull et al, 2008). Many mothers note that they had initially assumed this role, and later on – as their confidence grew – changed their approaches (Read, 2000; Kingston, 2007). A second option articulated by Reay, which occurs when a mother either disagrees with or finds the school's approach inadequate, is the *compensatory* role, in which she makes efforts to do the work that the school is not. Other literature has reported similar findings; Malacrida (2003) discusses mothers looking to private settings for alternatives, and Blum (2007)

describes mothers actively searching for other avenues to assist their children when they consider the school to be inadequate or wrong. The third role that mothers describe, according to Reay, is an *advocating* or *modifying* role; in undertaking this position, mothers frequently encounter a great deal of opposition from educational professionals. When assuming this advocacy role, mothers are regularly framed as troublesome and irrational. Panitch (2006) describes her participants as knowing that

their behaviour and outspokenness at times resulted in professionals dismissing them as ‘some kind of pariah, some kind of rare rebel.’ Even though it did not make them popular, they were more than willing to step outside women’s cultural role to redefine what it meant to be a “good mother” (p. 283).

Brown (1999) writes that, when parents take up a right-based rhetoric in their struggle for change, they

challenge deep-seated beliefs about disability in society, [and] often the experience becomes confrontational, and stress is experienced by all participants. Families ask for educational opportunities on the basis of rights, equality and justice. Some educationalists reel back at the unexpectedness of the rights discourse (p. 37).

This theme of conflict with professionals comes up again and again in the literature; tellingly, the participants in Kingston’s (2007) study frequently used war-like terms (ex. “battle” or “war”) to describe their relationships with their children’s professionals. In her article, *Dear Teacher*, McIntosh (2006) writes “Some of us have been fighting for so long that fighting became our default setting ... But if you continue to reach out to us, you’ll find that together, we can do the most important thing in the world: help our children reach their fullest potential” (no pagination). She asks for acknowledgement of the struggles that mothers go through to support their children, contextualizing mothers who appear “pushy” or “weird,” and seeks to re-orient the conversation towards working together towards student success.

Despite the “battles” and persistent challenges presented to mothers, some mothers report developing new sense of self and strength in adopting this advocacy role (McLaughlin, 2006; Hess, Molina, & Kozleski, 2006; Kingston, 2007; Todd and Jones, 2003). In an article designed to assist parents in advocating for their children, the author writes of a breakthrough in her self-understanding:

I remember being at a parent support meeting where we were introducing ourselves and hearing for the first time (when asked what she "did") a mother saying that she was her daughter’s advocate. I was very impressed and thought "Ya- that's what you call what I seem to spending much of my time on lately". I think at that moment I stopped thinking of myself as "just the mother" or "Mum" (as some professionals insisted on calling me - even though I was not their mother) and began to think of myself as "the advocate". It gave me a certain feeling of dignity and helped put me on more of an equal footing with those professionals that I encountered. Even if that feeling of equality was only in my own mind, it was very powerful (OACRS, retrieved May 2010).

Home (2002) notes that although “personal growth was a major reward” for mothers, it is the result of relentless “hard work” (no pagination, paragraph 4.2) Mothers of children with disabilities do discover and cultivate a new set of strengths, but this cultivation occurs under what are sometimes seemingly impossible circumstance.

Mothers report a struggle to have their knowledge heard and confirmed by professionals (Read, 2000; Kingston, 2007; Malacrida, 2003; Hillyer, 1993; Nierstheimer, 2000). The participants in Kingston’s research “felt strongly that maternal thinking is of great importance when discussing a child with a learning disability [here, autism] and deciding what support services are needed. The general consensus was that many professionals seemed to minimize or ignore that thinking” (p. 84). Hodge and Runswick Cole (2008) discovered that many mothers reported having information withheld from them, causing stress. Autism Ontario (2009) found that a significant number of parents are interested in being involved and informed of the “day-to-day education of their children,” but do not have this partnership (p. 16).

On a different note, Fine and Gardner (1994) suggest that parents may feel overwhelmed and pressured by the role that professionals expect them to play; the writers posit that this may result in a feeling “that they are letting their child down, guilty or angry,” and are thus inclined to withdraw from participation in educational decision-making (p. 295). Parents also report concerns about “surveillance” – that their association with an extended professional world puts them, and their parenting, under increased scrutiny (Heneghan et al, 2004; Kediye et al, 2009; Kingston, 2007; McDonnell, 1998; Todd and Jones, 2003).

#### **(D) Some Positive Results**

Of course, research has not revealed entirely negative relationships between parents and their children’s professionals. Parents have also reported positive experiences. Participants will sometimes “[go]out of their way” (Read, 2000, p.35) to mention those professionals with whom they had a good experience, whom they described as supportive and respectful (Autism Ontario, 2009, p16; Read, 2000).

Kingston’s (2007) participants appreciated the professionals who noted their children’s good qualities and advancements. Angell et al. (2009) point to communication, “authentic” child-focused caring, and awareness of student’s individual needs as some of the factors that mothers need to see in order to “trust” the child’s educational staff. Parents appreciate professionals who communicate with and develop a relationship with their child, noting the child’s strengths and various developmental progressions (Esquivel et al, 2008; Woodcock and Tregaskis, 2008). Esquivel et al. (2008) also noted that small meetings, often informal, were frequently the meetings which they considered most successful. Additionally, the participants interviewed by Hodge and Runswick-Cole (2008) identified positive experiences in which professionals had respectfully listened to parents, and in which professionals had been clearly

interested in the child. “Professionals do not always have to get it right, but they have to be perceived by the parents as trying to do so and by taking on board the parents’ expertise” (Hodge and Runswick-Cole, 2008, p. 645).

### **Closing Comments**

There are many dynamics at play in the lives of parents of children with disabilities – at personal, institutional and systemic levels. Mothers in particular encounter a plethora of stresses and responsibilities. One of dynamics that parents encounter is their relationships with their children’s professionals. The research reviewed here indicates a number of concerns regarding how parents perceive the role allotted to them within the context of their child’s professionals, and schooling professionals in particular. If policy is oriented towards incorporating and partnering with parents, it is essential to explore where this discrepancy between theory and lived experience is taking place. This study, in asking for the insights of mothers, points to some of the common experiences which they share, and what kinds of changes they would like to see in the education of their children with disabilities.

## **CHAPTER 3: FRAMEWORK & METHODOLOGY**

### **Introducing this study**

This study took the form of qualitative research. Inquiring into the narratives and insights of these mothers, they led me down paths of both astonishing joy and shocking treatment. I listened to these “expert witnesses” (Traustadottir, 1991) as their voices cracked in anger and in gratitude, and I tried to respectfully and sensitively allow them to lead our conversations. This chapter outlines the framework and methodology used in the development of this project.

## Qualitative Research

Marshall and Rossman (1995) suggest that two of the questions for which qualitative studies are suited are (a) to “understand differences between stated and implemented policies or theories” and (b) to “describe poorly understood phenomena” (in Merriam, 2007, p. 11). This study addresses both of these elements. From the contextualized and detailed accounts of their experiences, this study will develop a description of the relationships that mothers of children with multiple disabilities have with their children’s schools. As such, the goal of this research is qualitative: to learn how mothers “experience and interact with their social world [and] the meaning it has for them,” shedding light on their relationships with their children’s schooling (Merriam, 2002, p.4).

## Feminist Framework

*In combating marginality we must insist on telling the truth about our experiences, on stopping the self-censure that people adopt to meet what they think society expects. Mothers, in particular, need to speak the reality of how their daily lives unfold ... Mothers of children with disabilities can take a step toward resisting social invisibility by sharing the genuine details of their experience. No sugar coating should be required to meet some societal standard of self-sacrifice (Edelson, 2005, p. 231.)*

As discussed earlier, my focus on the experiences of *mothers* of children with multiple disabilities is a considered one. Because the work of caring and advocating for children with disabilities is gendered, this study is similarly gendered. My focus on mothers does not exclude the fact that others, like fathers and grandparents, can and do care for children with disabilities, and that these experiences are indeed worthy of research; nonetheless, this study explicitly considers the experiences of *women* as important and instructive. In my focus on mothers as main care-givers and advocates, I insist that mothers not be lost within the wave of gender-

neutral language, that they have knowledge and experiences that are unique and important to share.

Harding (1987) suggests that feminist research has at least three salient characteristics. First, feminist research places women's experiences at the center of its inquiries<sup>16</sup>; moreover, it recognizes that the experiences of women (and all people) vary according to a number of elements, and should be understood as such. Furthermore, feminist research has discovered that many women experience conflict between their many roles; "these fragmented identities," Harding writes, "are a rich source of feminist insight" (1987, p. 8). Second, Harding characterizes feminist research as to the benefit of women; within a feminist paradigm, research conducted about women is used to improve the lives of women. Olesen (2005) also posits this goal, asserting that "more sophisticated approaches and more incisive understandings enable feminists to grapple with the innumerable problems in women's lives, contexts, and situations in the hope of achieving, if not emancipation, at least some modest intervention and transformation" (p. 259). The third characteristic outlined by Harding is an overt rejection of the "objectivist" stance of traditional research. Haraway (1991), in her rejection of objectivist approaches, vindicates the situatedness of feminist research:

I am arguing for politics and epistemologies of locations, positioning, and situating, where partiality and not universality is the condition of being heard and making knowledge claims. These are claims on people's lives; the view from a body, always a complex, contradictory, structuring and structured body, versus the view from above, from nowhere, from simplicity (p. 92).

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<sup>16</sup> Harding's work is of great significance in feminist philosophy and methodology. However, I think it necessary to counterbalance her claim with a more recent theme in feminist thought, articulated here by Ramazanoglu and Holland (2002): "Research projects can be thought of as feminist if they are framed by feminist theory, and aim to produce knowledge that will be useful for effective transformation of gendered injustice and subordination. *But this does not mean that feminists have to study women, or only study gender...*" (p. 147, my emphasis). I am theoretically aligned with the above claim; I believe that there narrowing the scope of feminist research does not benefit anybody. Nonetheless, this study focuses on the particular experiences of mothers because my goal is to interrogate the gendered life experiences of care-giving and mothering, as they relate to special education. To deny the specific gendered element of this experience would be to cloud the issue at hand. As such, this study follows Harding in her instruction to foreground *women's* experiences.

Part of how feminist inquiry moves away from this simplistic objectivity, is through insisting that the researcher is present in the research “not as an invisible anonymous voice of authority, but as a real, historical individual with concrete, specific desires and interests” (Harding, 1987, p. 9). Indeed, considerations about the role and power of a researcher remains a central tenet of feminist research (deVault, 1990; Hesse-Beber, 2007; Olesen, 2005; Reinharz & Chase, 2002). A feminist framework insists that researchers remain reflexive<sup>17</sup> and candid about their biases and standpoints.

This study focuses exclusively on the experiences of mothers, choosing not to conflate their experiences of care-giving within the category of “family” or “parents.” Following Traustadottir (1991), the participating mothers will be considered “expert witnesses” (p. 216) with important information to share about their experiences. The experiences shared by participants were analyzed with the goal of describing the elements emerging from their stories. In the spirit of collaborative research, mothers were invited to read and comment on early interpretations and themes.

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<sup>17</sup> Reflexivity and a recognition of context, while central to honest feminist research, is not without challenges and variations. Reflexivity remains a contested subject, not a single accepted concept. Lynch (2000), for example, questions the “widespread tendency to identify reflexivity with ‘radical’ theoretical and critical programs” (p. 26), and challenges “the ‘epistemological’ hubris that often seems to accompany self-consciously reflexive claims” (p. 47). Haraway (1997) insists that we not seek out objectivity under the mantle of reflexive and self-aware research. However “self-aware” or reflexive we might deem ourselves, Haraway reminds us that the project is ongoing and unfinished: “Location is not a listing of adjectives or assigning of labels such as race, sex, and class ... Location is the always partial, always fraught play of foreground and background, text and context, that constitutes critical inquiry. *Above all, location is not self-evident or transparent*” (p.37, my emphasis). Haraway posits “diffraction” as a more appropriate critical practice, in that it fundamentally “interferes” and changes the way through which we look at things and one-another. Certainly, I must recognize that, however attentive I am as a researcher, I will never capture all of my biases, and I must be wary of claims to reflexivity that do not force me to confront and change how I am interfacing with the world. To be self-congratulatory about one’s reflexivity is to assume that what should be on-going process has been done satisfactorily and completely. I do try to explore my standpoints and biases in this text – in that I both consider my biases and prejudices, and (hopefully) challenge myself to ‘diffract’ my understandings, coming to look at the subject and myself in new and exploratory ways. Such an exploration cannot be done finitely; as such, this process has been tentative and remains unfinished.

Following feminist methods, I recognize that my role as researcher played a part throughout. I know that I was neither a fly on the wall, not an objective immobile recipient of information. Furthermore, my background and professional interests have certainly impacted the entire research process – from the research question I have formulated, to the interviews, to analysis of the data, and I must take this reality into account. Chapter Six’s personal reflections are an attempt to honestly acknowledge and share my own biases – an exercise that I have hopefully undertook without overriding the voices and stories of participants.<sup>18</sup>

### **Methodology: Hermeneutic Phenomenology**

*The aim of hermeneutic-phenomenology is to create a dialogical text which resonates with the experiences of readers while, at the same time, evoking a critical reflexivity about their own pedagogical actions (Geelan and Taylor, 2001, p. 2).*

Phenomenology searches for meaning and shared structures of experience, developing an account that is not infallible, but which tentatively holds out a kernel of a truth that “resonates” and encourages reflection. In phenomenology, “the aim is to describe and interpret how the situated body makes sense of a phenomenon” (Wolff, 2002, p. 97), and to develop a sense of the underlying structure of this shared phenomenon. This study, in looking to mothers’ stories and positing themes, aims to develop insights into the structure of mothers’ experiences and their understandings of these experiences – a goal that is the “defining characteristic” of phenomenology (Merriam, 2002, p. 93). Creswell (2007) describes phenomenology’s aim to be a “composite description” of the experiences of the participants (p. 58). It is my hope that, in developing a “composite description” of mother’s experiences, this study will have the potential

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<sup>18</sup> As Ranson (2010) writes, “Too much attention to the researcher drowns out the voices of the participants, who are the main focus, and diminishes their role as experts on the phenomenon under study” (p. 37). I take this warning seriously, and I hope that I have been able to walk the tightrope between (a) being a reflective and self-critical educational professional, interested in improving educational services to students with disabilities and their parents, and (b) being a respectful researcher, acknowledging the expertise and stories of the mothers participating in this research.

to inform both school policies and practices around the inclusion of, and partnership with, mothers, and other caregivers, of students with disabilities.

Specifically, this study will take the form of a hermeneutic phenomenology.

Hermeneutic phenomenology emphasizes the interpretive quality of experience, through which all experience is necessarily narrated. In contrast with transcendental phenomenology, hermeneutic phenomenology does not insist that the researcher “bracket” his/her experiences and standpoints; as such, it aligns with the feminist insistence that the researcher can not be subtracted from the research itself. In hermeneutic phenomenology, it is understood that experience does not stand outside of the situated beings understanding and reflecting on it. “The concept or subject under investigation possesses its meaning because of the context we supply for it” (Cohen & Omery, 1994, p. 149). I appreciate this emphasis on the interpretive quality of experience- the recognition that experiences occur and are understood according to a context, and within a horizon of possibility. In developing a set of themes that tie together the experiences of participating mothers, the concluding description of this study will not be objectively ‘right’ for all time and in all circumstances, but it will (hopefully) “resonate” as true to mothers’ experiences.

Hermeneutic phenomenology is explicitly attentive to the details and variety that colour lives, and I am comfortable with its “realization that no interpretation is ever complete, no explication is ever final, no insight is beyond challenge” (Van Manen, 2002, p.7). After I immersed myself in the transcriptions and my journals, I sought to develop *tentative* themes – themes inspired by the colourful lives of the participants, and mindful of where the colours bled into one-another. These themes are not objective facts that stand-alone in any quantifiable

fashion- rather they are reflective of the stories which I heard, and are deeply connected to the contexts from which they emerged.

Both the participating mothers and I made sense of both our experiences and one-another within the horizons of possibility determined by our standpoints, and a hermeneutic phenomenology acknowledges that this process of interpretation is irrevocably taking place. Importantly, the lived experiences of mothers, which are already-considered and shared through interviews, “gather hermeneutic significance as [they] (reflectively) gather them by giving memory to them”; the interpretations and descriptions that mothers supply regarding their experiences with their children’s school/ing will provide us with some important understandings of the “home-school” partnership (Van Manen, 1990, p. 27).

### **A Grounding in Stories**

*Telling stories, it can be argued as parents of disabled children, is still important. It is especially important that we as parents write well – truthfully and with dignity. ... For me, to tell these stories during those early stages of Adam’s development were exceptionally important in navigating our way through ignorance and understanding it ... Should I keep those stories to myself or do they benefit not only myself in my growth as Adam’s parent, but also others who are on the same path? (Klar, 2009, no pagination)*

This project relies on the stories that the participants shared with me. Some were absolutely heart-wrenching, some were full of kindness and gratitude, and some were hilarious. All were remembered and re/lived by the mothers I interviewed, as we engaged in “retrospective meaning-making” (Chase, 2005, p. 656). In sharing these stories, mothers offered up a rare opportunity – their stories held the potential to “make practice visible, ... show where [we] have gone wrong, ... show us what to do to in order to improve practice, ... inform social policy” (Koch, 1998, p. 1183). I hope that, in developing and sharing the themes that emerged from these stories, I have been able to harness some of this transformative power of storytelling.

This project is also tied up in my own set of stories. I have been working simultaneously on this project and on my new teaching career for two years, and –as such– can not help but shape my stories as I share those of my participants. I have been “epistemologically and ontologically engaged in using stories as an integral way to sort who we are as people,” as Leggo (2008) describes it, and have been deeply and “creatively engaged in processes of identity formation and transformation by attending to stories” (p. 3). As such, it would be unnatural for me not to offer some of my own stories into this process. Knowing this, I have tried to stir some of my stories into the reflective mix – in particular, in Chapter Six, I introduce Martha the Teacher and Martha the Researcher.

### **Participants**

Participant recruitment was one of the greatest challenges in this research project. It was essential that I remain extremely vigilant, as I am currently working in special education, in schools for students with multiple disabilities. With this in mind, I chose to recruit participants (a) through service-providers who were willing to help me to distribute flyers and (b) through the snowball effect, passing my flyers through acquaintances. Many dozen flyers were sent out through a number of service providers, but I received no response. In the end, all four of my participants heard of me through talking to various acquaintances, and contacted me directly to say they were interested in learning more about the project.

While I am convinced, given my discussions with these participants, that mothers have a lot to say about their experiences with their children’s schooling, I am just as convinced that they have little to no time during which to say it. I believe that this was the root cause of my challenges recruiting participants, and several of the mothers with whom I spoke echoed this suspicion. This was perhaps one of the essential ironies in my work: that I wanted mothers to talk about their experiences, their advocacy and their knowledge, but they were too busily

engaged in those things to actually speak with me about them. I am so grateful that my four participants took time out of their schedules to share their stories, and I hope to do them justice in this text.

The four mothers, who graciously took the time to speak to me, allowed me glimpses into the textured lives (both the smooth and the frayed parts). They told me about the professionals who were outstanding, and those that kept mothers up at night with “rage,” about the steps forward, and the setbacks, the celebrations and the angry meetings. They invited me into their kitchens – sometimes apologizing for the mess – and introduced me to their children. It was striking that each woman’s life was so different, with its own private colours and nuances, yet there remained the threads with which I could weave a composite. It is worth noting that all of the mothers with whom I spoke were Caucasian, all of them were comfortable and articulate speaking in English, and none of them seemed to be living in poverty. The sharing of these mothers’ stories makes a step in the development of an account of the experiences, meanings and structures that are central to the experiences of mothers dealing with their children’s schooling.

### **Qualitative Interview**

A qualitative interview has “unique potential for obtaining access to and describing the lived everyday world” (Kvale, 1996, p. 54). In phenomenology, interviews are the most common method to access the lived experiences of others (Cresswell, 2007). The interviews are typically “conversational” (Van Manen, 1990) and open-ended, with certain thematic goals in place (Polkinghorne, 1989). Such interviews serve “as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding,” one of the two potential purposes outlined by Van Manen for a phenomenological interview (1990, p. 66). In this study, interviews were designed and

conducted in a conversational fashion, adapted according to the outline provided by Kvale (1996), and using a loose guide with various prompts. Discussions were led more by the interests and emphases of the participants than according to a set list of questions (Lavery, 2003). In fact, participants largely led the way in our conversations, and twice I did not even have the chance to ask all of my prepared questions. I believe that this enthusiasm to speak and share their experiences exposes how much mothers have to share with us, and how little space they are typically given to share it. Interviews were recorded, with the consent of the participants.

### **Documents**

Participants were invited to share any document that they considered meaningful or illustrative (e.g.: a photo, an IEP, a journal or a letter). Documents, another common element of qualitative research, “already exist in the situation; they do not intrude upon or alter the setting,” and “often contain insights and clues into the phenomenon” (Merriam, 2002, p. 13). The research of Cairns (2001) remarked that women often save significant documents, acting as “archivists” of their lives; she noted that some of the objects “were used as aides-memoire or “gates to the memory” that helped the women revisit an event or time, to affirm an important value, to take comfort during a difficult time, or to clarify a current problem” (p. 5). Similarly, Turkle (2007) encourages a move towards considering “objects as companions in our emotional lives or as provocations or thoughts” (p. 5) and aligns this move with the feminist insistence on the power of “concrete, contextual reasoning” (p. 7).

Kristine and Patricia showed me documents that they had chosen as reflective of their experiences. Both of these mothers also indirectly showed me their role as “archivist,” as they sorted through files, boxes, folders and piles of paper looking for these documents. Interestingly,

both of these mothers shared parts of “communication books,” the book that is brought to and from school by the student, and updated each day (ideally) by the parents and the teacher.

Jessica commented that she wished she had a communication book/collage which she had long ago filed away; she described with vigour the various elements that had gone into these communication books – instead of the teacher writing a quick update, students were encouraged to participate in this communication project, adding various tangible elements that they considered relevant to their day (like band-aids or a box of raisins.) Emily, who had recently moved, described the photos that she had received from the school, which she felt illustrated the friendly atmosphere that was so strong within that environment; she also noted that every year she was sent a photo-album filled with photographs of her daughter doing things throughout the year. Emily appreciated these yearly updates, and still has them packed away. Because of the personal nature of these documents, I was unwilling to photograph them. Nevertheless, they did act as “aide-memoires” during our conversations, inspiring stories and comments.

### **Researcher - Participant Relationships**

Both feminist and hermeneutical phenomenological research emphasizes the importance of a comfortable and open relationship between the researcher and participant. As such, I made efforts to share information about myself, disclosing my past work in the homes and schools of students with disabilities, and describing how it has led me to research this subject. I was open about my status as “teacher.” In order to increase participants’ comfort levels, it was essential that I explained how my experiences had led me to ask about their experiences and knowledge. In the last two interviews, I was open about my current conundrum, where I find myself struggling to “walk the walk” of parental involvement – since this has become a recurring

element in my daily practice, as well as the “self-reflection” component of my research, I wanted to honestly share this with my conversation partners.

Undeniably, there were moments during the interviews when the Teacher in me flared up, disagreeing strongly with what participants were sharing. I tried to take note of this Teacher, contain her frustration and defensiveness for the duration of the conversation, and reflect upon those instances afterwards.<sup>19</sup> As such, I do not believe that my relationships with the participants were compromised by my personal feelings towards the subject matter, but my research was made thicker by my involvement and perspectives; as Laverly (2003) notes, the interpretations that arise with hermeneutic phenomenology are the result of “a fusion of the text and its context, as well as the participants, the researcher, and their contexts” (p. 21). I, the researcher, am part of the context; I, the teacher, am also part of the larger context. The interpretations that are made when we find our horizons merging are made richer in their accounting for multiple places and shifting horizons.

### **Immersing Myself in Stories (Data Analysis)**

*The mundane events of our lives are already stories, but they are only invested with significance in the ways they are told (Leggo, 2008, no pagination).*

Data, in hermeneutic phenomenology, is looked to inductively, with themes emerging from that data and thus directing the overarching “composite description.” Van Manen (1990) describes a theme-based reflection method in hermeneutic phenomenological research. In determining the various themes occurring in the research, the researcher develops “fasteners, foci or threads around which phenomenological description is facilitated” (p. 91). Analysis involves considering and shifting various lived experiences, seeing them in their contexts, and ideally

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<sup>19</sup> I tried to view these Teacher “flare-ups” as a space of potential insight, pointing to elements that needed further exploration. This is described further in my discussion of Peshkin in the next section, *Immersing Myself in Stories*.

arriving at a new “imaginative way” of seeing the experience, “other than it has been seen before” (Laverty, 2003, p. 30).

I immersed myself in data – journaling, taking notes as I transcribed, reflecting on my pedagogy. I considered the themes emerging from each individual participant’s story (chapter 4), and then considered the continuities and discontinuities emerging between the different narratives (chapter 5). Using the “selective” or “highlighting” technique (Van Manen, 1990, p. 93), I isolated certain statements which I considered to be telling or significant, marked them by colour (Mertler, 2009, p. 141), and grouped them under thematic headings. These thematic observations provide some of the shape and content of the phenomenon in question (Van Manen, 1990, p. 88). Together, these groups point to some of the shared experiences of my participants, and offer us an opportunity to see how these mothers experienced the schooling of their children.

Participants were invited to engage in a “member check,” in which the “data and tentative interpretations” are brought back to the participants for verification (Merriam, 2002, p. 31); I believe that having this opportunity to consider and comment on data assists in developing research that is both collaborative and close to participants’ experiences. I sent participants a copy of the transcription, with some of the comments which I considered to be potential themes in bold. I guaranteed that nothing that was not in the text they received would appear in the final document. I asked participants to get back to me within a month if there was anything that they wanted changed, added or deleted, and no-one requested any changes.

### **Journaling**

Throughout the process, I made an effort to maintain a vigilant and critical eye on my biases and dispositions. I journaled regularly, so as to have a fuller sense of my impact on the research and data analysis. One of the overriding marks – and challenges – of hermeneutic

phenomenology is its “demand” of “self-reflexivity, an ongoing conversation while living in the moment, actively constructing interpretations of the experience and questioning how those interpretations came about” (Lavery, p. 22). Journaling assists in this back-and-forth, provides a record of (part of) the conversation that is taking place around the role of the researcher in the research.

Journaling also permits exploration of the various “subjective-I”s that appear and force conversation, I turn to Peshkin’s (1989) suggestion that a researcher “systematically identify their subjectivity throughout the course of research” (p. 17). Peshkin, like feminist researchers, insists on reflexivity throughout the research process; he contends that a failure to be attentive to biases is an inattentiveness to an important element of the interview and data-analysis process. Throughout the research process, Peshkin insists that we remain attuned to our “situational subjectivity”, by staying alert to “the warm and cool spots, the emergence of positive and negative feelings, the experiences I wanted more or wanted to avoid, and when I felt moved to act in roles beyond those necessary to fulfill my research needs” (p. 18). Peshkin suggests, after locating these responsive moments, dwelling on them, and making an effort to determine what these responses are showing me about myself and my perspective on the research. He suggests naming each different thing I learn about myself as various “Subjective – I.” In Chapter Six, I describe some of these moments and how they may have come to play in this project.<sup>20</sup>

Reflecting on the “Subjective – I”s that influence my perspective, was a central element in honestly appraising and interacting with the stories and opinions of my participants. If, during my interviews, I had tried to remain unaware of the “I who has been involved in conflicts with

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<sup>20</sup> Of course, I must recognize the incomplete nature of these insights. As Haraway (1997) reminds us: “Location is the always partial, always fraught play of foreground and background, text and context, that constitutes critical inquiry” (p. 37), and no matter how much time I spend considering my various responses and naming my “Subjective – Is”, I will never have a complete set of my biases and standpoints to present as a testimony to my “epistemological, moral or political virtue,” reflexivity (Lynch, 2000, p.26).

mothers” or the “professionally trained I,” then I would not be doing justice to the experiences of my participants. An effort to “bracket” myself from the research would have made it impossible to listen appropriately to the experiences they are sharing, to develop comfortable and collaborative relationships with them, to glean shared themes, and to learn from them. I believe that my personal role in the realm of special education must be acknowledged in order to conduct honest and thorough research; I hope that my personal connection to the research topic has benefited, rather than impeded, the study.

### **The Writing**

Essential to hermeneutic phenomenology is textured writing which works to capture and unfold the central elements of the phenomenon in question (Van Manen, 1990, 2002). By providing “thick” descriptions of the phenomena, readers should hopefully be able to determine whether the information presented in the study is useful in a broader context (Merriam, 2002; Creswell, 2007). Following phenomenological methods, I have sought to develop a “validating circle of inquiry” – that is, a description that both validates lived experience and is validated by lived experiences – a description that resonates (Ray, 1994, p. 131; Van Manen, 1990, p. 27). As I have already noted, despite the many differences between my participants, some themes rose up immediately and organically, “resonating,” with little need for heavy-handedness on my part.

As I wrote, I was challenged continually by the desire to include everything. I was so taken in by these women’s passionate and engaging stories that I wanted to offer them up, whole, to the reader. Why not write about Emily’s search to find a mainstream school that would be willing to include her daughter in their classroom, and her decision not to follow through? Why not include some of the priceless statements made by Kristine about her desire to have her son play like any child would (“*Dirt in his nose! Sand in his pants! That’s exactly what I want!*”) I

struggled with this challenge – how to incorporate each woman’s viewpoint and experience, without retelling every compelling and touching thing she had said to me? I drafted and redrafted my themes. I made a routine of highlighting, copying, pasting, and erasing, and then highlighting, cutting, pasting, and erasing all of the themes and statements that I considered significant.<sup>21</sup> Ultimately, I am satisfied that (a) each woman has her voice shared in Chapter Four, and (b) the five themes which I included in Chapter Five’s composite are reflective of all of the women with whom I spoke.

I am also comforted by the assertion that “all interpretive phenomenological inquiry is cognizant of the realization that no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge” (Van Manen, 2002, p. 7). As Leggo (2004) notes, “any story we tell will always be a fragment of the complex and wide-ranging experiences that each of us lives daily” (p. 98). This acknowledgement of incompleteness ensures that the researcher engaging in hermeneutic phenomenological inquiry is ever-attentive to the variety, the colour, and the possibilities of human experiences. I have tried to engage in such critical and attentive readings/writings in my efforts to describe the lived experiences that mothers of children with multiple disabilities share with me about their experiences with schooling. And still I know that this interpretive process is never fully complete, and always holds out the possibility of something more to be shared.

### **Implications for Theory, Practice and Policy**

While current educational policy emphasizes respectful “partnerships” between “parents” and schools, research has begun to indicate that satisfying partnerships are not the status quo. Thus, this study turns to the experiences of mothers, as the main caregivers and advocates of

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<sup>21</sup> An activity that, I believe, is reminiscent to Van Manen’s (1990) activity of writing and rewriting in order to describe a phenomenon (p. 30-1).

children with disabilities, to shed light on how these relationships are experienced. I hope that, in developing a rich “composite description” of the phenomenon of mothers’ experiences of their children’s schooling, this study might play a small role in the adapting of practices and policies such that partnerships may truly flourish, and mothers may have opportunities to express their knowledge about their children in a responsive and respectful environment.

## **CHAPTER 4: THE MOTHERS**

This chapter provides some of the contours of each participant’s experiences. As I spoke with each woman, reflected on our time together, and transcribed our interviews, themes began to emerge. Although hermeneutic phenomenology consists of a “composite description” (Creswell, 2007, p. 58), I feel it important to begin with a consideration of each participant’s personal descriptions – each woman held some stories and themes dear to them, and these themes reappeared throughout our conversations. Although most of these personal themes do weave into the composite description in Chapter Five, each woman’s stories and insights also stand on their own. As such, before delving into Chapter Five’s composite, I want to devote time and thematic attention to each participant in order to honestly present their words and concerns, quoting and emphasizing some of their most significant statements. I turn your attention to (in no particular order) Jessica, Kristine, Emily, and Patricia.

### **4.1: Jessica, Mother of Jonathan**

Jessica lives with her husband, her daughter who is in graduate school, and son, Jonathan, who is in his mid-twenties and has multiple disabilities (including a mild developmental disability, Asperger syndrome, vision and hearing impairments, and some fine motor challenges). Jessica met me in her living room on a bright winter day, sipping drinks and chatting for slightly over an hour, as various family members popped in to listen or comment

about the football game. She works in a field where she is in regular contact with parents who have young children with disabilities, and I asked her to feel free to comment on her dual roles of mother and professional throughout the interview. She is enthusiastic about her job, considers it rewarding and helpful, and she identifies with the circumstances of the parents with whom she works – an element of her work which is “*hard*” but which undoubtedly enriches her interactions with them.

Several themes emerged from my conversation with Jessica. She is motivated and passionate about her son’s experiences and successes, as well as the experiences of other mothers who have children with disabilities. She articulated many moving and insightful stories from her own experience, and reflected upon them in both a personal sense and with a sense of the broader implications for other mothers and children. Especially evident were her reflections on the various schools which Jonathan attended (particularly in reference to inclusive<sup>22</sup> versus specialized settings), the spectrum of educational professionals that she encountered over time, the challenge and complexity of navigating various structures to meet her child’s needs, and the importance of advocacy in her and Jonathan’s lives.

### **Choosing Schools, Meeting Needs**

Jessica and her husband enrolled Jonathan in a number of schools, both specialized and inclusive, over the course of his education. Jessica commented that his needs changed over time, guiding the kinds of schooling choices were appropriate. She considers both of these alternatives as helpful in Jonathan’s progress:

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<sup>22</sup> I use the term “inclusive” throughout the text, to indicate the ideal towards which schools and classrooms are allegedly working. Some of the examples participants discussed are closer to the older term/concept “integration,” and some may even be considered exclusionary. Nonetheless, I employ the term “inclusive” because that is what these classrooms are alleged to be.

*When he went to that [specialized] high school, it was great for him. And when he was [integrated] in elementary, it was great. It really was great, but it was a lot of work, and it wasn't always easy. It was a lot of work ... work for me!*

Jonathan's educational trajectory began in a specialized setting for young children with communication needs, but within a couple of years, he had moved into mainstream, inclusive classrooms. Jessica described several years of trying to sort out how to best meet Jonathan's educational needs during this period; in grade one, Jonathan "spent his entire year in the hall with his aide," which Jessica considered to be absolutely opposite to the sentiment of inclusion. Because of this experience, as well as some other concerns about safety at recess, Jessica and her husband found another inclusive school for Jonathan, which they considered a much better fit. At this school, Jonathan was more included in his classrooms, although Jessica makes a point of noting that this varied according to each teacher. Despite a better attitude towards inclusion in this school, Jessica remarks on a lack of inclusion on the *social* level; she identified a need for other children to be educated about Jonathan's needs, for teachers and staff to encourage engagement between Jonathan and his peers during unstructured times like recess and lunch. Overall, however, Jessica described this elementary school as positive.

When Jonathan hit puberty, he began to struggle with different challenges, and Jessica and her husband re-evaluated his placement. As a result, Jonathan attended a high school for students with learning disabilities, which Jessica describes as "good for him":

*We felt that the gap between him [and the typically-developing children at the mainstreamed school] was becoming more obvious, and it was just becoming harder and harder for him. So we sent him there [specialized high school] for that. At that stage in his life, it was appropriate.*

Overall, Jessica was satisfied with the education that Jonathan had received. Throughout our conversation, however, she highlighted how much of the positive outcomes were related to

her constant advocacy. Jessica spent a lot of time in Jonathan's schools, talking to his teachers and principals, and working at the level of the school board as well. She knows that her relentless advocacy "paid off" for Jonathan, but recognizes that this level of work is both time-consuming and impossible for some parents:

*You really have to advocate for you child, you really have to be there. And not everyone can. And then what happens to those kids? Right?*

Jessica remarked several times that her level of satisfaction with Jonathan's educational experiences varied year by year and teacher by teacher. She had numerous examples to illustrate the impact of these educational professionals, some of which we turn to now.

### **Educational Professionals: the Good, the Bad and the "Bizarre"**

*With the teachers, yes they could do this [better] and this [better], but they're all – most of them, not all – having the kids best interest at heart.*

Jessica, like most of the mothers with whom I spoke, had a wide variety of experiences with the educational professionals in Jonathan's life. She noted that a lot depends on the teacher and the principal; how much Jessica got to know about her son's school experience (in terms of both his day to day and his long-term educational goals) depended on the approach of the educational professionals surrounding her son. Sometimes communication was not a problem, but "*some years, the door was closed and that was it.*"

Jessica remarked on one situation with a teacher that stood out to her as an exemplary interaction. Jonathan had just begun a new school year with a new elementary teacher, and Jessica was receiving daily phone calls from the teacher, phone calls in which the teacher "*complained*" about Jonathan's various misbehaviours. Jessica found that she was dreading these phone calls every day, and finally decided to address this issue with Jonathan's teacher:

*Finally, I said to her, “You know, you’re talking about my child. Surely there’s something good that he did during the day. Is there a reason why I have to only hear about all the bad things that he did? ... It really hurts my feelings! It’s really hard to hear every day” ... Wow! Did she ever turn around. After that, she’d call me and she’d say “Oh, he was so cute today!” instead of “He did this and he did that and he did this!” Yeah – so that was a really positive thing. ... It was amazing. I think she was trying [before] to be helpful. It was nice of her to take her time to call me everyday. And I guess she thought she was being helpful by telling me these things, that I’d want to hear everything. But I wanted to hear good things and bad things, I didn’t just want to hear the bad things. So she still told me sometimes – obviously – the things that he did that he shouldn’t have, but she told me a lot more positive things after that. So that was really nice.*

Jessica reflected that this situation is an example of what good advocacy can do. Instead of approaching the teacher in an aggressive manner, she noted that she used her “*I-statements*” to deflect blame. Jessica, like the other participants in this study<sup>23</sup>, recognized a situation that she did not find acceptable, screwed up her courage, and addressed it head-on. She changed her relationship with her son’s teacher – and potentially, her teacher’s perspective on Jonathan – through her advocacy and sense of what was right.

Unfortunately, not all of Jessica’s stories contained such happy-endings. As noted earlier, the year that Jonathan spent most of his time in the hallway with his assistant was troubling to Jessica, but her advocacy had little effect: “*I tried to address it but there was nothing I could do.*” More troubling still was Jessica’s example of the worst experience she had with educational professionals. For a period in his life, Jonathan struggled with various behaviours inappropriate to a school setting; he began “*acting out, and saying inappropriate things.*” Although Jessica was actively working to address the problem, alongside a psychologist and an assistant focused on behaviour modification, the school had a strict zero-tolerance policy,

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<sup>23</sup> As we note in Chapter 5: A Composite

to which the principal held Jonathan accountable. As a result, every time that Jonathan acted out, he was sent to spend a few days at a school for students with disabilities:

*That was his punishment! ... So he would go over to the [specialized school] and he would spend a few days there in a class with [those] kids and then he was allowed to come back and try again. And ... he'd say, "Well, are the kids at [that] school the bad kids?" because he was sent there when he was bad. And I'd say "No, no, they're not bad – they're good!" (laughter) So that was really bizarre. That was so bizarre.*

Jessica noted that this was just one example of one professional who had a “*very strange way of doing things*,” and that not all of her experiences with educational professionals were negative. Jessica described herself as “*lucky*” to have had access to a variety of professionals throughout Jonathan’s education, and listed a number of teachers, aides, itinerant teachers, psychologists and other professionals involved in Jonathan’s life. The next section reflects Jessica’s “*full time job*” of organizing and working with these professionals.

### **Jessica’s Job: The Full-Time Challenge of Navigating Various Structures**

Jessica noted several times during our conversation that she was “*lucky*” to have been able to take seven years off of paid work in order to devote herself full-time to Jonathan. Because Jonathan was receiving services through a variety of providers, Jessica “*spent a lot of time*” dealing with different institutions. “*That was my full time job, just getting him organized.*” Jessica emphasized how much work it was for her to stay on top of everything needed to set up Jonathan for success:

*Parents have to talk to ev-er-y-body and it’s exhausting, but it’s what you have to do ... Even the educators don’t know ... I’m still not [aware of everything], and I’ve been looking at these things for all these years. And things change ... and you’ve got to stay on top of these things! And it’s a lot of work. A lot of work.*

In addition to the schooling aspect of Jonathan’s life, he had multiple other needs:

*He had all kinds of feeding problems, and [I was] doing OT, and PT, and all that stuff! Yeah, it's a full time job ... But it pays off! You get back what you put in. But like I said-again, I was lucky because I was available to do that. Not all parents are able to do that.*

Again and again, Jessica compared her experiences of raising Jonathan to those of the mothers she encounters in her professional capacity. She remarked repeatedly that she was fortunate to have been able to take time out of the paid workforce to devote to Jonathan, and to have the language and skills needed to negotiate the various service-providers and institutions available to meet Jonathan's needs.

*We say, "You've got to advocate for your children, it's so important, it's this and it's that." But not all parents can do that.*

Jessica connected her own struggles to organize all the necessary components of Jonathan's life, with the challenges other parents encounter. As such, she repeatedly remarked on the need for "case-managers" to help parents know what is available, and to thus relieve some of the stress of constantly researching and seeking out the services best suited for their children.

### **Advocacy: All Day and All Night**

Jessica described a plethora of interactions with various professionals connected to Jonathan's education. As noted earlier in this section, some of these interactions went well, some poorly, and some were "bizarre." The common denominator in all of these interactions was, of course, Jessica herself. (*"I was busy. Yeah. Like, I said, it was a full time job."*)

Jessica made efforts to keep open communication with Jonathan's teachers and school administrators. Additionally, she became a regular face around the school community:

*I tried to get on every parent committee, so I knew all the teachers and staff and the principal. I got really involved that way. I was on the school board parent committee too. And I did pizza lunches. And wherever I could volunteer and kinda see what was going on.*

Jessica did all of this volunteer work in the hopes of both seeing what was happening at Jonathan's school, as well as in an effort to ensure that she was viewed by staff as a helpful friendly face instead of a demanding "*bull in a china shop*." Furthermore, Jessica got involved at the level of the school board, attending meetings and advocating for children with disabilities. She considered her advocacy work, alongside her daily caring for Jonathan, both time-consuming and rewarding. Jessica knows that, ultimately, her hard work benefitted Jonathan, but she sympathizes with families and mothers that can not afford to expend such an amount of time and effort on this work:

*I think that because of my experience working with other parents, that's what has become more obvious to me. As important as I felt it was, and as much as I did it, I see that it's not always possible for all parents.*

Jessica's passion and commitment to Jonathan's best interest demanded that she devote herself full time to advocating and organizing the services essential to his success. She worked hard, and her work over the years has "*paid off*" – she now sees Jonathan flourishing as a young man pursuing his interests and enjoying a full life. She considers herself "*lucky*" to have been able to position herself as Jonathan's fulltime advocate, and – despite some of the negative experiences she described during the interview – she describes her family as "*in general, very fortunate*."

#### **4.2: Kristine, Mother of James**

When Kristine first contacted me via email, she told me she "*could write a book*" about her experiences with James' schooling. And when I called her to introduce myself and talk about the study, we talked for over fifteen minutes about how "*exhausting*" she found the school officials and school policies – Kristine was ready and keen to talk! We met in late June, just after James had finished his last exam, and together we basked in the early moments of summer

vacation – when the summer seems endless and full of sunny potential. James, an extremely well-spoken teenager, who has a physical disability and a visual impairment<sup>24</sup>, wheeled himself in and out of the dining room, commenting on teachers who had made him angry, and board policies which he found exclusionary or inappropriate. While I did not transcribe any of the comments James made, he did influence the direction of our conversation, reminding Kristine of various stories and situations. It was clear that he and Kristine were a team, cemented in the goal of James succeeding in his schooling – on his own terms, and with pride.

Kristine and James live together in a sunny adapted home. James is in a mainstream high-school, taking a reduced course-load and working towards the goal of graduating with a high-school diploma. Because he can not read or write, he uses various adaptive technologies to do his work. Kristine spends a lot of her time helping him to succeed using these various accommodations, and acting as his advocate with various education professionals – from educational assistants to individuals at the board. She is committed and passionate about her son and his successes –at both educational and personal levels. We spoke for over two hours, emptying teacup after teacup, while we discussed her and James’ journey through the educational system. The themes that emerged from our conversation centred around her advocacy role, the specific knowledge that she has as James’ mother, and the importance of “*thinking outside the box*” in educational settings.

### **Kristine’s Advocacy: “I’m a Mum Who Doesn’t Sit.”**

*I’ve learned how to say things so that nobody’s taking it personally. We’ve all built that skill ... If you do not understand my child, you’re gonna understand really friggin quick! (laughs) So don’t do that. And when you [the educational professionals] finally get it, then you’re on board with trying to help him out.*

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<sup>24</sup> Until the middle of elementary school, James also had severe medical and behavioural issues. As such, he attended a school attached to a treatment centre, and only entered the school board in the later elementary years. Kristine has fond memories of that original school, which we discuss in further length shortly.

Kristine was confident in her knowledge of her son's strengths and needs, and seemed unafraid to go to bat for him. Twice, she described herself as “*a lion*” when it comes to dealing with the professionals in James' life. Indeed, she described countless situations wherein she had been “*forceful*” with educational professionals at different levels. Although James is a very articulate young man, Kristine emphasized that she is nonetheless still quite involved as his key advocate. Reflecting on a recent misunderstanding at James' school, she said:

*With kids who are special needs ... you have the parent who is very much the advocator. Even though the child is very aware of what they can not do, they don't seem able to get that message across. They're aware of what their body's not doing, but they're not advocating.*

Kristine described James as a “*fool-the-eye kid*,” because of his extensive vocabulary and interest in learning. Educators would see these skills and expect him to be able to read and write like their other, able-bodied, students. (At one point during our conversation, Kristine took advantage of a ‘teachable moment,’ turning to James and looking pointedly at him as she said:

*“But there's a lesson here. Because he wasn't advocating for himself. He has a mother who's a lion, but he's playing devil's advocate insofar as he's not standing up to say that this is ridiculous!”*) Due to James' “*fool-the-eye*” abilities, Kristine found herself constantly explaining his needs and demanding appropriate accommodations – “*my advocacy has involved a lot of initiating things at the school.*”

Despite her strength and advocacy, there were some battles that Kristine could not win. When it came time for James to transition into the local school board for the end of elementary school, for example, there was only one school placement option provided for him – and that school was an hour away from his home by bus.

*We didn't have a choice. It was: if your child is going to go in anywhere, the only school that's going to take you in is [this one]... I had to [accept it] Otherwise, my child's at home.*

Kristine accepted the placement, seeing no other options, and ultimately – although the transportation was an ongoing problem – considers his years at that school to be positive . However, when James was ready to transition into secondary school, the school board approached Kristine with a few options – all specialized, and all requiring over an hour in transportation.

*And we didn't take any of them. ... I said, "I'm not doing that anymore! He's travelling like an hour or an hour and a half to the school ... There has got to be something out here. I don't care! ... [In addition to travel time], I'm not seeing what I need to see when James comes home!" ... and I was calling the trustees about bussing issues ... James was having seizures because he was too hot. So I had to get that (laughs) addressed. So it was quite a challenge, dealing with the bussing, in addition to dealing with his medical issues in relation to education.*

Ultimately, Kristine found a school closer to home, which was willing (and structurally able) to accommodate James' needs. James is still attending this school, and Kristine shared a number of stories about how she struggled to have his learning needs accommodated there. James is an auditory learner, something which Kristine has had to be “forceful” about, but she sees that the teachers and assistants have finally started trying to accommodate this need.

The story to which Kristine kept returning, and which she identified as the worst experience she has had in terms of her experiences with James' schooling, is an example of when advocacy simply hit a brick wall. In high school, James was required to take the literacy test – an obvious blunder because, as Kristine pointed out, James can not read and requires an auditory environment in which to learn. Despite his IEP and list of accommodations, James was still required to write the test if he hoped to graduate high school. In terms of accommodations, James was allowed extra time, and his EA was allowed to read and scribe for James, but not to edit (i.e., James had to say things like “comma” or “apostrophe,” as he dictated his text.) On his

first attempt, James failed. Kristine, who was “*furious*,” flew into action, talking to teachers, principals, and eventually calling the board.

*I called the Board ... and got a hold of the guy in charge of special needs kids. He said that they were implementing something for special needs kids, because James was not the only case ... And I'm saying, "Can't we exempt him? I have the letter from the doctor saying he's visually impaired." No, he needs a cognition impairment to be exempt ... So the literacy test was I guess the biggest issue that we had ... [His regular EA] is someone who really should be recognizing that it doesn't make sense to ask [this of James.] ... But the EA is directed by the school board that 'Sorry, you cannot help James, he has to do this.' So I'm saying to the EA and to the resource teacher: "Come on – when we write, we read it over and over again, so we can summarize in our own words. You're expecting James to have this read to him once, know exactly where everything is, say things in a perfect sentence, only once, without revision. Whereas everyone else can read it four times, and edit. So this is when school staff realizes that he can not edit. I'm going, "How can you expect him to edit when he CAN NOT READ?! And that's not news to you, it's in his IEP and the doctor's letter!"*

Ultimately, James was able to pass the test, with private tutoring, assistance from the EA, and a lot of hard work on behalf of James and Kristine.

*And when it was all over, I was still grudging. And I was talking to the guidance teacher, and talking to the principal, and the resource teacher. I was furious about the literacy [test], what I've had to do in order to get him to fit into their mould. Just – it's intolerable.*

Kristine's frustration with this event was palpable. She was visibly agitated, reflecting back on the humiliation that James experienced, and the inability of her advocacy to effect any change in the situation:

*James, once again, had to be subjected to something that was completely unreasonable. ... Here's this special needs kid that ... is unable to do a lot of what is expected of him. They forced it. And you're still having to stand up and say 'No!' millions of times. Saying, 'That's enough!' But nobody can say 'Oh, you're right.'*

### **Thinking Outside the Box: Creatively (Re)thinking Education**

*Why can't we just sort of accept [disability]? Because you're only going to get that child frustrated! And then you're gonna have the parent who's trying to advocate, exhausted, because they're supposed to make that child fit into that box! And we're all trying to do*

*that box thing, but I'm saying "NO!" Unleash all of those doors in your box. And start thinking collectively about how to be creative in how to teach these kids.*

As briefly mentioned earlier, James struggled with many medical and behavioural issues in his early years. As a result, he spent the majority of his elementary years in a school associated with a rehabilitation/treatment center. Kristine looks back on these years happily, describing them as *"the absolute best."* She appreciated that, at school, James' medical needs were being looked after, his behaviours were being addressed, and he was being *"taught how to accept himself."* This school was not divided by grade – another difference which Kristine embraced:

*We found a lot of the parents wanting the child to fit into the grade one standard... So they're forceful with the kid ... Well, he's already got some big medical issues - and emotional issues. So who cares? So we do have this society where the expectations our kids with special needs are to fit into. And I don't think we should even have any kind of a 'every body fit into a box' [approach] – I don't believe that at all.*

This theme of children being squeezed into prefab educational boxes came up repeatedly in our conversation. Kristine believes strongly that the standards and policies that abound within the educational system serve not only to harm students with disabilities, but all students. (*"I think in order for us to be in a diverse society, we should all accept whatever it is that we fit into [instead of boxes]."*)

Kristine felt that this lack of creativity was endemic to the educational system, and felt that James would have benefited from looser "policies" and more open concepts of teaching:

*That's where I'm finding the school boards don't have an imagination. They don't allow the teachers to have imagination. They have a strong structure to it, and they can't go beyond that structure.*

Kristine cited the example of the literacy test as a box from which, with a little creative thinking, her son could have been spared.

Despite her overall critique of the education system as lacking creative approaches, Kristine was able to think of some of the “*wonderful people*” who had worked with James over the years. She described these people as “*a little bit more creative, [people] that can explore the outside of the box ... there are teachers out there that will do it, and EAs – and thank goodness.*” These individuals were bright lights in a dim bureaucratic world for Kristine. She appreciated their willingness to take James as he was, and work with him on his terms. Eschewing the structures that box students in, Kristine said she had always insisted to James that “*learning is different than schooling.*” She has wondered about other ways of viewing and reframing a successful life and a love of learning:

*So I've always taught James the love part of learning. School is just school. Do you really need it in life? Well, it teaches you a lot of things. Certainly, you've gotta go through that. If James is [going to be] an individual who can go through life without going to college and university, we have to be the ones who explore how we can get through life without college and university. ... Learning is always something that is non-stop.*

### **Kristine's Maternal Knowledge<sup>25</sup>**

Kristine felt strongly that her role as a mother was particularly valuable, and was confident that her knowledge and hard work could make mountains move for her son. As an example, she explained how, through years of research and alternative treatments, she was able to get James healthy and drug-free. As she put it: “*My intuition was huge.*” She believed that she was able to start on this path when she first refused to accept the authoritative knowledge

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<sup>25</sup> Here, I am purposefully echoing Sara Ruddick's (1998) conception of “maternal thinking.” Ruddick's work claims that mothers, as a result of their specific standpoints, develop particular ways of thinking, speaking about, and framing the world. She emphasizes that, although there is nothing essential or innate about maternal thinking, it has a real epistemological validity. Ruddick argues that, from experiencing mothering within certain social contexts, mothers begin to develop unique conceptual frameworks, which include specific types of reflection, judgement, and evaluation. In short, mothers develop new ways of thinking about, measuring, and seeing the world; entirely new ways of thinking develop from their lived experiences.

from the medical professionals involved in James' early care, who thought that he would be ill his whole life, and may not live as long as he already has. (*"I'm not letting the medical society tell me that the road he's travelling isn't going to last. I'm gonna find a different way."*)

Kristine had similar insights about her role in James' education, noting that her knowledge has the potential to set James up for success, and believes there should be more space for this knowledge to be shared:

*Really, it wasn't effective [when the school board and teachers were making all of the decisions], because of the number of kids, the responsibility, the paperwork required, the in-the-box criteria. They were already with their heads only in this [small space], where I was looking at it from all aspects. Maybe that's just me, but I think that if parents all got involved in the community of sharing information, working with our kids, getting the schools working on behalf of what's best, then we might see bigger improvements.*

Kristine also articulated her belief that a mother's role is a *particularly* special one with regards to raising and advocating for a child:

*The love and connection that a mother has is truly an honourable thing. And that's something in our society that I honestly believe is [smothered.] We don't give enough admiration to the mothers who stay at home.*

Kristine came to this insight through a personal struggle. She worked hard to maintain a career throughout most of James' life, only recently leaving it to devote herself to her and James' welfare. Reflecting back on her life as a fulltime member of the paid workforce, and a mother to a child with multiple disabilities, she noted the struggle and the self-sacrifice she was demanding of herself:

*I was actually doing nothing for myself, when [you consider] all of the attention that James needed. It's clear, when I look back, that he was craving for all of the attention ... He's fine. But how I did it? I did pay a lot of attention to James, but I didn't pay attention to me. I would tell any mother who has a special needs [child]: by all means, stay at home.*

Kristine now feels healthier and happier than she has in years. Her advocacy and support of James has him continuing on a positive and successful path, one that may result in a high-school diploma sooner than later, and which has already resulted in a healthy, well-spoken and knowledgeable young man.

#### **4.3: Emily, Mother of Lydia**

Emily invited me to lunch at her home. Eating fresh vegetables in her sunny backyard while her son's cat watched us disinterestedly, we shared several hours together – although only an hour and a half were recorded and transcribed. Over home-grown peppers and tomatoes, Emily discussed her experiences with her daughter Lydia's schooling, both marvelling at some of the wonderful people who had worked with her daughter, and expressing concerns about how well her daughter had actually been cared for and educated.

Emily lives with her son, not far from the group home where her daughter, Lydia, now lives. Lydia is a young woman in her early twenties, who has spastic quadriplegia and a developmental disability, is also blind and non-verbal. Nonetheless, Lydia charms everyone she meets, with a wide smile and bright attentive face. Emily and Lydia see each other regularly, as they live in the same community. Emily struggled to find Lydia post-school options after she turned 21, but recently found an enjoyable day-program where Lydia is flourishing.

During our conversation, two overarching themes developed and were revisited repeatedly. The first was one – which is echoed by other participants, but is especially notable in Emily's experience – was the challenge of accessing a school with appropriate services to meet Lydia's needs. This challenge is also connected to the second theme that emerged, as Emily reiterated that Lydia's school was strong in its familial and welcoming atmosphere, but lacked some of the essential components of a specialized school (e.g., rehabilitation and adequate

personal care), which caused Emily to feel conflicted in terms of what was best for Lydia.

Throughout the interview, Emily emphasized that she was grateful for the specialized school in which Lydia spent 17 years, but was also able to delineate precisely where it had come short in meeting Lydia and Emily's needs.

### **The First Hurdle: Finding a School**

*It was a relief to have found a school for Lydia.*

It was a serious challenge to find a school that could meet all of Lydia's needs. In fact, although Emily and her then-husband had contacted a number of specialized schools, in both English and French school boards, Lydia was not admitted to any of them. Emily was at a loss about what to do in terms of Lydia's schooling, until "by pure chance," she heard about another school:

*Just by luck, I was at a park with the children, and there was a woman with her children on the swings, and she approached me because she saw Lydia. (This woman was there because she had had a problem with her car! She was from somewhere else. She'd had her children in her car, so as she was waiting for a mechanic, she came to the park with her children!) She saw Lydia and she told me about [this other] school.*

When I expressed shock that no-one she had spoken to throughout her search had been able to point her towards this school, Emily told me that at that early stage of Lydia's life, she had been left to negotiate various structures and institutions essentially alone:

*I remember when Lydia was very young it was very very difficult to find somebody, because the social workers were either specialists in some field, or not specialized at all, and knew nothing about people with multiple disabilities. It was very hard. And until Lydia was oriented towards [a children's rehabilitation centre], and there I met somebody who worked – was telling me all these resources. But ... from the beginning, I had help from the [the local community service centre], but the people there had nothing – they did not know the different resources.*

While things began to improve as Lydia grew up, Emily is not certain how much of the improvements were related to improved service co-ordination, or her own research and advocacy.

*I'd realized that I needed to get information for myself. And speaking with people, and then they tell you - so you don't look for someone in the governmental structures to give you [help.] And at this point, I had given up about these people anyways. So it's more talking with people ... parents, a therapist here, teacher there. And you end up getting to know lots of resources that are there ... That was the first five or six years. Later on, I was assigned a social worker through the [local community service centre], who was really very helpful, especially in terms of financial support.*

After finding a school for Lydia, registering her in it, and meeting the woman who would be her teacher for several years, Emily felt “*a relief,*” and “*enthusiastic*” about her daughter’s placement. As we see in the next section, Emily had both wonderful and appreciative things to say about Lydia’s school over the next 17 years, but also had some serious concerns. The next section looks at Emily’s feelings about the school, and how she tried to balance the good with the bad.

### **An Either/Or? Family Atmosphere or Professional Roles and Responsibilities**

The major reason that Emily had initially struggled to find a school to accept Lydia was because of her unique set of multiple disabilities. As such, Emily was both happy to have found a school, and to have found one that “*suited her particular needs.*” She was pleased that the school offered both a fun activity-filled calendar, as well as some more “*serious*” programming, including “*communication, music, relationship-building, toilet-training ... hygiene, swimming, fine motor skills...*” She considered Lydia’s teacher to be imaginative and interested in the students’ best interest. She was happy that Lydia’s school was “*welcoming,*” and she felt comfortable communicating with the staff and visiting the school:

*It was really like a second family for Lydia. And the teachers not only made Lydia feel that, but the parents also. I mean, the parents were really welcomed ... [When you mentioned documents], I wished that I could find this picture for you, but I don't know where it is. It was on Halloween, and I had to come to the school for something, and [I was goofing around with two of the staff members] and someone took a picture. (laughs) You know, that kind of thing. For me, it's a terrific image of what we had in that school, and the kind of relationship – very professional, but at the same time, extremely friendly. Yes, there were those two – but I think that the friendliness came first.*

That Emily felt welcomed in the school is a wonderful exception to both what research has shown about parents' experiences at their children's schools, as well as what this study's other participants shared. While other mothers, as we will discuss in Chapter Five, made efforts to *make* themselves welcomed in their children's schools, Emily simply felt welcomed. Emily prized this atmosphere and said that, because Lydia is primarily a “*person of heart*,” she benefitted from this loving environment. As she talked about how hard the teachers at the school worked, and described the graduation party which she had held to celebrate Lydia's achievements and thank her educators, Emily started to become emotional and said: “*You see, I have tears, thinking how grateful I am to the teachers for their dedication.*”<sup>26</sup>

Nonetheless, Emily did have significant concerns about Lydia's schooling, and had difficulty getting them addressed. As Emily mentioned several times during our conversation, Lydia's school – although all of its students had multiple disabilities – had no rehabilitation specialists working in or with it, a lack which Emily felt really failed the children.

*I found that they had not quite turned the corner to really address the needs of people like Lydia. For instance, in a school like that, it seems to me that there should be physiotherapy. Every child should have physiotherapy at least three times a week. And occupational therapy. They should both be part of the staff... And I remember at one point,*

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<sup>26</sup> A few months before our interview, and years after graduating from her school, Lydia was hospitalized and gravely ill. Emily noted that “*So many teachers of that school came. When Lydia was sick, we had [so many school visitors] that staff asked us not to allow anyone else, there were too many people visiting!! There was a constant flow of visitors at Lydia's bedside. So, you see, that tells a lot about that school.*” Indeed, this is a strong example of caring staff going well out of their way to show a student that she is cared for and loved.

*I talked about that to the director of the school and he said that ‘we have tried, and made ads in the papers, and we haven’t found anybody.’ I couldn’t believe that, because how can there be no young physiotherapists that come out of school and want to work with children? So I didn’t question it, but I found it quite strange.*

Emily wondered whether this lack of rehabilitation specialists was at least partially related to the emphasis that the school placed on its friendly atmosphere:

*Well, I wonder. My feeling when Lydia got there was – about the first principal when Lydia started – was that he was more a man that tried to have a nice environment for impaired children. I don’t think he had much imagination in terms of rehab, etc. That was not his orientation, so he didn’t give that support to the teachers. He didn’t hire the teachers who would have knowledge about kids like Lydia...*

*So that was the drawback of the family feeling in that school, where they hired anybody, it seems to me ...[anybody] who had a keen spirit, who was happy to work with these children. And, so I think it was probably the priority at that school – the friendliness, the atmosphere.*

The multidisciplinary approach that Emily believed was missing from Lydia’s school did exist in other nearby schools and institutions. Emily knew from time spent at a nearby specialized school that they had teams of therapists working with children, *and* maintained a friendly and fun atmosphere; she expressed regret that Lydia was not accepted at that school (“*That’s the kind of school I would have looked for. And I was very disappointed when [they] refused Lydia.*”) While Emily appreciated the swimming and massage programs that were available to Lydia, she could not help but see a real missed opportunity in terms of rehabilitation.

Emily also had concerns about the quality of care that Lydia was receiving. She wondered several times about the training of educational assistants and teachers.

*My feeling was that most teachers were not necessarily trained to teach people like Lydia ... Maybe [the training] doesn’t exist! But they didn’t even – I don’t know if they went to any training sessions outside ... and the school was not really oriented in terms of rehabilitation ... And, I’m not sure how much emphasis was put on the training of those teachers. I don’t know, I did not ask.*

Perhaps more concerning was the fact that Lydia often came home positioned incorrectly in her wheelchair, stuck in an uncomfortable position and unable to shift her body throughout her entire bus ride home.

*The assistants, often times, they were not good at what they were doing. I can remember thousands of times when Lydia came home not properly dressed, her diaper not well put, she had peed all over her wheelchair, her clothes were not comfortable, she was not put in a comfortable position in her wheelchair, she looked like this (mimics a strained neck), when she came out of the bus, so - Uh!! And that happened almost every day. And so I complained several times. But of course, I think there was no one who had the power, they would have had to hire different people or something.*

*Me, as a mother, I suffered from that. So I complained – almost everyday – when Lydia came back from school. ... For me, [Lydia's comfort] is very important... It's because of my focus on Lydia's inability to say that she's uncomfortable or to change anything about her discomfort. That's something that's always been a great source of concern for me.*

As concerned as Emily was, and much as she advocated and attempted to explain Lydia's needs to the school staff, this issue of positioning was never fully addressed. Although Emily "suffered" for her daughter's discomfort, she tried to rationalize the situation and make the best of it. She repeated several times that she "consoled" herself in this regard by looking at how much Lydia loved school and the people who worked with her: "*She still was happy to see these people when she got to school in the morning. She was happy to be handled by them, even though they didn't do a good job.*"

Emily repeatedly noted during our conversation how much Lydia had loved her school. Emily believed that this love was the result of the staff and atmosphere being friendly and warm. As such, Emily's overall conception of Lydia's school was two-fold. On the one hand, it was exceptional in its warmth and the quality of its relationships. On the other hand, it failed to meet Lydia's physical needs in two important ways, rehabilitation and adequate personal care. Although regularly upset by the latter concern, Emily explained that:

*I consoled myself saying 'Lydia is mostly a person of heart, and she needs more heart than techniques or whatever.' So I sort of consoled myself, but if you think of it in terms of school, it didn't really meet Lydia's needs.*

Reflecting on this two-sidedness of her experience with Lydia's schooling, Emily put it this way:

*And if the spirit in the school had been less friendly, because of better trained teachers, I'm not sure which one I would choose in the end. And I can not say that I would choose the better trained teachers. I think that spirit was very important.*

Of course, ultimately, these two elements should not be mutually exclusive. Professional and well-trained staff can meet students' physical needs in a fun and loving manner. Placed in a situation where she felt that not all of her daughter's needs could be met, Emily was left to rationalize and appreciate what the school *could* offer her daughter, instead of focusing on what it was not providing.

Emily's love and concern for her daughter was palpable as we spoke. After a lonely struggle to find a school that could meet her daughter's needs, Emily found a school that had both strong advantages and drawbacks. Her appreciation for what the school had been able to provide for Lydia, and her "admiration" for the teachers was genuine and passionate. But, "as a mother," she had to "suffer" and "console" herself because some of Lydia's basic needs were not being met. Although she felt "welcomed" into a familial school environment – a fact which, in itself, is a wonderful exception to the 'rule' – Emily's concerns for her daughter were repeatedly left unaddressed.

#### **4.4: Patricia, Mother of Derek**

Patricia and I struggled to get our interview lined up. As she explained to me, "I don't want to make Derek wait around while I'm talking to you." Derek has recently completed his schooling, leaving his specialized class in an inclusive high-school at the age of 21, and he is

spending a lot of time at home as Patricia tries to organize the next steps and activities in his life. Over several months, during which we established contact, lost touch, and re-established contact again and again, Patricia was clear that she was interested in talking to me, and had a lot to say. Eventually, we met one late fall afternoon, as Derek had gone out bowling with one of his workers. We sat drinking tea, me in my dirty work clothes (having rushed straight from school to her home) and Derek's slippers, and she cocooned in a heavy woollen sweater. As we sat at the kitchen table, there was no doubt about whose needs were placed foremost in this home: there were sensory toys in boxes on the table and floor, a large trampoline in the hallway, as well as numerous visual schedules placed on counters and chairs. Derek came first, and Patricia made no bones about it – apologizing repeatedly for “the mess,” but telling me that her priorities were with Derek and not a tidy home. Can't argue with that.

Patricia and Derek live together and are quite involved in their local community, attending numerous events, joining clubs, and visiting friends. Derek has a moderate-to-severe developmental disability, a variety of OCD, Autism, and some serious health concerns. Although, at the beginning of our conversation, Patricia was initially concerned that she would not be able to remember anything, she sat with me for over two hours, describing her many years of advocacy, her most pleasant and most infuriating moments trying to find a space for herself and her knowledge in Derek's schooling. Three themes emerged during our conversation. Perhaps the most apparent was Patricia's belief in inclusion, and her vision of what inclusion should look like. This vision, tied with her strong awareness of Derek's needs, led to many changes in his educational path, as well as numerous stories of advocacy and agitation. The third theme emerging from our conversation, directly connected to Patricia's advocacy, was that of

communication, and its essential role in providing for the educational needs of students with disabilities.

### **Inclusion: Its Many Forms & Patricia's Vision for it**

Even before Derek was school-aged, Patricia was a strong supporter of inclusion. As such, Patricia found herself advocating for Derek to attend an integrated classroom from the very beginning of his schooling:

*I was already very interested in inclusion. So I wanted him in the neighbourhood school. Along the way, it was often suggested to us that he go to... schools which were either specialized whole schools, or schools that had classes within regular schools. But they all involved, you know, taking him out of his neighbourhood, and long bus rides ... And one of the things with inclusion is that the kids that you meet at school, then you meet them in the local neighbourhood. And that happened a lot.*

Patricia remained committed to her image of him attending neighbourhood schools and interacting with neighbourhood peers. Right from the beginning, however, her vision was challenged – even ignored:

*I just insisted. There actually was a special class at [his first] school, that he could have been in, but I just insisted that he be in the regular [kindergarten] class. And that was a battle, all along. It was a battle. And, in fact, I even found out that they were putting him in the special class and not telling me.*

Over the years, Patricia encountered a number of educational professionals who shared her vision, were willing to compromise and work with her ideals, or were uninterested and unhelpful in her quest for Derek's inclusion within the community.

Perhaps one of her most poignant stories was of the event that convinced Patricia to switch Derek's school in fourth grade. Derek, although he was toilet trained, would have the occasional accident (Patricia believes that these accidents were his way of "protesting" what was happening in his classroom.) Whenever Derek had an accident, Patricia was called at work

to come to school and change him, despite him having a 1:1 assistant, and being able to change himself independently. One day in fourth grade, Derek had an accident and Patricia was not available to answer the phone when the school called her; her voice cracked telling this story:

*So one time, they called me to change him and they couldn't reach me right away. Maybe I was in a meeting or whatever. So they had him sit in the hallway, the big hallway in the school where there were kids going back and forth. He was wet. And it was a long time before they reached me, like maybe an hour and a half. In the meantime, he wet more, and he pooped, and the poo was running down his leg. Right there. In front of everybody. I've never forgiven them for that. That's inhuman, to allow that to happen.*

Although Patricia already knew that this school was not truly amenable to her sense of what an inclusive environment should look like, this was the incident which convinced her to take action. And, ironically, after being spurred into action by this “*inhuman*” experience, Patricia found a school for Derek where inclusion was top priority; she described the years at this school as “*the golden years.*” At this school, Derek was included into a mainstream classroom, with an EA, participating in school life, and having “*two wonderful years.*” As an example of how extraordinary the staff at this school was, Patricia pointed out that, for Derek’s high school graduation party, the school’s principal came to the celebration. Patricia was moved that “*all those years later,*” his elementary principal would still care enough to attend a party for Derek.<sup>27</sup>

During Derek’s high school years, Patricia continued to struggle to share her vision of an inclusive education for Derek. Although, as she described it, “*they convinced me that Derek would sort of get lost in the regular stream*” and she placed Derek in a specialized class from grade 7 to 12, she remained set on him being a member of the school community as a whole. Unfortunately, she felt that Derek was – once again – in an environment that was not fundamentally inclusive. For example, she noted that students in the specialized class did not

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<sup>27</sup> We return to a discussion of these “*golden years*” in the next section, in our discussion of advocating to meet Derek’s needs at school.

have lunch in the cafeteria with the other students. She also reported being angry after an exchange that she had with a neighbourhood teenager who was friendly with Derek:

*But she [his school-mate] would say to me, that she passes him the corridor and greets him, but he and his EA would just walk right by. Now, sometimes, Derek will not respond, but the EA could've stopped and told him to say hi. So it was obvious to me that they were not making as much of an effort as I would've liked to have him be part of the school community. If you don't even respond to someone who says hello!*

Patricia attempted to address this lack of inclusivity in her son's education. Because Derek is a very enthusiastic about sports, Patricia suggested that he attend the school's intramurals during recess – a suggestion that was met with much resistance:

*[They said] to me, "Oh no! We couldn't do that. You – meaning me – would have to take him!" I'm like, "No-one has to take him! Just show him how to get there once. He'll be so motivated. There are adults in the room, and they can keep an eye on him. If there's a problem, can someone figure out where his EA is?" And it never happened ... It would have been wonderful.*

Patricia found this refusal to be indicative of the school's approach to students with disabilities. She knew that one of her son's strengths and motivators was his love of sports, and identified this as a way through which to join the school community. She felt that the professionals involved with Derek at high school were not interested in including him in this way; she described him and his classmates as "isolated" from their peers. Regarding the failure of the school to take up her intramurals suggestion, Patricia said:

*He would've loved that, and he has some good basic skills ... He would've joined in and – even if there's a game, there's a way to include him. Like, he's the kid who grabs the ball when it goes to the sidelines, or helps keep score, or even just watches. There's ways to include kids. But no, it was completely out of the question – "Oh, he'd have to go with an EA!" [The teacher] had this idea that it was almost like he was dangerous to the rest of the school community ... I was so disappointed in that.*

Patricia's suggestion of Derek joining his school intramurals is an example of one of her many efforts to find one of the "ways to include kids." She knew that Derek loves sports and loves

being near other people; she tried to create a situation in which he could have both of these things, and be part of an inclusive school community. Her intimate knowledge of Derek's strengths and needs led her to think of creative ways to include him in his community. Patricia's knowledge of Derek's various needs, along with her belief in inclusion, resulted in years of advocacy, at a series of levels. The next section looks with more depth into her various advocacy experiences.

### **Finding Ways to Meet Derek's Needs: Advocacy and Agitation**

*You have to have a big broad dream. And then, what he learns at school, and not just what he's learning academically, but all of his experiences at school should be built with that dream [in mind.] ... It's holistic.*

A significant part of Patricia's experience with Derek's schooling was her advocacy for his needs and inclusion. As mentioned in the previous section, after the shocking experience of Derek sitting soiled in the hallway convinced Patricia to find him a new school, he entered "the golden years" of his inclusive education. Her very first encounter with the school's principal led her to feel that she had found a school that would include Derek, treat him with dignity, and meet his unique set of needs:

*I remember saying to [the principal], ... "If he goes to your school, what will he get?" And he said, "Well, what does he need?" And I said, "OH! Derek needs lots of things – an EA, etc. So what will he get?" And he just kept saying "Well, what does he need? Whatever he needs, he'll get. He'll get." And that's the way it was, he had two wonderful years at [that school], with that attitude.*

Patricia reflects on the years that Derek spent at that school with fondness – as a school that set a standard for what inclusive education could look like, both in terms of his needs being met and his inclusion in the school community:

*Here's an example of the inclusion. When it was time to go out to recess – he had his own EA, but she was taking lunch break – they would assign two kids each day to accompany*

*Derek out to the recess. And the kids would fight over it – “It’s my day!” “No, it’s my day” – so they would take him out and he would just be playing with the kids. You know, in line for basketball. And if there was ever any problem, they learned that they were to go to the teacher on duty, or run into the lunchroom and get his EA. And that’s such a wonderful and relaxed way [of dealing with it.]*

After Derek’s two years at this elementary school, it came time to find an intermediate school that would meet his needs. Patricia accepted that Derek be placed in a specialized classroom within an inclusive school, and worked hard to ensure that Derek was being included as much as possible. She noted that, while the school was not doing the job perfectly, they were open to suggestions, a quality which she appreciated. (*“They’d never had a system class, so in a way, they didn’t have a history of how things are done a certain way. They were very open.”*) Patricia felt that there was space for her as an advocate within this school. She described an example of a whole school spirit activity, which the students in the specialized class had to leave early; this situation made her *“boil,”* and she asked the vice-principal *“Why didn’t you just get on the loud speaker and say to the entire school community that ... [these kids with disabilities] don’t deserve to stay, [because] they’re different? You couldn’t have said it more powerfully.”* The vice-principal agreed with Patricia’s point, and they changed the protocol. Patricia felt that *“they had some good people there, and they had the right attitude.”* She felt heard as a parent, and her advocacy for Derek’s inclusion was met with acceptance and respect.

Patricia also advocated on a broader scale. She spent well over ten years on the school board’s Special Education Advisory Council (SEAC), representing an organization focussed on inclusion. This responsibility was a lot of extra work for Patricia, but she continued until Derek graduated from the school system. As she described it, she *“was pretty much the only thorn. But I saw that as my role on SEAC, to be a little thorn.”* Over her years on the council, Patricia dealt with numerous issues, but during our interview she kept coming back to one in particular –

which affected Derek, as well as many students with disabilities, and which she raised repeatedly until SEAC finally passed a motion making some changes to the school days of students with disabilities.<sup>28</sup> Patricia looked both proud and shocked as she repeated to me, “*I actually won.*” This win was short-lived, however, as the superintendent of the school board ultimately overwrote the movement, repealing any of the changes brought forth by SEAC, a frustrating moment for Patricia and her colleagues.

### **Communication – the Basis of a Partnership**

*I say that if I'm working on the same side of the fence as the educators, I can go through anything. But if you're on opposite sides, you just don't cooperate.*

Patricia considered communication to be a key element in what makes a good schooling experience. Over the course of Derek's education, she encountered a range of types of communication. In fact, the document which Patricia chose to share with me is telling about the degree to which she believed communication to be important. The document that Patricia fished out was Derek's communication book/agenda from his last year of high school; she opened the pages randomly, showing me a lot of *her* writing, and little to no writing from his classroom teacher.

*In some cases, the communication dribbled to almost nothing – on the teacher's side. And because Derek does not tell me stuff, I want to talk to him about his day. I want to know if something is going wrong before [something happens]. That happened. He was having a terrible time in his last year or two at [high school], and I didn't know about it until it was a huge crisis. I was stunned.*

In Derek's last year of school, he began acting out aggressively (something that was extremely out of character for him.) Patricia only learned that this had been ongoing when she was called in for a meeting that resulted in Derek being prescribed medication by a psychiatrist associated

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<sup>28</sup> For reasons of confidentiality, I will not disclose what the issue was. I am confident that she could be identified by her involvement in this issue.

with the school board. Patricia agreed that Derek could receive a P.R.N. if she was informed afterwards; unfortunately, even this was not communicated to her (*“I would only hear when they needed more.”*)

On the other hand, Patricia also encountered educational professionals who went out of their way to communicate with her. During *“the golden years”* at Derek’s second elementary school, a monthly meeting was held, which many professionals would attend (including teachers, EAs, administrators, consultants from the board.) Patricia was appreciative of this meeting at the time, and after describing it during the interview, said:

*I think, looking back, I was asking for too much. They were agreeable, but we didn’t need to continue to have monthly meetings. That was asking a lot, especially the Autism consultant. But they were willing – they did it. Whereas, in the negative places, it was hard to get meetings and someone who was supposed to show up didn’t.*

Patricia believed that this willingness of professionals to attend a meeting that she requested, but which – in retrospect – was not quite necessary, speaks to the seriousness with which the school tried to address Derek’s needs and view him as a central member of their community. Patricia viewed the results of this attitude as two-fold. First, she felt confident that her son was valued and accommodated, and she felt that she was an informed partner in this process. Second, as a result of her sense of involvement and her belief in Derek’s educational team, Patricia felt more comfortable acquiescing and agreeing to ideas that the educational professionals suggested.

*If there’s communication and partnership, then I can think of cases where [I] put it more in their hands. You’re at peace with it more. Or saying “Oh, OK – I’d have thought to do it another way, but I respect your [thinking] since you’re the one in there every day. OK, I accept that.”*

For instance, at the suggestion of Derek’s second elementary school’s principal, Patricia quickly acquiesced to a suggestion about specialized transportation – an issue over which she *“had dug [her] heels in”* with previous administrators. (*“So when you’re working with them, I guess you*

*listen more, you're more willing to compromise ... And it was just wonderful.*") Patricia was not looking to fight the professionals involved in Derek's life, she was looking for a "*partnership*" that kept his needs and rights front and centre. Her passion for finding this partnership drove her throughout Derek's educational path.

### **Closing Comments**

In this chapter, I hoped to crack a window for us to peer into each participant's particular set of experiences and themes. Through these stories, some overarching themes that inform the composite have already been revealed. The next chapter takes up some of these threads, and offers a composite description, informed by the spaces where the participants' stories came together. In the next section, I strive to describe the patterns that appeared to me in this process of interviewing, reflecting, and considering the data; however, I must echo Van Manen (2002) and his emphasis that "No interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge" (p. 7). Each story has its own shape, which is continuing to evolve, without me, even as I work at creating a tentative composite. I now offer an effort at developing a description that "resonates," and it is my hope that this composite does not *erase* the women who are the very base of this story, but reflects their experiences with solidarity<sup>29</sup>.

## **CHAPTER 5: A COMPOSITE Intertwining Tales & Shared Structures of Experience**

Jessica, Kristine, Emily and Patricia were generous to sit and share their stories. Each woman held certain experiences and insights dear to her, and Chapter Four was devoted to ensuring that these experiences were shared and thematized in their own right. Having

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<sup>29</sup> As my participants repeatedly noted (see Chapter 5), mothering a child with multiple disabilities can be an "*isolating*" experience. As such, opportunities to share with other mothers in similar situations and to discover that, in fact, their stories resonate and point to shared experience and concerns, are –at best– rare.

introduced you to my participants, I now turn to a description of the five themes which appeared in all of the conversations – themes which we might describe as characterizing these mothers’ experiences of the schooling of their children.

### **Where Can I Get What is Best for my Child? Searching for Appropriate Settings and Services**

A thread that ran through each mother’s story was the struggle that she encountered in trying to locate and access what she considered best for her child. While the services and accommodations required to meet each child’s needs varied, what remained the same was the difficulty in actually getting the services provided to their child. Although three of the mothers considered themselves “*lucky*,” they did so in comparison to their perceptions of other families with children with disabilities, who were caught deeper in the levels of bureaucracy and paperwork.

This struggle to access appropriate services began even at the level of *finding* a school. Each mother had intricate stories about finding a school that met her child’s need; three talked about being unsatisfied with what was being provided to their child, and seeking out something better. Emily’s story about finding a school through a random discussion with a stranger in a park is perhaps the most extreme example of the lonely job of finding an appropriate school, but the other participants echoed this experience. Kristine put her foot down and refused the suggestion of a high school that would require James to bus for an hour, and then took the responsibility of finding him a school onto herself. Jessica both did not like how Jonathan was being educated, and was concerned for his safety, so she pulled him from his first school and found one better suited for his needs. Similarly, Patricia, outraged by the treatment of Derek, set out to talk to principals about what they could provide for her son at their schools, ultimately finding what she considered to be a near-perfect schooling environment.

The participants differed in their opinions of whether inclusive or specialized settings were better for their children<sup>30</sup>, but all were united in their focus on providing what they perceived as best for their children. They appreciated their children's differences, their specific sets of strengths and needs, and sought to meet their children exactly where they were. Three of the four mothers had their children enrolled in both types of settings over the course of their educations, identifying their child's shifting needs and providing appropriate supports. As Jessica succinctly put it: *“Yes, it's important to pick the right school and everything, but it's not always the be-all end-all, and things can change, and you have other choices.”*

All participating mothers identified both positive and negative elements that had occurred throughout their children's educational paths. Each had encountered some teachers and administrators who had made the road smoother or rockier through their actions. Kristine returned repeatedly to how helpful James' first school was – because it was associated with a treatment centre, it was able to meet his medical and behavioural needs without her constantly orchestrating these (not-so) separate elements:

*[It] was the absolute best ... I would have to say, though, that when it comes to education ... they dealt with the child and his or her medical issues first and foremost. And as a parent, we could send our kids off [with confidence] – here was a school that actually had themselves set up so that any medical need could be addressed. And at the same time, the confidence of the parents was that 'you are going to receive that call if you need to be there.' And so the connection was medical first, parents and school working together, and then when it came to the education it just fit in there. (Kristine)*

It was a relief for Kristine to know that, at school, James was being treated holistically, and she felt comfortable that the professionals there were able to meet all of his needs.

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<sup>30</sup> Interestingly, all of the mothers – even Patricia, who was extremely pro-inclusion – held fairly fluid senses of which type of schooling was best for their child. As their children's needs changed, the mothers' preferred educational settings changed accordingly. All but one child (Lydia) had attended both inclusive and specialized schools over the course of their educations.

One of the elements that consistently made their children's schooling a difficult experience for mothers was the lack of resources and accommodations made in schools. One of Emily's main concerns, as we discussed in Chapter 4, was the lack of physical and occupational therapy in a school for students with severe multiple disabilities – there was a need for a rehabilitation element to the school, but it was consistently overlooked. For Kristine, the fact that staff expected James to be a capable reader and writer, as well as their inflexibility regarding the literacy test, illustrated that – even in a school that was making great efforts to be inclusive – one of James' most basic educational needs (to have an auditory learning environment) was being forgotten. Jessica talked about how disjointed service provision was for Jonathan, and how she was left to juggle numerous organizations and professionals – an enormous responsibility which we turn to in the next section. She longed for a service co-ordinator who could locate all of the services essential for Jonathan's success and ensure that they were provided.

Finding schools and securing services was a common thread held by all of the mothers with whom I met. Often this narrative (of finding a school and ensuring that it met the children's needs) provided the framework of the entire interview, as anecdotes and asides emerged from within a 15+ year-long story of changing classrooms and schools. These stories consisted of almost incessant and time-consuming research and advocacy undertaken by the mothers – a reality that leads us to our next theme.

### **Always on the Run: Staying (or Trying to Stay) On Top of Everything**

*I was always on the run and life always was chaotic. (Patricia)*

*Really the coordinator is the parent – is the mother, as you say. And so it's really tough, because if you don't know the system, you have to learn all about it yourself. So you're kind of making your way as you're going through alone. (Jessica)*

It is no surprise that being busy is an experience that characterizes the lives of mothers of children with disabilities (see the Roeher Report, 2000). The women with whom I spoke were no exception - as Jessica reiterated several times, “*it was a full time job*” ensuring that Jonathan’s needs were being met. Part of this busy juggling act included the school and associated professionals that were significant players in their children’s lives. Kristine tried to unpack the confusing layers of educational bureaucracy that she had encountered:

*Everybody seems involved in education, yet nobody seems to be involved. And so if you’re gonna look at the families, and the struggles that we have, it always goes right up to the top. But if you blame the top, you’re only pointing the finger at one person, and they’ve tried to build a system that they thought would work.*

Ultimately, parts of the system were not working, and mothers were left to do a lot of the heavy-lifting alone.

*I was really the pilot. And I found that hard. And very frustrating, because I’m not knowledgeable, and so ... anyways, so I was orchestrating each [institution] and, as I said, there was some connection but I was orchestrating... Amazingly [I was organized], because I’m not a very organized person. (Emily)*

*I always was the one advocating. You almost felt as a parent, alone. And it’s hard to connect with other people because your issues when you come home are your own issues, you don’t have time to even think about calling someone else up that might have had the same experience ... it just doesn’t seem to stop. (Kristine)*

It fell to the mothers to make sure that teachers and other school staff knew about medical needs, visual impairments, proper seating, etc. Each woman pointed out how much work it took to ensure that everything was orchestrated, that everyone at school was on-board in terms of what their child needed. Patricia asked herself: “*Honestly, how did I do it? How did I do it all? I know that I was tired most of the time. I didn’t get enough sleep.*”

Jessica repeatedly pointed out that, given both her personal experience raising Jonathan, as well as her professional work with parents of children with disabilities, she sees how some parents simply can not put in the amount of time and energy to ensure that everything is dealt with, and wondered aloud about the consequences this had on the children.

All of the mothers, at various points in their stories, noted that there came a point where they recognized that they could not expect themselves to be in complete control of all these various elements. Jessica shared a story of cooking stew one night as Jonathan played nearby:

*You have to keep it in perspective ... I can remember one day making stew. And I made this stew and got it all ready, and I put it on the stove, and I looked over, and Jonathan was there and I said "Oh my gosh, I didn't even talk to him while I was making the stew! I could've had all this language - the carrots! The turnips! Cut, cut, cut, and chop, chop!" And I thought "How did I lose that moment?" But you can't beat up on yourself. You have to have some moments where you just don't want to talk, you just want to make the stew.*

Similarly, other mothers shared stories where they simply realized that they could not continue to do everything they wanted. Patricia described "giving up" her active involvement in Derek's schooling: *"I'd given up on the school. I'm a real fighter, but five years in that class and, you know, as I say, I realized at one point that I was the only one that was up [at night.]"* This sub-theme of "giving up" reappears in our next section, under a discussion of communication and advocacy. It would seem that mothers of children with multiple disabilities have so much on their plates, that something simply needs to give.

### **The Importance and Im/possibility of Advocacy**

Advocacy is a staple in the experience of mothers of children with disabilities. Jessica reiterated multiple times how essential advocacy is, decrying how the children of parents who can not advocate suffer from this standard. Similarly, Kristine phrased it this way: *"The road is tough, be ready ... If you can advocate, it's a must."*

The mothers I spoke to advocated in numerous ways. All of them were in touch with the teachers and other school officials, trying to ensure that everyone was up-to-date and working together.

*[There are] all of the VPs, officials, etc ... So you've got all of these people you've got to deal with, and you've already got a child who's a lot to deal with just there... My advocating has involved a lot of initiating things at the school. (Kristine)*

*Communication is so so important. If you keep communicating, you generally manage to work together and see the other person's side, you know? ... But if you're not communicating, then – at least, for me – I start imagining negative things. And then finally when I get around to talking to her, I find there's all sorts of good things going on. I wish I'd known! I wouldn't have been harbouring all these resentful feelings. So communication is so important. (Patricia)*

As noted in the previous section, this work of ensuring that everyone at the school has all relevant knowledge and is working towards the student's success is a huge amount of work. Patricia commented that, if schools are not onside with the parents, are not acting as true partners, then advocacy and communication are sidelined. She believed that it was easy for schools and educational professionals to act in such a manner, because parents are often so isolated and intimidated by the institution.

*I think – I would venture to say that the majority of parents don't get involved very much. And I think it's not that they don't want to. It's because they're not encouraged to. In fact, parents are kind of discouraged, you know? Like, "Oh yes, don't worry, it's fine, and we'll take care of everything." So it's intimidating, talking to principals and teachers. It's intimidating. So unless you're encouraged to communicate and be involved, you probably won't. Unless you're a strong parent, which I was. Parents are also isolated, because it's just you, with your school, your kid's teacher ... So many parents who are isolated.*

Sometimes, no matter how much advocating a mother did for her child, nothing would change. Emily, for example, was consistently upset by the condition Lydia arrived home in from school, and tried several times to encourage and show staff the proper way to position her daughter. When Lydia continued to come home uncomfortably positioned, Emily finally

“*consoled*” herself, and silently “*suffered from that.*” Similarly, Emily recalled an incident where she was trying to talk with a teacher about proper method for some occupational therapy:

*I remember for instance, a little bout with [the teacher]. We were talking about Lydia’s hands, and using them. [The teacher] had this idea of how she was going to do it. But I knew from the OT at [the rehabilitation centre] that this movement would not be the best way. And [the teacher] would not have it ... Or maybe I didn’t dare tell her that her approach was counter-productive.*

Emily found herself picking and choosing which issues she raised (and to what level) with the staff at Lydia’s school. She chose<sup>31</sup> to stop advocating around this issue, although she didn’t stop caring. Similarly, Patricia tried to explain how she began to let go of a bit of her advocacy role: “*And I kind of thought I could work with them, and then at a certain point I kind of gave up. I realized I was the only one lying awake at night, angry.*”

Of course, mothers also shared that their advocacy at the school/professional level also had many positive results. Jessica’s story about respectfully confronting the teacher who called to “complain” about Jonathan every day is one such example. Kristine also described, in broad terms, how she always made efforts to explain various things to teachers, and saw some good results. Two of the examples of initiatives that Kristine had seen educators gradually get “*on board*” were the use of educational technologies, and providing auditory learning environments for James.

While Kristine repeatedly described herself as a “*lion*” when it comes to advocating for James’ needs, many mothers did note that it requires some bravery to stand up to educators and advocate for their children’s needs. In one of Patricia’s stories, she framed it this way: “*I tell you, as much as I think I’m a strong parent, that took courage, to step up and say no [to the school.] I was frightened to say it. It felt brave.*” Reflecting on how much work she had put

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<sup>31</sup> Here I use the verb “to choose” in a loose sense – seeing that her advocacy was getting her nowhere, did Emily make a calculated decision to lay down her arms and rest up for the next issue?

into developing relationships and advocating for Jonathan, Jessica expressed concerns for the parents who do not undertake these actions: *“We have parents from other countries that are very intimidated by educators and institutions. So it’s hard.”*

Although advocacy was an essential component of the lives of the mothers with whom I met, it was not always comfortable or natural for them. It was hard work for mothers to make space for themselves and their knowledge in their children’s schools. While Emily felt welcomed in Lydia’s school, the other mothers did not report a similar feeling. Rather, the other three tried to make themselves welcomed there. Both Patricia and Jessica mentioned getting involved on school committees and volunteering whenever the opportunity arose. As Jessica described it:

*I really tried to get on every parent committee, so I knew all the teachers, and the staff, and the principal. I got really involved that way. I was on the school board parent committee too. And I did pizza lunches, and wherever I could volunteer and be in the school and sorta see what was going on. I tried to do that. And that’s what I encouraged other parents to do. Because I think it’s really important- you’re not just seen as calling when there’s a complaint or coming to the school when there’s a problem. You’re there all the time and you’re helping out, and the kids know you, and the teachers know you, and at the same time you’re keeping an eye on [the situation].*

Patricia echoed this impulse:

*I felt that the more visible you are, the better it is for your child. Like, if you sit on school council, and then of course you get to see the principal once a month and he knows who you are.*

Both of these mothers also got themselves involved at the board level. Jessica was involved on the school board, and Patricia spent well over a decade on the Special Education Advisory Council. I believe that what these women’s involvement shows us is the lengths to which they felt they had to go in order to gain a sense of some control over their children’s

educational journeys. These mothers were essentially working all day and all evening in their efforts to support and advocate for their children.

### **“Every Child’s Experience is Different”: Dismantling the Construction of ‘the Disabled Student’**

Without explicitly addressing disability or deconstructivist theory, each mother – in her own way – challenged the conception of disability as a single entity. They knew, intimately, through their children, that every person (with or without a disability) is unique and requires accommodations geared towards their particular strengths and needs. Patricia put it powerfully: *“I’m scared of the teacher who says ‘I’ve had lots of Down’s kids. I know how to handle them.’”*

There was one question in my interview guide – as it was positioned towards the end of the guide, I sometimes had to awkwardly throw it out at the very end of the conversation – which elicited some shockingly similar remarks from all participants. I always asked some variation of “If you were going to give some advice to the mother of a child with special needs who is just starting school, what advice would it be?” Participants inevitably paused, thoughtfully picking through their memories and feelings, and then – either before or after offering their personal advice – issued some variation of *“Every child is different and every child’s experience is different”* (Jessica), *“It would be very hard to give the right advice”* (Kristine), or *“Reinforce that you know your child best and don’t let the board or the school do a number on you.”* (Patricia) The mothers insisted that there was no one type of education best suited for children with disabilities, no singular approach that would stand for all children, no standard advice could apply to all situations. Emily chose to couch her answer in terms of doing what’s right for each child: *“I would ask [parents] to check if their child is happy. I think for me, it has been a very*

*important factor.*” Different settings and different approaches allow different children to thrive; no advice can overlook that fact of the personhood of a student with a disability.

Patricia shared a story about a teacher she encountered one year when she enrolled Derek in summer programming, a story which illustrated how important it is to have an attitude and pedagogy that is person-first:

*Derek went to a [summer program] one time ... and the teacher said ‘I’ve been a special ed. teacher, I can handle him.’ Well, you know, before the camp was over, she was no longer his teacher. They transferred him. Because she couldn’t handle it – she used an approach with him where she was the boss and she was gonna make him behave. [I thought] “It’s not gonna work, lady, but you’ll find out!” She was really the Authority – I’m afraid of people like that, who think they’re the expert and say “I’ve had lots of kids like this.” Well, no. Everyone’s different. Let me tell you about Derek...*

Each of the mothers I spoke to echoed this request: *Let me tell you about Derek/Lydia/James/Jonathan.* They knew their children, were intimately aware of strengths and weaknesses, abilities and disabilities. Knowing that their child did not fit any particular construction of “Spec. Ed. Student,” they wanted to share their child’s uniqueness with the educational professionals who worked with them.

### **Thinking Outside the Box – Challenging Schools to Change, Challenging Society to Change**

*The school board has these legislative things that enforce the teacher to do these things... People seem to work inside of boxes. And when you have a special kid, you can’t work inside the box ... and so I think that’s why we have these special needs kids, because we’re telling the public to get out there and think outside of the box. And so these kids can come to us as a blessing ... You’ve been doing this all the time, and it’s so mundane, and you’ve created all these rules and regulations (she laughs) and - VOILA! Here’s this kid, and he’s gonna challenge your thought, your thought processes. (Kristine)*

A strong theme that had struck me before I had even completed my transcriptions was the language of “imagination” and “thinking outside of the box.” The mothers seemed to thirst for educators and administrators willing to think and work in novel ways. They listed both incidents

that would have benefitted from some original thought, and described situations where someone had done something unique and their child had benefitted.

Patricia was concerned about the limits that professional knowledge can place on a child. She believed that it is essential to maintain a “*beautiful big open dream*” of what is possible for a child, and that a parent must cling to that dream in spite of those who do not accept it:

*... Think high. Educators and doctors, etcetera, can limit your expectations. Yeah - you have to have a dream for your child, you have to have a long term dream. A really beautiful, big open dream for your child because other people won't. And if you don't have a dream, their ideas will take over. What they see, they see limitations, that he'll never do this or that, you have to have a dream and keep it in your mind.*

Similarly, Kristine expressed frustration at the education systems' insistence of placing children “*in boxes.*” What she had most appreciated about James' first school was their holistic, child-centred approach; at this school, Kristine said, “*they didn't have to have the kids put in a box.*” Emily, as we have discussed, was ambivalent about Lydia's school – including whether the school used its imagination in its education of students. First, she stated, regarding the administrator at Lydia's school, “*I don't think he had much imagination in terms of rehab, etc. That was not his orientation, so he didn't give that support to the teachers.*” However, she did feel that the teachers made great efforts to meet the children where they were, saying that they strove to be open and welcoming to new ideas; of one of Lydia's teachers, Emily said:

*I was enthusiastic about her because she is so positive, enthusiastic, she has so much imagination, she believed in the children, she had them do so many different things! ... She would do those things that are just crazy and marvellous for the children, it's great for someone like Lydia.*

Jessica and Patricia both described creative initiatives that their children's schools undertook. Jessica talked about an encounter with an administrator that she still looks back on with an almost giddy appreciation:

*One of the principals did what I thought was so great. Jonathan was working on his cursive writing and he didn't have the fine motor – and I mean he spent hours working on this crazy [activity.] And [the principal] said, “C'mon! Everybody's going to be working on computers. What does he need cursive writing for?” And I was so happy! I said “Oh - THANK-YOU!!” (laughter) And that was a long time ago, and she was right. So we got him a computer and said “Ok, forget about it!” and he started doing things on the computer... That was amazing.*

Patricia described an initiative undertaken at Derek's intermediate school (she considered this school very “open” because “they'd never had a system class, so in a way, they didn't have a history of things are done a certain way.”) Much to her delight, even students with disabilities who were registered in specialized programs began their morning included with their peers:

*His home classroom was a regular classroom. The [specialized] class was where he would go when it was time for reading or math. And the ten kids in the [specialized] class were each in a regular class. And at the beginning of the day, there were announcements and whatever, whatever needs to be done, and you're with your peers. That was beyond me! I didn't even think about that, and suddenly they were doing it ... [The school] was very open that way.*

When educational professionals moved away from the norms and preconceived notions that they had, spaces opened up for children to thrive. As Patricia framed it: “*Making things work, it's really, it's all a matter of creative solutions and attitude and trust ... Creative common sense.*” Creative solutions and imaginative responses to children's needs delighted the mothers I interviewed. Kristine said it with gusto: “*Start thinking collectively about how to be creative in how to teach these kids.*”

Rethinking how education is provided to children with disabilities can have significant impact on society as a whole. Emily believed that Lydia's school had an “*invaluable*” element, one which she considers important for society in general:

*The children were first and foremost people. Secondly, they were students. And that's why all in all, I think I would rather go to a friendly school with those values ... The respect, and the belief in people with disabilities as people who can teach you something, who can*

*make you a better person. I think that they have it [at that school], and that's really invaluable for me.*

Kristine agreed with this person-first mentality. She believed this attitude would make positive change in society in general:

*Society has to learn to accept these kids as exactly who they are. And not confine them to places where they can be isolated. We have to adopt a way that says "Welcome. Welcome, child that has [ADHD], welcome child with physical needs, welcome child that is Autistic. And I think if every individual started [adopting] that concept, then dealing with these issues will be easier ... Because once you accept them – love is huge, and that changes everything.*

## **CHAPTER 6: FINAL THOUGHTS**

### **Personal Reflections & Tentative Contentions**

The process of undertaking this study (from the literature review to the interviews to the thematic analysis) has been a wild and dis/heartening ride. I undertook this project with a sense of outrage and necessity. I was adamant that mothers' knowledges and experiences need to be included and welcomed by schools and schooling professionals, and I wanted to develop a sense of what some mothers might tell us of their experiences and knowledge, given the chance. What I heard in my four conversations confirmed my belief in this pressing need. Indeed, echoing Estee Klar's (2010) poetic claim about her knowledge of her son, all of these mothers "seemed to understand" something that educational professionals are not likely to grasp on their own. The stories of participants highlighted just how important their knowledge can be to in their children's educations, when given an opportunity to share it.

Some of the stories that mothers shared were truly wonderful – stories of teachers and other professionals creatively working with mothers in their children's best interests. Others were outrageous (worse, frankly, than I had expected to hear) – I still shudder to think of how Derek was left to sit, soiled, in a public hallway, and I am profoundly shocked that Jonathan's

“punishment” for acting out was to spend a few days at a specialized school. I wonder what these educators were thinking, and whether they remember these incidents (which are seared into the memories of the mothers I spoke to) at all. I wonder, after all is said and done (and transcribed and thematized and written), what can be done?

This final chapter outlines some of the challenges and personal reflections that came up throughout this research process. My various “subjective I”s make some explicit appearances. I then make an attempt to frame both my challenges and the results of the study within a broader context. I would suggest that there is more the situation than terms like “parent-teachers” might imply.

### **Martha the Teacher: A Story**

A factor that complicated the experience of conducting this study was my newly emerging sense of myself as a special educator. Just weeks after my first interview with a participant, I was given my first classroom. Flabbergasted by the workload, I prepped all night, worked all day, wrote in communication books, sent home a weekly letter, etc, etc. I loved ‘my’ students and wanted to help them do well. Only two weeks into my new job, I received a *very* angry message from a mother whose child had become sick at school. I panicked. The “office” (principal and administrators) quickly came to my side, coaching me in how to handle the conversation, making it clear that they supported me. I was so grateful for that support – without it, I would have felt completely hung out to dry. Ultimately, the issue was ironed out rather easily, and I developed a fairly open and solid relationship with the mother involved. But I looked (and look) back on that situation often, trying to figure out what else was happening during that exchange.

Initially, although pathetically grateful for the office's support, I felt that the mother (who was reacting with anger to what was a valid complaint/point) had been frozen out – overpowered and outflanked by the Teacher and Administration. I was uncomfortable to have been part of that complex. However, as my friends and loved ones kept reiterating, there was more at play than this. I too am a person with feelings, who cared for the student, and who was feeling threatened and intimidated by the mother's anger. Where would I, a new teacher, have been without a support structure that came to guide me through an awkward interaction – and why did I feel guilty about that structure? I know that mothers can often feel alone and unheard when they contact schools, but am I also to feel alone because of this? It is worth noting that, by the end of the term, the mother and I had developed a fairly warm and child-centred approach to communicating, and I feel that such a relationship makes a significant difference in mother's experiences. Nonetheless, this story was one of the many challenges that I have encountered in my short teaching career – where walking the walk of parental engagement is no easy task.

### **Martha the Researcher: Meeting Some “Subjective I”s**

When I finally got up the gumption to return the phone call of my first participant, I was – to say the least – nervous. Thankfully, Kristine was only too happy to talk with me – and assured me that she intended to one day “*fill a book*” with her stories. I walked into her home feeling unsure and staggeringly unprepared. But my time with her proved to be heartening. I began to get the feeling that Kristine, and other mothers like her, had been waiting a long time for this outlet – for a person to meet their concerns and complaints and suggestions with affirming head-nods and the question, “Could you tell me more about that?”

Nonetheless, I also began to get a first-hand feeling for what Peshkin (1989) described as the “subjective I”s. I felt myself resist some of Kristine's claims, and tried to look more closely

at my visceral responses. One of the first claims that I internally resisted concerned the importance of school in a person's life. While Kristine was certainly doing her best to ensure that James received his high school diploma, and was looking into postsecondary options, she was careful to insist that school is not the only way for a person to succeed. While, of course, I know this, the teacher and graduate student in me reared up in strong disagreement.

My "subjective I's" also flared up when talking to Patricia about scheduling staff lunches and breaks, and when Kristine talked about the "specialness" of motherhood<sup>32</sup>. I flared up when specialized schools were spoken of disparagingly, and when one participant suggested that teachers call parents every day after school to talk about the day's activities. Hopefully, these flare-ups were not apparent as I spoke to the mothers. I have not tried to set them aside, but to consider them and negotiate carefully with them as I worked on the transcripts and developed themes.

### **What can be said in closing?**

The four participants who so generously and trustingly shared their stories allowed me to glimpse into their lives and construct a sense of the shared structures of their experiences. Their stories were at times heart-warming, at times infuriating, and always interesting. Participants shed light on the need for more space for mothers in their children's educational journeys, the relentless work and advocacy that is required of them in order to get their children's needs

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<sup>32</sup> I responded strongly to Kristine's claims about the naturalness and specialness of her "maternal thinking," and about women as nurturers. As a feminist with a grounding in social constructivist thought, I have always been wary about the 'nurturer' turn in discourses around motherhood and womanhood. While I am not a mother myself, and I am certainly not opposed to having nurturers in the world (we could use some more, frankly), my concern is with how these claims are so often tied up in biological/essentialist discourses. To me, if you are going to talk about the specialness of being a mother, it's important to locate it outside of biological language and situate it within a contextualized understanding of loving and being the primary caregiver for a helpless child. As I looked back on this subjective flare-up of mine, I realized that Kristine was not necessarily locating her conversation in an essentialist discourse – because I am sensitive to this subject, I had reacted quickly and with assumptions to what she said about motherhood. After all, who would disagree that "*The love and connection that a mother has is truly an honourable thing*"? If the stories and experience of the women I interviewed are any indication, this is truly the case.

addressed, the need to view each student as an individual whose needs can not be met through any prescribed policy or traditional practice.

Meeting these women and listening to these stories, I have been challenged as a researcher – but, moreover, I have been challenged as an educational professional. Conducting this research has been tied up with some guilty feelings connected to my current teaching praxis. How do I treat mothers and their knowledge? Why do I feel threatened by their intricate knowledge and humiliated by their questions?<sup>33</sup>

I scribbled the following in my thesis-related journal, long after I had conducted my last interview:

*Why do I feel threatened by mothers' intricate knowledge and humiliated by their questions? Well, maybe it's because I do know that I'm not doing everything that the students need – I'm not even convinced it's possible for me to do this. ... I know that I can not meet all of the needs in my classroom all the time. The physical, behavioural, academic, communication, occupational and physical therapy goals all set upon me every day, as I struggle to even maintain each child's safety and happiness. I know mothers have a right to demand more from their children's teachers, but I'm not convinced that my team and I can actually provide more.*

This has become the crux of the issue for me. More is required of us – my participants have made that very clear – but can we provide it?

I would suggest that this is a two-pronged problem (at least). Personally, I can continue striving to improve, and keep making changes in my practice. But there is a second, systemic, level to this as well. (The mothers identified this when they spoke of access to services and resources.) If we look to the themes that developed over the course of this research project, we see how hard mothers have to work to help their children succeed, and we see the highly routinized, highly standardized “boxes” which education professionals use out of habit and ease.

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<sup>33</sup> I suspect that it may, in part, be connected to Murray's (2000) claim that “When a professional view is challenged, then the very basis of the professional identity is at stake.” (p. 692) Especially as a new teacher, I am constantly feeling my professional identity heaving beneath the weight of things I am *supposed* to know.

We see, as Jessica repeatedly pointed out, how children suffer when their parents do not have the time or skills to advocate effectively. And mothers, engaged and “*exhausted*” (Kristine) by their advocacy work, also suffer; as Kingston (2007) points out, if there were more resources and attentiveness to children’s needs, then the “stress and struggle” of trying to share knowledge and access resources, would abate, and “women would have more options as regards to their personal choices of life fulfillment” (p. 75). In short, the most activist parents get the most resources for their children, and there simply does not seem to be enough resources to go around.

What needs to change in order to meet these children’s rights to an appropriate education? In addition to the interpersonal changes that were suggested by participants, we would need more resources, smaller classes, etc. How, we have to ask, can we afford it?<sup>34</sup> A project that I entered in the hopes of finding a ‘set’ of themes and mother’s insights about their children’s schooling has left me instead with questions about how to move forward. Nonetheless, it is my hope that this research has highlighted some of the central factors characterizing the experiences of mothers of children with multiple disabilities, with an eye towards the adjustments and overhauls that need to be made. The knowledge that mothers hold about their children, and about living with a disability, is essential to the improvement of special education services. In order for this improvement to be realized, mothers’ experiences and knowledge need to be acknowledged as the informative and instructive tools that they are. As Kristine framed it:

*I think that if parents all got involved in the community of sharing information, working with our kids, getting the schools working on behalf of what’s best, then we might see bigger improvements. But whether that will happen?*

Our challenge, then, is to use our “*creative common sense*,” and to make it happen.

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<sup>34</sup> Perhaps, in a time where the Canadian is planning to build more prisons, and is engaged in a decade-long conflict overseas, I can suggest that we *could* afford better supports for students with disabilities – but stipulate that it comes down to a question of priorities.

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**APPENDIX 1: INTERVIEW GUIDE**

-Tell me a bit about (your child, his/her needs, what kinds of schools and classrooms best met these needs.)

-When did s/he begin school? How was the initial transition into that setting?

-Can you tell me what three words you prepared to describe your experiences?

-What have you experienced as most positive or negative (best/worst) in terms of his/her schooling? (clarifying questions about specific examples...)

-prompts: Best/worst teacher? Therapists? Buses? Meetings?

-If you could change something that you've encountered in terms of your child's school, what would it be?

-How would you describe your perfect relationship with your child's school?

-If you were going to give advice to a parent with a child with special needs going into kindergarten, what would it be?

-Did you bring any documents that are meaningful to you and your story?

-Tell me about it. Why did you choose this? What's the story behind it?

-Can I take a picture and potentially use it in my final report?

## APPENDIX 2: PARTICIPANT CONSENT

**Title of the Study:** *Mother Knows Best? A Hermeneutic Phenomenological Inquiry into Mothers' Experiences of the Schooling of their Children with Severe, Profound or Multiple Special Needs*

**Name of Researcher:** Martha Brown      **Supervisor:** Dr. Cynthia Morawski  
 Graduate Student, University of Ottawa      Faculty of Education, University of Ottawa  
**Phone:** X      **Phone:** X  
**Email:** X      **Email:** X

**Invitation to Participate:** I am invited to participate in the above-mentioned research study conducted by Martha Brown

**Purpose of Study:** The purpose of the study is to develop an understanding of the experiences of mothers of children with profound, severe, or multiple disabilities regarding their children's schooling.

**Participation:** My participation will consist of a brief introductory telephone conversation, and one interview (about 60 minutes.)

**Risks:** My participation will entail answering questions about my experiences with my child and his/her schooling. This may cause me to feel uncomfortable. I have received assurance from the researcher that every effort will be made to minimize these risks. I know that I have the option of withdrawing from the research and/or not answering questions, without any negative consequences whatsoever.

**Benefits:** My participation in this study will help us to understand the experiences of mothers of children with special needs, so that recommendations for improved practices and relationships can be made.

**Confidentiality and Anonymity:** The information that I share with the researcher will be strictly confidential. I understand that the information will only be used for the purposes outlined above. **Confidentiality** will be protected because only the researcher and her supervisor will have access to it. **Anonymity** will be protected, because no identifying information about participants will be revealed in any paper or presentation of the material. My personal information will be kept strictly confidential except as required or permitted by law. I will not be identified in any publication or presentation of the data.

**Conservation of Data:** The data collected will be kept in a secure manner. It will be kept for five years in a locked filing cabinet belonging to the researcher and in pass-protected electronic files. Only the researcher and her supervisor will have access to the files. The data will be shredded, erased and deleted at the end of the five years.

**Voluntary Participation:** I am under no obligation to participate, and I may also withdraw from the study at any time. I may also decline to answer questions at any time, without suffering any negative consequences. If I choose to withdraw, any data gathered up until that time will be removed from the study and destroyed.

**Acceptance:** I, \_\_\_\_\_, agree to participate in the above research study conducted by Martha Brown (University of Ottawa). My participation will only consist of a brief phone call and one interview.

I will be provided with a copy of results of the study upon request to the researcher listed on this form.

If I have any questions, I can contact Martha Brown or Dr. Cynthia Morawski.

If I have any questions about the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research at University of Ottawa.

Telephone: X

Email: X

**There are two copies of the consent form, one of which is mine to keep.**

**Participant's name:** \_\_\_\_\_

**Participant's signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Researcher's Name :** \_\_\_\_\_

**Researcher's Signature :** \_\_\_\_\_

**Date:** \_\_\_\_\_