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# 'To Have a Paddle and a Rudder': A Postmodern Narrative Study of the Lives of Families with Disability

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UNIVERSITY OF CALGARY

‘To Have a Paddle and a Rudder’: A Postmodern Narrative Study of the Lives of  
Families with Disability

by

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A THESIS

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## **Abstract**

This is a narrative study of daily lives for families who have a member with a disability (families with disability). Families with disability are often studied in a way that centralizes disability rather than personhood. The medical model and social models of disability work to create a framework of how disability might be viewed. However, these models are problematic because they have a tendency to cover over the smaller, more subjective stories of disability. Stories told by families with disability are important to tell, hear, and understand because they provide new and alternative ways of looking at life with disability. In this study, I interviewed families (being any group of people that consider themselves to be family) with disability. I conducted interviews with two or more members of five families who have a member with disability. Narrative analysis of data resulted in the writing of three stories that tell of daily life for families with disability. The stories are then further analyzed to reveal conventional and unconventional readings. Conventional readings show how dominant narratives shape understanding of family life with disability. Unconventional readings were derived using a postmodern lens. These readings uncover lesser heard, as well as difficult to tell and hear stories. The dissertation concludes with recommendations and suggestions for health and social care providers that work with families with disability or in other disability-related contexts.

*Keywords:* disability, families with disability, family, narrative, story, postmodern

## **Acknowledgements**

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## **Dedication**

I would like to dedicate this work to my late grandmother, Grace Keegan, who loved nothing more than her family and valued nothing more than education.

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## CHAPTER ONE - INTRODUCTION

This is a narrative study into stories told by families who have a member with a disability (hereafter referred to as *families with disability*). The families in this study told rich and complex stories, which offer valuable insights into how their lives are lived (Connelly & Clandinin, 1990). The narrative approach used in this study compares what can be thought of as conventional (or more dominant) and postmodern readings of the families' stories. The findings from this study show that daily life in the presence of disability can be both surprising and ordinary in many different ways. This research makes a contribution to knowledge by offering alternative ways of thinking about life with disability.

The purpose of this kind of research work (informed by narrative inquiry) is not to theorize or produce "better" stories of disability or impairment. The purpose is also not to propose improved definitions or terms associated with disability because new terms and definitions, in turn, introduce new complexities and problems to the disability landscape (Foucault, 1978). Telling stories about family life with disability can, however, lead to different conversations about life with disability, opening these conversations in contexts where perhaps they have not happened before (Goddard et al., 2000). Dominant narratives of disability tend towards stories of deficit, not coping (Bacon & Lalvani, 2019). Although these are legitimate narratives in the sense that they describe some aspects of people's experiences with disabilities, there are other stories that illuminate different aspects of experience. If these other stories are not told, then disability experiences remain one-dimensional stories of deficit.

The landscape of disability service provision can benefit from hearing diverse accounts of experience. Different conversations, derived from stories of experience can become generative gathering places (Gordon et al., 2007) for people with disabilities and their providers. These conversations can serve to disrupt, and challenge taken for granted understanding and norms about the “disability paradox,” whereby dominant narratives about disability are created, but are not necessarily representative of life with an impairment (Carona et al., 2013, p. 971). That is, dominant narratives about disability are written about disability but not necessarily by those with lived experience of disability. This current study is, then, about the generative possibility of alternative stories.

### **Background to the Study**

This study was informed by the need to explore more deeply the experiences of families with disability. Families with disability are a rich source of knowledge about daily life with disability (Bellin et al., 2011). While families with disability are called upon to inform research (Charlton, 1998; Rios et al., 2016), this research can be a form of scrutiny and evaluation of family function and coping. This means there are certain aspects of families’ experiences that are able to be shown and others that remain under-explored and hidden. As such, important insights into family life in the context of disability is lost. As well, families with disability risk being spoken for, rather than informing research that shapes care and service provision.

Although the experiences of families with disability are represented in existing research, to some degree, the *voices* of families with disability seem somewhat marginal. Carona et al. (2013) criticized the practice of generating knowledge about disability without centralizing the perspectives and subjective experiences of people who

experience disability. They warned this perpetuates the aforementioned, *disability paradox* (Carona et al., 2013, p. 971). These assertions in the extant literature point to the need for a study that attends to voices on the margins, to consider what knowledge might be called forth and given value.

Valuing the voices of families with disability is one important way to address marginal experiences. Reynaert and Gelman (2007) problematized the ways language is used to disenfranchise groups. They suggested that linguistic form and conventional wording have social consequences that reinforce disadvantage. Language that categorizes people with disability as “different” (Asbjørnslett et al., 2013, p. 369) assumes they are “defective” (Baur et al., 2014, p. 3) or “less than” (Kumari Campbell, 2008, p. 151). Language influences our perceptions and, in this case, reinforces long-standing judgments about life with disability (Reynaert & Gelman, 2007). Listening to families’ experiences in this study provides a starting point to speak back to language that labels and perpetuates assumptions and the status quo.

This current study is informed by postmodern thinking. Postmodernism troubles practices of categorizing and applying labels because this can lead to the impression of a fixed truth about a given phenomenon or experience (Goodley & Runswick-Cole, 2012). Disability and the people who experience them are diverse. Clustering people together using an umbrella term like “disability” is contested (Brisenden, 1986<sup>1</sup>). This language

<sup>1</sup> In this literature review, I cite an influential author, Simon Brisenden. Throughout my literature searches, his work surfaced frequently. Brisenden’s (1986) standpoint on disability relates both to the social model of disability lens as well as his own personal experiences as a disabled person himself. The postmodern lens I take in this research relates closely to his perspectives on the intersection of society and disability. As such, his seminal 1986 publication is cited across my work.

lacks descriptive variance; that is to say, the word cannot capture the richness and diversity of experience.

I began this research with certain terminology in mind, but also prepared to unpack or critique my use of it as I engaged with and analyzed participants' stories. For the purposes of researching disability experiences, it was necessary to settle on a way to identify and describe the people (or population) of interest. Therefore, I made particular choices about language and terminology that I outline below.

The literature points to the need to foreground personhood: to place the person ahead of disability. Health and social care scholarship also uses (although not exclusively) *person-first*<sup>2</sup> language as a way to speak back to the power of labels to create identities for people, which in turn can lead to labeling, stigma, judgment, and oppression (Bedell et al., 2018; Dunn & Andrews, 2015; Tassé et al., 2005). The use of inclusive, respectful language for people with disability has and will continue to change over time and context (Collier, 2012). Presently, there are differing perspectives about how to meaningfully represent disability in the literature. Two common ways to speak about disability in the literature are person-first (i.e., people with disability) and identity-first (i.e., disabled person) language (Dunn & Andrews, 2015). Some have used the term disability-first language (i.e., disabled person) as a way to resist the idea that disability is a problem that individual people have (e.g. person with a disability) and, instead, turn to societal structures as problematic (Titchkosky & Michalko, 2009). While I agree that

<sup>2</sup> Person-first language is the practice of placing the person before a label, effectively communicating that a disability (for example) is something a person "has" rather than being what they "are."

identity-first language has merit, in this study, I have opted to use the person-first phrase, *people with disability*. This was for two reasons: first, it is the language used by many of the families that I have encountered over the years (including the five families interviewed in this study); and, second, it shifts the language to identify the person before their disability as a means to respect their personhood (Collier, 2012).

In this study, I tell, analyze, and interpret stories about life with disability told by families with disability. Sharing and engaging with these stories is an important way to explore and question what is “known” about disability and how that “knowledge” has come to be (Razack, 2006). When stories are read, or analyzed, in unconventional ways new ways of thinking become possible (McAllister, 2001). Approaching stories of experience in unconventional ways can reveal--and begin to trouble--dominant narratives about disability and influence attitudes and beliefs about disability and living with impairment (Goddard et al., 2000; Lalvani, 2008).

### **Research Question**

To address the aforementioned knowledge landscape, in this study, I asked an open question characteristic of narrative inquiry (Clandinin, 2013). The question for this study was, “how do families experience daily life with disability?” This question formed the basis to explore participants' experiences and draw narrative insights without predetermining what would be considered important or relevant by families. As is customary in some types of narrative research (Caine et al, 2013; Clandinin & Connelly, 2000; Riessman, 1993), I begin this dissertation by locating myself in this work. I do this to reflexively position myself in the research and practice landscape, and to be

transparent about the experiences and understanding that I bring to the conceptualization, design, and conduct of the research.

### **Positioning Myself**

I position myself in this work as a way to acknowledge and affirm my subjectivity and, thus, the value of the intersubjective relationship I engaged in with my participants (Walshaw, 2008). My own story explains something about where I have drawn knowledge from in the past and how that knowledge informs this study. My own story also helps to make sense of acts of meaning making in the researcher-participant relationship (McLean & Pratt, 2006) and in the analysis and interpretation of data collected in this study.

I have had many different experiences working as a health and social care provider with families with disability. These experiences have caused me to think about ways that my “support” could be valuable to families. Through developing relationships with families, I learned about day-to-day happenings within families with disability and how these happenings contributed to their experience of disability. My exchanges with these families as they navigated life with disability were a lived, practical impetus for this research.

It feels important to me to say, at this point in the writing, that I do not identify as a person with a disability. I live my life alongside extended family members who experience disability and, early in my graduate program, I was diagnosed with an autoimmune disease. I do not live directly with the implications of disability in my extended family and my own impairment is invisible. As such, I am able to avoid many of the social implications of disability, although I have experienced first-hand what it

feels like to have to fight for my well-being, to be heard, and how frustrating, arduous, and tiresome that can be.

My other identities have afforded me different insights into experiences of disability: as a past and present volunteer in the disability sector, I have worked closely with families with disability; as a registered nurse, I have experience of providing professional care in the context of disability; and, as a health and social care entrepreneur, I am building a business that sustains my engagement with--and service to--the disability community. As such, I occupy a privileged position of being able to “look into” the lives of families with disability, and my practice and entrepreneurship confers the ability to also “act upon” families with disability in different ways. This privilege comes with a responsibility to cultivate sensitivity and awareness of my position in relation to families with disability and in how I speak about the families in this research.

My choice to make this master’s research a narrative study is one of the ways that I have tried to attend to the aforementioned responsibilities. In their seminal work on narrative inquiry, Clandinin and Connelly (2000) stated that “we are in the parade we presume to study” (p. 63). Narrative research makes room for the researcher’s story to be told in a way that embeds the researcher in the context under investigation. Narrative research generates or calls forth stories and engages with those stories in ways that are evocative, *life-like*, and that help experiences that might be hidden to be shown (Caine et al., 2019). As such, narrative research is a way to attend to voices on the margins; it is a way to represent and centralize the voices of participants as well as attend to the voices of researchers.

### ***Between Friends***

Disability has been a focal interest of mine since 2008. I was a second-year Bachelor of Science student at the University of Calgary when I attended a hiring fair on campus. One organization at the fair jumped out at me: Between Friends<sup>3</sup>. I noticed photos of a young boy with Down Syndrome wearing a harness on a high ropes course. I was excited by the prospect of attending a summer camp and working with children. I applied later that week and was hired as a camp counsellor for the coming summer.

Working and volunteering with this Between Friends was where I got my start working with families with disability. I have been involved in many levels of the organization, including as a volunteer, fundraiser, camp counsellor, program lead, recreation inclusion coordinator, and finally as camp director. My greatest learning from these experiences was that quality of life and disability are not mutually exclusive. My work with Between Friends was instrumental in helping me to recognize the happiness, joy, and fullness of life for people who experience disability and their families.

Camp is a special place. It holds the hearts of both the campers and the counsellors. In my first days at camp, I noticed that campers rarely argued or became upset with one another. The campers played together and helped one another. The children did not bully one another; they were observant of each other's emotions and well-being. Their demeanour took me by surprise as I expected at least a handful of quarrels during a day. When I looked back on the experience of camp, I wondered what was it about camp that brought out collaboration and friendliness in the children? For

<sup>3</sup> Between Friends is a Calgary-based organization that delivers social and recreational programming for people with disability.



me, it felt like camp was a safe place: one place that they could just *be*. It was a place where timelines were flexible, fun was the priority and where “rules” were treated more like flexible shades of grey. As I recall some experiences, I hear in my mind:

*Hey, you want to use a marker to draw a mustache on your favourite counsellor?*

*Sure, go for it! You want to dye their hair today? You got it! You want to do what...*

*throw water balloons at them? Wait...I'll get the balloons!*

On the last day of camp, many of our campers and counsellors cried. The last day marked the end of a fun-filled summer and heralded the long fall and winter months ahead when we would not see each other.

On this last day of camp, one boy in particular stood out to me. He was waiting for his mother to pick him up. He waved me over behind one of the bushes, out of view of the other counsellors. He shared a plan to dump a bucket of cold water on one of the counsellors but needed my help. We gathered all the supplies and launched a surprise “attack” on this counsellor. It turned out we were not as stealthy as we originally thought, and we too were soaked with water from buckets and hoses. Absorbed as we were in our play, we had not noticed that the boy’s mother had arrived. She stood on the sidewalk, wiping her eyes. She shared with me that her son had never made a friend before. He lacked confidence and believed his autism diagnosis would mean that nobody would want to befriend him. She told us that, over the past weeks, his confidence had been building. Earlier that week, he came home and alerted his mother, “I have autism!”. He stayed overnight at camp; it was his first-ever night away from his mother and he was eager to attend. We were surprised to learn about this boy’s demeanor prior to camp. He told us that being at camp made him feel that having autism was not bad; at camp, he

could be himself and part of being himself was having autism. We reflected upon this conversation at our group huddle before we went home. Each of us left with this family's story replaying in our minds.

A few years after that summer, I saw that boy and his mother in the community. I was excited when I saw them but thought they were unlikely to remember me. The boy's mother called my name and I went to speak to them. I heard about all the great milestones her son achieved since we last spoke. He asked if I would write a reference letter for him to start volunteering with Between Friends and I happily agreed. He started as a volunteer and has now worked many summers as a camp counsellor himself. I was also present at the Between Friends Annual General Meeting when this now young man was honored with an award for service to the organization.

### ***Lauryn***

That same summer, I met Lauryn<sup>4</sup>. Lauryn was diagnosed with autism and a genetic anomaly. Together, these diagnoses are expressed as restricted interests, repetitive behaviours like echolalia<sup>5</sup>, and rigid thinking<sup>6</sup>. Lauryn is willful, resilient, expressive and gentle. She drew me in on the first days that I met her. I became enthralled trying to find ways to best communicate with her and support her in her learning. I was drawn to her gentle spirit and when I met her mother at pick-up time, I could understand how Lauryn

<sup>4</sup> Pseudonyms are used throughout this dissertation in place of actual names of people and places.

<sup>5</sup> Echolalia is the repetitive use of a word, phrase, or noise heard. These can be functional (e.g., learning or recalling a process) or non-functional (e.g., out of context rehearsal of a clip from a television show).

<sup>6</sup> Rigid thinking is the compulsion, obsession, and/or perseveration with specific thoughts or processes (e.g. using an object or ordering items in a specific way).

came to be the person she is. Her mother is caring, humorous, light-hearted, and careful not to let challenges derail Lauryn's or their family's progress and successes.

A few weeks after camp ended, I noticed a posting through the camp website about a family looking for a support worker for their 12-year-old girl. They described her needs and what they were looking for from a prospective support worker. I noticed the similarities between this posting and my experiences with Lauryn. I phoned to express my interest and learned I was speaking with Lauryn's father. He explained that Lauryn's mother organized her support and I would need to wait until her return on Sunday evening. The weekend dragged on as I imagined other, more educated or experienced applicants than me getting the position. I wondered if Lauryn's mother would remember me from camp and whether that would set me apart from the competition.

On Monday, Lauryn's mother returned my call and we arranged to meet. She did remember me from camp and presumed she would hire me when she saw the scribbled messages from her husband. I started working with Lauryn that week and I subsequently saw her twice a week: an arrangement that lasted for eight years.

I remember the time when Lauryn read her first book from start to finish. Due to Lauryn's processing and repetitive behaviours, when we read together, Lauryn would memorize the first letters of a word and match them to the sound of the spoken word. This meant that Lauryn would mix up words like, "there," "they," and "them," for example. She would also need me to repeat each word she read after she read it, then have me repeat the sentence before turning the page and moving to the next words. If I challenged Lauryn by encouraging her to say more than one word at a time or by correcting her, she would become frustrated and disengage with the reading task.

For nearly one year, we worked through one particular *my-first-reading* book, “One” by Kathryn Otoshi. We went to Chapters to read this book once per week. I applied the strategies I had learned from Lauryn’s speech language pathologist and negotiated with Lauryn to keep persevering. We worked through the book word by word, then sentence by sentence, and page by page. I purchased the book and brought it with me to Lauryn’s house one week. I gave it to her, and she quickly opened the cover and began to read it aloud. She did not turn to me to repeat the words or sentences and she flipped through the pages, reading each word until she closed the back cover. Her mother watched and I noticed she was crying. It was a milestone that Lauryn hit as her “Sweet 16” birthday approached.

The kindness Lauryn and her family have shown me over the years has guided my personal and professional philosophy of uncovering the often-hidden quality of life that people with disability and their families experience. In fact, Lauryn’s family is the reason I pursued my Bachelor of Nursing degree (BN’13) as I hoped to find a place in nursing that would make me feel the way I felt with Lauryn, every day. They are also a great source of motivation for my other endeavours as I look to strengthen the health and social care landscape for families with disability.

### ***Camp Fun’zAmust***

During and following my experiences in working with Lauryn and her family, I also pursued my passion for working with young people with disabilities through a new camp that Between Friends launched in partnership with Easter Seals. Camp Fun’zAmust is a fully accessible, 7-day and 6-night outdoor camp that hosts 130 children, youth, and young adults in Kananaskis. I started as the recreation inclusion coordinator in 2013,

when the camp was only one year old. I supported camp counsellors by providing one-to-one support to campers when they became overwhelmed or were demonstrating escalating aggressive behaviours. This position was well suited to my experience and I grew my repertoire of tools for best supporting people with disability. At the conclusion of the summer, I advocated for the position to be developed into a director role, to allow for the information from counsellors and campers to be applied into strengthening procedures and future training for staff. The request was approved, and I became the camp director for the following four summers.

I met and worked alongside hundreds of children, youth, and young adults over these summers. I learned a lot about the preparations that parents make to ensure their child's success. For example, alongside purchasing and packing their child's belongings and overnight camp packing list, parents also had to educate the staff on how to best support their child through activities, social relationships, mealtimes, transitions, and nighttime. As many of these young people also had medical needs, they also came to camp equipped with breathing machines, oxygen tanks, blister packs of medications, EpiPen and rescue inhalers, wheelchairs and ankle foot orthotics.

The parents made various phone calls to me, ensuring that I would make sure their child did not lose their glasses and that their shower chair would not be used by others to avoid one or both becoming ill. Although it often seemed like parents were "overprotective" or lacked trust in other caregivers, I revered the parents for their insistence--despite their stressors and stress--that their child still attended camp. Unbeknown to the parents, their children rarely expressed missing home. The campers all did very well in the camp setting, often thriving in social situations and making

friendships for the very first time. During numerous phone conversations with parents during the week, however, I always made sure parents knew their children missed them too.

### ***Enable***

I now had built up my knowledge of life with disability by living alongside hundreds of young people with disability at camp, as well as hearing their parents' stories from home. I had gained a lot from these experiences and I was looking for ways to apply what I had learned and was continuing to learn. I enrolled in the Master of Nursing program at the University of Calgary in January of 2015. I weaved my passion for advocating and living alongside people with disability into my coursework.

The following year, I had the opportunity to expand my experiences by taking entrepreneurship and innovation courses and workshops in the Hunter Centre for Entrepreneurship and Innovation, through Haskayne School of Business. Here I met Michael Purdy, the co-founder of my social enterprise, *Enable*. Michael and I wanted to address gaps in care that I had noticed while working with families with disability. These were the same gaps that I was noticing while also working as a registered nurse with the Psychiatric Emergency Services team at the Alberta Children's Hospital: lack of community-based support.

In my registered nurse practice, I noticed that families often presented to the emergency department overwhelmed, feeling burned out, and experiencing family tension and breakdown. Many of their stressors were caused or compounded by lack of access to services in the community and feelings of isolation. The community services we could refer these families to included community counselling and psychiatry; however, this

approach felt too downstream to be appropriate to meet the needs of these families. I wondered: Were we treating problems in the system by treating the people the system is supposed to support? I shared with Michael story after story of how families' needs remain unmet and how they felt their only option left was to go to the emergency department. That evening, with full coffees and a backpack of sticky note pads, we set off for the library, determined to come up with a solution.

Since that night, countless hours have been invested into development and operations of our solution, Enable. Enable is a social enterprise that connects families with disability to much-needed support workers. Our mission is to create a community where all members feel safe, understood, and valued. We meet this mission by recruiting, training, and creating connections between people with disability and support workers. Our support workers offer families with disability support when and where they need it. In our first four years of service, Enable support workers have completed nearly 20,000 hours of support. We have hundreds of interested support workers on our waitlist and have a handful of new families apply to be matched with an Enable support worker each week.

### ***Home Life***

When my husband and I began dating, I remember us talking about how I spent many hours working. I either worked as a registered nurse, taught at the hospital or spent my "off" hours with clients. After my husband (then boyfriend and subsequently fiancée) spent time with two young women that I was an overnight support worker for, he

suggested to me that we become supportive roommates<sup>7</sup>. Together, we have found the time we spend with young people with disability both enjoyable and challenging, and we have appreciated that it was work that we could do together. As supportive roommates since 2017, we have worked hard to create an inclusive community around our roommates. Our families and friends are open and supportive of clients joining and leading in activities alongside us, and many of our family members have come to develop friendships with them.

In 2018, we took our supportive roommate activities to a new level with our, “Roomies Take on South America” trip. We backpacked through Bolivia and Chile with our roommate and three of our friends. We learned of the many rewards (and challenges) of travelling with a young adult with autism who enjoys his independence at home in Canada. He fought to continue his autonomy which, at times, was stressful for him and for us; the different context and culture heightened his sensitivity and responses to stimuli, and it heightened our vigilance around him.

Our time in South America also helped us to see our roommate’s determination and ability to take on new challenges. With the helpful support of an adventure coordinator, we took a mountain bike trip down Bolivia’s Death Road, a 60-kilometre stretch of winding highway with steep rock faces. The tour coordinator had booked a third guide for the trip without charging us more or drawing attention to the fact that the third guide was to help to provide one-to-one support for our roommate. Although we felt

<sup>7</sup> Supportive roommates are people that provide full-time accommodations and care to people with disability and/or mental health challenges in their own homes.



comfortable keeping him safe (or at least, as safe as we could be on Death Road and, of course with permission from his parents), we appreciated having the support available as we needed it.

In summary, living and working in the context of disability over the last decade has become part of my everyday life in such a way that I am exposed to many dimensions of disability experiences. Although many I have written about here have been positive, some have been more materially, socially, and emotionally challenging. There have been times where my involvement has been financially costly. There have also been times where I have sacrificed my social life, and my privacy and relationships have been affected. In my professional practice, I am sensitized to many complexities associated with disability, in my business, I am becoming aware of the desire and potential for connections between people in supportive relationships, and, at home, I have learned about the rewards and challenges of living “in the midst” (Clandinin, 2013, p. 43) of disability. I proudly take up identities as advocate, ally, carer, and friend. It is from these perspectives that I have ventured into this research.

### **Structure of the Dissertation**

In this chapter, I have provided background to this research, defined some key terms, and told my own story to position myself in the study. In Chapter Two, I review the literature related to impairment and disability, families, and the ways that disability is experienced in contemporary families. In Chapter Three, I explore the postmodern sensibilities that underpin the research. In Chapter Three I make links between these theoretical positions and the narrative approach used in this research. I also delineate the research methods, including participant recruitment, data collection and analysis, ethics,

and rigour. In Chapter Four, I tell three composite<sup>8</sup> stories: *The Morris Family*, “*To Our Healthcare Team*,” and *Conversations Between Mothers*. I tell the stories in a way that attempts to preserve the voices of those who shared them with me. Chapter Five is an analysis and discussion of the stories. In Chapter Five I draw upon the literature and a postmodern narrative approach to explore different possibilities for understanding disability experiences within families. Chapter Six concludes this dissertation with reflections on the stories, the research process, and the strengths and limitations of this research. In Chapter Six, I also make recommendations for health and social care practices and suggestions for further research.

<sup>8</sup> Composite stories are derived from aspects of separate, individual stories woven together. The method used to compose the composite stories is described in Chapter Three.

## **CHAPTER TWO – LITERATURE REVIEW**

In this chapter, I review literature that informs the topic under study: the experiences of families with disability. I begin with a brief overview of the ways that disability intersects with family experiences. I explore the barriers and assets that people and families with disability experience. I then provide a brief overview of the current health and social care landscape. In the literature review, I unpack the difference between impairment and disability to set the scene for later discussion of dominant narratives that equate life with impairment with life with disability. I discuss two prominent models of disability in this chapter: the medical and the social models of disability. I detail how these models contribute to understanding life with impairment, perpetuating narratives that disable people with impairments. I conclude by exploring the ways the care landscape contributes to the disability narrative.

In the literature, the terms impairment and disability are often used interchangeably (Coleman-Fountain & McLaughlin, 2013), but there is a complex relationship between them (Kumari Campbell, 2008). Impairment is the functional limitation of a person's body (Hughes & Paterson, 1997; Stamou et al., 2016; Zablotzky et al., 2019). In other words, impairment relates to what a person can and cannot do. Disability, conversely, is not a bodily characteristic; disability is an artefact of the oppression and marginalization of people with impairments (Coleman-Fountain & McLaughlin, 2013; Deal, 2006). When societies, communities, institutions, and people

fail to accommodate or adapt for people with impairment, those who have an impairment become disenfranchised and experience disability (Kumari Campbell, 2008).

In this study, I was interested in interviewing families with disability. For this study, family is taken to be those people who are living alongside one another and who would be considered to be affected by disability. This could be either through biological ties, living in the same dwelling, or those that choose one another as family. In the current study, families comprised mother, father, and their children. I recognize that family is diverse, and I explore this in the coming paragraphs.

Although this research addresses families' experiences, it is not a study "of" family in a structural or functional sense; therefore, family systems theories are not addressed in this review. I explore what makes a family a family and the ways that impairment is present in families. While the literature on families with impairment is fragmented (Farrell & Krahn, 2014), I integrate the available literature as it informs the research question for this study: "How do families experience daily life with disability?"

### **Families and Disability**

The composition of families and family experiences are dynamic phenomena. The ways that family is thought about in western societies is strongly influenced by 20th century sociological theory, in which a division is made between the nuclear (those who share the same dwelling and are closely related) and extended (close or more distant relatives who live outside of a household) family (Lynch, 2013a). Dominant conceptions of family in western society have meant that, until the latter half of the twentieth century, family was equated with heterosexuality, marriage, and procreation. In other words,

families were understood to comprise male and female couples, who were married and had children.

Over time this perspective is changing. The expectation of marriage as a necessary condition for family has been in decline since the latter part of the twentieth century (Morris et al., 2017). In Canada, over 70% of families are heterosexual (Statistics Canada, 2012). However, blended families<sup>9</sup>, same-sex couples, and common law partners with or without children, are becoming more common (Statistics Canada, 2012). As Blackie (2014) pointed out: families are ever-changing.

Current and evolving perspectives on family represent a challenge to more traditional understanding of what constitutes family. Experiences of family are beginning to transcend traditional biological and legal ties. In some respects, family is becoming a more intentional rather than biological or accidental phenomenon (Lynch, 2013a). While some contemporary families are biologically related and legally affirmed, others coalesce around those that provide love and care to one another (Neely-Barnes & Dia, 2008). Contemporary families can be composed in many different ways.

The family landscape is, thus, becoming increasingly diverse. According to nursing family theorists, family can be understood as those who care about and for each other (Bell, 1995; Wright & Leahey, 1994; 2016). Rather than being recognizable as a defined and bound unit, diversity is becoming the hallmark of the contemporary family (Farrell & Krahn, 2014). With this diversity comes diverse bodies and functions. In

<sup>9</sup> A blended family is a complex stepfamily in which there is a child of one parent and a child of both parents (Statistics Canada, 2012).

Canada, one in five people live with disability (Morris et al., 2017) and most contemporary families have a member with disability (Farrell & Krahn, 2014). Disability has long been a feature of traditional families, and disability remains an experience for families today (Farrell & Krahn, 2014; Zablotzky et al., 2019).

The presence and recognition of disability in families is increasing for a number of reasons. Disability can present early in a person's life (such as a developmental impairment) or it can be acquired over time, such as in the case of injury, onset of illness (Farrell & Krahn, 2014), or with age (Zola, 1997). Healthcare advances, increased awareness, and screening means there is more frequent detection and recognition of impairment (Institute of Medicine, 2007; Wister & Speechley, 2015). The shift away from institutionalized care has also resulted in more people with disability living in family settings (Lynch, 2013b). People with disabilities are living with their families more now than in past decades (Garland-Thomson, 2002).

Families serve as more than a context for emotional comfort. Families have practical, pragmatic applications for most families, and especially for families with disability (Neely-Barnes & Dia, 2008). With more than 80% of people with disability requiring support in their daily lives (Statistics Canada, 2012), families care for their family member with disability (Farrell & Krahn, 2014) and work with health and social care providers to meet their needs (Blacher et al., 2005; Caicedo, 2014; Eddy, 2013; Knox, 2000; Neely-Barnes & Dia, 2008; Olsson & Hwang, 2008). For those families with disability, disability is an individual and a family experience (Blacher et al., 2005; Knox, 2000).

Although families are becoming increasingly diverse, research on people with disability and their families underrepresents certain families with disability. Frederick and Shifrer (2019) found that the literature privileges the voices of white women and their voices are then taken to be representative of all women. The narrator of family disability stories is often the mother and the mothers are often white and middle class (Frederick & Shifrer, 2019). This means that people of colour (as well as other minority groups) are excluded from disability stories. In some instances, the perspectives of minority groups might not be sought; in other cases, people in minorities might be less inclined to participate in health and social care-related research because they disproportionately experience barriers to accessing care when compared to white people (Frederick & Shifrer, 2019).

### ***The Health of Families with Disability***

Peoples' and families' experiences with disability remain complex and problematic. People and families with disability experience poorer health outcomes than people without disability (Morris et al., 2017). People with disability are prone to health challenges such as chronic pain and fatigue (Goering, 2015), increased rates of autoimmune disorders, mental illness, cancer, coronary and respiratory diseases, and increased rates of mortality are common for people with disability (Wolverson, 2012). Caicedo (2014), in their longitudinal study of parents caring for their children with disability, found that parents reported poor physical, mental, and social health (Caicedo, 2014). They noted high levels of fatigue, emotional frustration and anger, poor focus, stress about the future, and feelings of social isolation (Caicedo, 2014). The health of

people and families with disability is an important topic to address in health and social care settings.

Care by health and social care providers through service delivery can help buffer some of the health impacts of disability (Davey & Lignugaris/Kraft, 2006; Caicedo, 2014; Peterson et al., 2010). Effective care can prevent prolonged or frequent hospital stays (Caicedo, 2014); decrease caregiver burden and stress (Davey & Lignugaris/Kraft, 2006); and protect against further health-related risk factors (Peterson et al., 2010). Families reported that effective care was care that was proactive (Bellin et al., 2001); focused (Houtrow et al., 2012); ongoing (Hendriks et al., 2000; James, 2013); timely (Caicedo, 2014); inclusive (Burke et al., 2008; Houtrow et al., 2012); and empathic to their needs (Caicedo, 2014; James, 2013). Manteuffel et al. (2002) also noted that when families received effective care, it positively impacted persons' and families' perceptions of impairment. Mattevi et al. (2012) stressed the importance of carer health as positive carer attitudes were an important indicator for quality of life for people with disability. Effective care buffered against long-term problems for the family member with a disability (Kutash et al., 2002).

While there are different services available for families with disability, these services are not always easy to source and engage. Inadequate support can result in families' needs being underserved (Manteuffel et al., 2002), or unmet over time (Hendriks et al., 2000). Barriers persist for people with disability and families in meeting these needs (Hendriks et al., 2000; Houtrow et al., 2012; Keller et al., 2005; Manteuffel et al., 2002; Morris et al., 2017), included wait times (Hendriks et al., 2000; Houtrow et al., 2012); feelings of inadequacy or feeling undeserving of the care (McColl et al., 2010);



unavailability of needed services or narrow inclusion criteria (Houtrow et al., 2012; Keller et al., 2005; Manteuffel et al., 2002); and cost (Morris et al., 2017). Similarly, in a recent release of the 2017 Statistics Canada *Canadian Survey on Disability* data, Morris et al. (2017) reported the primary barrier for people with disability to obtain needed medication and mobility aids and devices was cost. Families also reported that they were not permitted to use certain services based on their family member having too low physical ability (Houtrow et al., 2012); mental illness (Keller et al., 2005); and too poor of a social aptitude (Manteuffel et al., 2002). Families' needs can be too complex for certain services (Baker-Ericzén et al., 2010). Borreani et al. (2014) analyzed semi-structured interview data with participants with Multiple Sclerosis. They found that poor availability of information about, access to, and appropriateness of services were barriers to having people's needs met (Borreani et al., 2014). Due to barriers and ineffective health and social care, families face additional challenges.

People and families with disability are susceptible to health decline as their needs go unmet<sup>10</sup> over time (Caicedo, 2014; McColl et al., 2010; Milner & Kelly, 2009; Morris et al., 2017; Vilaseca et al., 2015). Compared to people without disability, McColl et al. (2010), in their examination of 2003 Statistics Canada population level data on the relationship between people with disability and unmet needs, people with disability had three-times more unmet needs than people without disability. Data collected from a cross-sectional study of 417 people with disability found that as the number of unmet needs

<sup>10</sup> Needs are the necessities that people and families felt were essential to their health and well-being. In particular, the needs that families identified were physical health and personal assistance; psychosocial and social health; leisure activities; and emotional or mental (Caicedo, 2014; Koch et al., 2015; McColl et al., 2010; Milner & Kelly, 2009; Morris et al., 2017; Vilaseca et al., 2015).

increased, the self-reported quality of life for the person with disability fell (Koch et al., 2015). Similarly, Vilaseca et al. (2015), in their *Needs and Supports for People with Intellectual Disability and Their Families* questionnaire (developed *ad hoc* for the study) answered by over 2000 people with disability and their families, found that unmet needs resulted in low levels of family quality of life. With increased incidences of unmet needs, consideration to peoples' and families' health and well-being is important.

While family members of people with disability have their own needs as primary carers<sup>11</sup>, they also face other challenges. Secondary to needs going unmet, families experience increased rates of crisis and family breakdown (Baker-Ericzén et al., 2010; James, 2013; Keller et al., 2005), and carer burnout (Davey & Lignugaris/Kraft, 2006; McKenzie et al., 2016; Yamada et al., 2012). Families also reported feelings of hopelessness and helplessness (Caicedo, 2014), and a lack of control and unpredictability in their lives (Knox, 2000). In their retrospective cohort study of over 3000 people with disability, McKenzie et al. (2016) also found that as carer status<sup>12</sup> declined, people with disability became twice as likely that the family member with disability would be admitted to an institutionalized setting to offload care from the family. Yamada et al. (2012), in their secondary analysis of a randomized interventional study of over 5,500 people with disability living with their families, found that as families used more and more services, it became more likely that the family member would be admitted to

<sup>11</sup> A carer is a person who cares for a person who is in need of care or benefits from care. Carers can be family members and health and social care providers. Most often, Caring roles within families are taken up by mothers (Blacher et al, 2005; Findler et al., 2016; Fisher & Goodley, 2007; Montes & Halterman, 2007).

<sup>12</sup> As per McKenzie et al. (2016), carer status is measured by how willing or able the carer is to continue to provide care, their satisfaction with community support, and the mental state of the carer (poor mental states were considered to be feelings of depression, anger, frustration, etc.).

institutionalized care. That is, when at-home this support is no longer sufficient, families resort to institutionalized care (McKenzie et al., 2016; Yamada et al., 2012).

## **Disability and Impairment**

There are varying degrees of visibility associated with impairment and disability. A person's disability can be visible, invisible, or both based on the context (Zablotsky et al., 2019). People might have an observable impairment in their physical body or a less visible impairment with the ways they learn and process information. The variation in degrees of visibility and actual impairment/disability means there is a multiplicity of ways to experience and think about impairment and the construct of disability (Berghs et al., 2016). There are, however, dominant medical and social narratives about disability that influence the ways that people define and understand disability.

### ***Dominant Narratives: Models of Disability***

Over time, models of disability have emerged as means of categorizing disability and their associated features and experiences. Models have provided different ways of thinking about disability (Charlton, 1998). Although theoretical models aid in putting boundaries around ways of understanding, models can never fully describe or evoke the complexity of life with disability. Two prominent models of disability influence health and social care provision: the *medical model* and the *social model* of disability.

**The Medical Model of Disability.** The medical model of disability is one way of thinking about disability, derived from the broader medical model of health and illness. The medical model proposes that disease or disorder can be observed, described, and differentiated by following standardised approaches to inquiry and intervention derived from the sciences (Swain, 2011); it is the most discussed model in the disability literature

(Berghs et al., 2016). The medical model positions disability within a larger framework of biomedical knowledge and practice, which aims to diagnose, treat, contain, or cure deficits (Goodley & Runswick-Cole, 2012). The medical model emphasizes a problem orientation, toward a physical or developmental impairment (Goddard et al., 2000; Goodley & Runswick-Cole, 2012), in need of fixing, curing, managing, minimizing, or preventing (Anastasiou & Kauffman, 2013).

When care is provided using a medical model, the “patient” or “service user” (Goodley & Runswick-Cole, 2012, p. 52) enters into a relationship with a healthcare provider in which the provider is expected to know best how to respond to the patient’s problems and needs (Berghs et al., 2016). In other words, the patient has to become--to varying degrees--dependent upon the health care provider in order to receive the care that is needed, and the needs and wants of the patient or service user can be marginalized (Goodley & Runswick Cole, 2012). While the medicalization of disability has made possible treatments and interventions, it also serves to construct the disability as requiring the ongoing surveillance and intervention of medicine and other health care professions (Brisenden, 1986).

The medical model has limitations of note. The medical model is able to account for and treat problems of individual anatomy, physiology, and behaviour (Frederick & Shifrer, 2019), but the medical model is limited in its ability to account for *individuality*: the range of intersecting variables that comprise human experiences such as disability. Goodley and Tregaskis (2006) cautioned that by identifying the person as problematic or as flawed, the model “dissolves” the human behind the impairment (p. 62). Brisenden (1986) considered this model to render persons with disability “victims...[forced to]

accept a dependent status in which their life takes place only by proxy...” (p. 178). The goal of the provider is to return a person to “normal,” (to cure or rehabilitate) and take the necessary means for others to avoid similar deficits through health surveillance, health education, and illness prevention (Anastasiou & Kauffman, 2013).

A reliance on the medical model can lead to assumptions that impairment and disability are deviations from accepted biological, physiological, and behavioural norms. One of the consequences of understanding disability in this way is that people with disability can, themselves, be constructed as in deficit and even deviant. This particular construction of disability can then make possible the enactment of paternalistic and controlling care, containment, and treatment. Understanding the experiences of families with disability is one way to evoke and show the richness of life as it is lived, perhaps lessening the need for professional control over people’s lives.

**The Social Model of Disability.** The social model of disability, or the *social model* stands in contrast to the medical model (Symeonidou, 2009). The social model looks to society, not the person, to explore apparent problems of individuals and groups, such as those with disability and their families. Whereas the medical model tends to de-emphasize the difference between disability and impairment, the social model does not. Within the social model, disability and impairment are not equal (Coleman-Fountain & McLaughlin, 2013). The social model positions impairment as a natural occurrence across the human condition. Impairment can be defined as the limitation or limitations in a person’s physical body or mentation that affects function in a certain activity of living (Ontario Human Rights Commission, 2016). Impairments can be permanent, transient or sporadic, or temporary (Ontario Human Rights Commission, 2016). In the social model,

disability arises when ableist belief systems are imposed upon people with impairments (Goodley, 2010). These oppressive social circumstances serve to restrict the ways that people live their lives (Goodley & Tregaskis, 2006; Wolbring, 2012).

The social model rejects the notion that impairment is a problem with the person, asserting that people with impairments only experience problems when their needs are not met. Brisenden (1986) offered a key example of such circumstances, saying:

*...we are disabled by buildings that are not designed to admit us, and this in turn leads to a whole range of further disablements regarding our education, our chances of gaining employment, our social lives, and so on* (p. 176).

The social model of disability shifts the focus for health and social and social care providers, from a concern with individuals and groups, towards attending to those concerns in the midst of complex social dynamics and circumstances. In this model, disability is compounded by social structures, attitudes, deliberate or inadvertent barriers, and mechanisms of exclusion from participation in social life (Goering, 2015).

The existence of mechanisms of exclusion of people with disability suggests that society is *ableist*. Ableism is the enactment of discrimination that favours able-bodied people (*Oxford Advanced American Dictionary*, n.d.). The Ontario Human Rights Commission (2016) expands on this definition, describing ableism as a belief system that views people with disability as somehow less worthy, less valuable, and holding less life potential. Ableism is sustained by treating people with disability “adversely” through attitudinal barriers and making information and built environments inaccessible (Ontario Human Rights Commission, 2016, n.p.). Titchkosky and Michalko (2009) argued that the social exclusion of people with impairment is a means to rationalize oppression and

discrimination. While those who work within a medical model do not practice with an intent to oppress or discriminate, the focus on fixing, remediating, and “managing” disability can (albeit inadvertently) imply an ableist orientation. Titchkosky and Michalko (2009) wrote about how such a perspective means the ever-present diversity in the human condition becomes an insult to normalcy (Titchkosky & Michalko, 2009).

The social model treats disability as a socially constructed phenomenon (Anastasiou & Kauffman, 2013; Coleman-Fountain & McLaughlin, 2013). Whereas the medical model categorizes the person with a disability as an anomaly (Ontario Human Rights Commission, 2016), attempts to put boundaries around disability as an individual (and thus knowable and treatable) phenomenon are problematized in a social model. Although these models can be helpful in generating different perspectives about life with disability, neither model has the capacity in and of itself to capture the richness, depth, and complexity of life as it is lived.

This current study is a postmodern narrative of life for families with disability. As such, it bears mentioning that persisting with a medical model/social model dichotomy to explain the landscape of disability risks creating a false distinction. That which is medical--for example, a broken limb--can also be social, in that the broken limb might have relational, social, and occupational implications. Both approaches to understanding are involved (creating messy spaces and tensions between these understandings) depending on where a person is on their health/illness continuum.

Context is also influential in how a disability experience might be understood (Goodley & Runswick-Cole, 2012). For example, a person with a disability might subscribe to the social model to relate their experiences of having difficulty locating

accessible means of transportation, but they may then rely upon more medicalized knowledge when seeking pain treatments through their local clinic. While the medical model of disability has utility for health and social care providers positioned to address medical needs, it is limited. I wonder, then, how can health and social care providers work with families with disability in a way that is attentive to both the social implications of disability, but also the medical implications that accompany impairment and disability? As a registered nurse working with families with disability, I find it difficult to reconcile the idea that the medicalization of disability perpetuates damaging, ableist narratives that marginalize people with impairments (Goodley & Runswick-Cole, 2012). The medical model, to which much knowledge in health and social care is attributed, has a history of losing sight of the person amid their impairment.

The social model of disability is also limited. The social model of disability is both a reaction to and an extension of the medical model. This means that the social model comes to understand disability through, and needs to negotiate with, medical discourse (Hughes & Paterson, 1997). In responding to the medical model, social perspectives politicize disabled bodies as a means to challenge ableism but this, in turn, creates an ironic *disablist* perspective of people with disability as victims of an ill-belonging and ableist society (Goodley & Runswick-Cole, 2012). Over time, the social model has failed to move past some of the dominant social assumptions about disability and continues to position the disabled body as an object of inquiry and intervention (Goodley & Runswick-Cole, 2012).

The tensions between medical and social models in the literature are not easy to resolve. Between medical and social approaches lie a variety of experiences and identities



that may be an uncomfortable fit in either “camp.” In this regard, a postmodern perspective, with its emphasis on multiplicity, discontinuity, anti-identity, and scepticism towards *grand narratives* (Alvesson, 2002; Lyotard, 1984) might represent a generative space in which “many stories can be told” (Goodley & Runswick-Cole, 2012, p. 62).

### **The Health and Social Care Landscape**

Dominant medical and social narratives of disability draw attention first to disability itself. One way this manifests is that in health and social care settings, families with disability often frame and express their needs by emphasizing their impairment rather than their experience of living in the context of disability (Clandinin & Raymond, 2007). These are different kinds of knowledge, the latter being often downplayed or subjugated by living according to the plotlines of dominant narratives. The presence of impairment, in and of itself, says little about experience, yet health and social care professionals are not necessarily trained to respond to families’ experiences (Moulster & Ames, 2012; Smeltzer et al., 2005).

Different health and social care providers practice within the structures and institutions of disability services. While some researchers have found that providers felt equipped to develop effective treatment plans for people with disability (Smeltzer et al., 2005), other researchers have found otherwise. Moulster and Ames (2012), for example, argued that providers are not equipped with appropriate awareness of disability experiences. Mattevi et al. (2012) conducted a qualitative content analysis study of family and caregiver perspectives on attitudes towards disability. The authors found that health and social care providers’ attitudes towards disability influenced the attitudes of persons with disability and their families. The authors also noted that the attitudes that people

with disability have toward themselves also influences the attitudes of others around them, including in the general public (Mattevi et al., 2012). Research that is able to helpfully inform health and social care providers' knowledge and attitudes might be important for offering helpful interventions for families with disability.

Generating insights into families' experiences seems particularly important given that inadequate provider knowledge can serve as a professional/relational barrier to care for people with disability and their families (Kirschner et al., 2009; Wolverson, 2012). Providers can act as facilitators as well as barriers to effective support. For example, in a survey study, Vilaseca et al. (2015) found that the family-provider<sup>13</sup> relationship to have the most profound impact on families' reported quality of life. Although the authors of that study noted limitations in their survey design, it seems to suggest there is value in understanding how to approach the provider/family relationship to promote effective intervention and support. Deepening insights into experiences of families may be one way for providers to cultivate relational connections so that, as Kutash et al. (2002) suggested, families can work together with care providers to ensure care is well informed, effectively meets families' expressed needs, and is impactful.

Achieving the aims expressed above is predicated on insight and understanding into the circumstances of people with disability and their families. Brisenden (1986) and Smeltzer et al. (2005) emphasized the importance of understanding the life that the person with a disability wants to lead, not the life that the health and social care provider

<sup>13</sup> Provider is shorthand for a "health and social care provider".

(and in some cases, their family) thinks is best. Family-centered care<sup>14</sup> is one of the approaches that has been used to sensitize care providers to the needs of individuals with illness or impairment and families as a whole. This approach works to convey respect to family members (Bellin et al., 2011), and enacts better outcomes through carer involvement (Kutash et al., 2002).

Families are often involved in many aspects of daily life for people with disability (Keeley & Clarke, 2002). Families can, then, influence the care and services that their family member with disability receives (Keeley & Clarke, 2002). Families have their own needs, and these might not be the same as those of their family member with disability (Keeley & Clarke, 2002), and these needs might even conflict (Williams & Robinson, 2001). Williams and Robinson (2001) discussed the risk for loss of autonomy for the person with disability when their needs are overshadowed by the needs of their family members (Williams & Robinson, 2001). While families are often storied as a supportive relational context--as partners and facilitators of care for people with disability--there are also times where family can be constraining for the person with a disability.

Health and social care for families in the context of disability is multifaceted and complex. Healthcare professionals play a crucial role in addressing the needs of families through a range of models and modalities such as: case management (Bellin et al., 2011; Caicedo, 2014; Hendriks et al., 2000; James, 2013; Peterson et al., 2010); coordinated service delivery (Bellin et al., 2011; Burke et al., 2008; Hendriks et al., 2000; James, 2013; Peterson et al., 2010); socially integrated support (Caicedo, 2014); and specialized

<sup>14</sup> Family-centred care is revered in recent studies as the “gold-standard” for care (Bellin et al., 2011; Ruffolo et al., 2005).

care (Bellin et al., 2011). These are important and necessary approaches because, without appropriate care, families can experience further deterioration in individual health and collective well-being (Kirschner et al., 2009).

There are many reasons families struggle and experience reduced well-being. Green (2007) spoke to the societal burdens of disability being greater than the emotional burdens of caring for a child with disability. That is to say, struggles arise due to social conditions rather than the burden of disability per se. While reporting increased caregiver burden, families with disability have reported similar or better quality of life in comparison to families without disability (Carona et al., 2013). In many instances, it seems families cope and adapt to the stress and demands of caregiving, rate their quality of life as “good” or “excellent” (Carona et al., 2013, p. 871) and thus stand in contrast to dominant social narratives that experiences with disability are stressful, negative, and burdensome. These dominant narratives can be so prevalent that healthcare providers often “label some families’ positive discourse as unrealistic or confusing, underscoring their adaptation levels” (Carona et al., 2013, p. 972). It seems, then, that dominant social narratives intersect with and take up a place in other professional and institutional narratives of disability. Therefore, examining these narratives through different lenses can reveal useful information for thinking about health and social care practice (Larson, 2010).

Given that there is a relationship between social, institutional, and professional narratives, health and social care provider practice requires attention and scrutiny. Smeltzer et al. (2005) called for service delivery (and educational settings where providers are trained) to be evaluated for sensitivity to disability. Other researchers have

called for an increasing need for awareness, advocacy, and partnership with families (Daruwalla & Darcy, 2005). In their analysis of responses from a questionnaire that addressed the knowledge that nursing students held about disability, Smeltzer et al (2005) found that exposure to people with an impairment can help providers to learn about and gain comfort in responding to the complexities and challenges faced by people with disability. Daruwalla and Darcy (2005), studied the effect of disability awareness training with tourism students. They found that those who had greater exposure to people with disability, by taking part in the awareness training, reported more positive attitudes towards people with disability than the control group (Daruwalla & Darcy, 2005). It seems that insight into and experience with disability is a way to change how people think about impairment and disability.

In order for knowledge for practice to have value, the literature suggests that professionals must source knowledge from families for effective care (Smeltzer et al., 2005). It is necessary that this knowledge takes up a place in the education and socialization of practitioners in order that knowledge for practice is meaningful, can be critiqued, evaluated, and transferred into helping and supportive practice contexts (Smeltzer et al., 2005). This might also act to challenge conscious and unconscious ableist attitudes that providers might hold (Ontario Human Rights Commission, 2016). Rather than attempting to design inquiry that can answer universal questions about impairment and disability, it might benefit health and social care professionals to more fully explore particulars in order to show a diverse range of experiences that can inform sensitive, nuanced, and effective care for families.

## **Conclusion**

The present-day landscape of family life is complex and diverse. Although the definition of family has changed over time, an enduring characteristic of families seems to be the commitment to come together to meet one another's needs. Disability is a part of the characteristic diversity of present-day families, meaning that disability is both an individual and family experience. Although families have reported good quality of life in the context of disability, people with disability experience poorer health outcomes than people without disability. While impairment is an individual, bodily issue, it is not clear if poor health outcomes are due to impairment or because of peoples' and families' needs going unmet over time.

Health and social care workers can help buffer some of these health outcomes through services that are effective. Barriers exist for families in accessing services, including long waitlists, poor availability, narrow inclusion criteria, and cost. When families cannot access needed services, they experience declines in carer status, family burnout, or breakdown.

There are dominant narratives about disability that are revealed in models and practices that inform care and intervention. The medical model of disability equates impairment and disability. The medical model focuses attention towards an individual with a view to treat, ameliorate, or perhaps cure. The social model was created as a way to challenge the medical model of disability. The social model treats impairment as a functional limitation and disability as a social construct that arises from and contributes to social oppression of people with impairments. While these models provide context by

which we can begin to think about disability, neither model can fully describe the experience of living with disability.

Health and social care providers must be attentive to both the medical needs and the social aspects of their patients, while also being aware of the ableism that exists in social, professional, and institutional environments. It is necessary for care providers to build their knowledge of disability care and cultivate sensitive and effective practices alongside exposure to people and families with disability. Research that is able to evoke something of the context of family experience is one way to contribute useful insights for providers.

### **CHAPTER THREE – RESEARCH DESIGN**

This research focuses on everyday stories of families with disability to answer the research question, “how do families experience daily life with disability?”. Hearing and analyzing families’ stories are one way to begin to explore, understand, and address complexities and tensions experienced by families affected by disability. In this research, I attend to how the experiences of families with disability take up a place within and across dominant sociocultural, historical, and structural narratives.

Attending to stories is a powerful means to evoke experience and generate new insights. This research is a narrative study, drawing upon principles and practices of narrative inquiry (Caine et al., 2019; Clandinin, 2013; Clandinin & Connelly, 2000) and narrative analysis (Holstein & Gubrium, 2012; McAllister, 2001; Riessman, 1993). One purpose for this study is to examine different experiences and meanings of disability for family life. In this research, I do this by telling the stories of families and by paying attention to the often-untold stories about everyday happenings for families with disability. Disability is not a rare or unique experience yet accounts of how ordinary, daily life is lived amid experiences of disability is underrepresented in the nursing literature.

In the literature review, I explored how disability is talked about and understood. The narrative approach to this research is informed by postmodern perspectives, which call into question the authority and legitimacy of dominant ways of understanding disability experiences. The literature also suggests that disability experiences are characterized by difference. This calls for a research approach that emphasizes multiplicity rather than seeking a singular understanding of a complex phenomenon. In



the forthcoming section, I position postmodernism and the theoretical lens that shapes my orientation to the research. I make links between narrative methodology and the research methods applied in this study. Where I discuss research methods, I attend to recruitment and selection, data collection, data analysis, ethics, and rigour.

### **Theoretical Underpinnings for this Study**

There are a number of ways that narrative research can be undertaken, and different terms are often used to name and describe different forms of narrative research. Although I describe this study as narrative research, this study draws on the principles and tenets of two types of narrative research: narrative inquiry and narrative analysis. The narrative approach is underpinned by postmodern considerations and I address this first as a way to position the research theoretically. I then discuss narrative inquiry to provide an orientation to how the research field, participants, research conduct, and purpose of inquiry are viewed as narrative phenomena. I then discuss narrative analysis in order to provide background to the analytic/interpretive methods used in this study.

### ***Acknowledging Postmodern Influence in the Research***

Postmodernism is a complex term that resists definition. Postmodern thinking and practice extend across contexts and disciplines as a “set of critical, strategic, and rhetorical practices employing concepts such as difference, repetition ... and hyperreality to destabilize other concepts such as presence, identity, historical progress, epistemic certainty and the univocity of meaning” (Aylesworth, 2015, n. p.). Postmodernism can, thus, be applied in a number of ways across diverse disciplines, meaning that a clear summation of its use in this study is warranted.

In this study, I apply postmodernism as a theoretical position that problematizes overarching *dominant narratives*, calling into question their legitimacy and explanatory potential (Alvesson, 2002; Lyotard, 1984). Postmodern social research (such as that which is undertaken by nurses) attends to the local and particular as a source of knowledge; postmodern research attends to marginal voices as offering valuable insights into phenomena, and it can reveal irony and inconsistency in dominant modes of thinking that have assumed authority to speak for all (Alvesson, 2002; Crotty, 1998). Postmodernism thus represents a movement away from the certainties, categories, and apparent consistencies that are characteristic of modernity and the attempts of modern science to define, delineate, and capture certain phenomena as they truly are (Crotty, 1998).

Postmodern thinking proposes that, in place of categories (such as particular identities) and coherent narratives (that sustain those identities), lie complex language games that result in performances that are capable of creating the objects of which they speak (Butler, 2012; Foucault, 1978). In the context of this research, disability “talk” comprises stories that construct identities and experiences in the midst of family life; in turn, those identities and experiences serve to author and legitimate disability. In taking a postmodern turn in this research, I look to alternate readings of disability experiences that contrast dominant, accepted, and taken-for-granted understandings.

Researchers who adopt a postmodern lens are cautious of categorization because categories perpetuate and are an effect of language (Foucault, 1978). Categories of *us* (the non-disabled) and *them* (the disabled), for example, become problematic, dualistic silos in postmodern thought (Roets & Goedgeluck, 2007). Although I have used the term

disability and terms for non-disabled persons in the literature review, the review shows how the category of disabled, alone, does little to help understand and explore the intersections and intricacies of the experiences of impairment, disability, and family life. A postmodern approach turns attention towards the spaces between categories that are made in language, taking a theoretical stance that is more playful and ironic.

Trying to group together, categorize, and delineate is one of the ways that western cultures make sense of phenomena; the process of categorizing helps us to know *this* in relation to *that*. The way we think about, make sense of, and live alongside disability is, in part, culture based, and embedded within culture lies values about what this is *worth* in relation to that. Thus, the enactment of categories upon people (for example, the application of a diagnosis or labeling of a behaviour) involves more than objective description: it is the enactment of values, judgment, and also labeling. Amid these social, institutional, and cultural practices lies the experiences of those being described, defined, evaluated, and judged.

Categorization and attempting to know this from that is an historical problem for people with disability and their families both within and beyond Western societal contexts. A number of non-Western languages do not have words or terms to describe disability as a phenomenon. Instead of grouping people with disability together (Reynaert & Gelman, 2007) under the label of disability, some languages describe people based on their specific impairment, such as blindness or deafness. Cultural differences in how disability is spoken about and described illustrates that disability identity and practices are contingent and situated rather than fixed and clearly able to be defined.

While referring only to people's impairments might imply a more specific perspective about disability, which resists "grand narratives" (Goodley & Runswick-Cole, 2012, p. 63), this language practice is also problematic. Talking about specific impairments emphasizes bodily deficit or limitation. This emphasis creates a physical boundary around disability that makes it easier to focus—and act—upon the disabled body. In combination, the physical and linguistic boundaries that arise around disability can make it difficult to think about other, nuanced, dimensions of experience that may be lived alongside it. As Goodley and Runswick-Cole (2012) said, when a person is viewed as "an object...a body that should be measured, administered, assessed, governed, educated and at times eradicated," we totalize and reduce people to their impairment (p. 63) even though disability is a lived, socially located experience.

If disability is an individual experience that unfolds in social places, over time, then it is an experience that is particular, nuanced, and shaped in ways that are determined by numerous factors. Postmodernism posits that knowledge about phenomena such as disability is not universal, nor can knowledge that is contingent and situated be universally applied (Crotty, 1998). In this way, postmodern research offers an opportunity to inquire into, problematize, and challenge dominant medical, social, and institutional narratives that have claimed authority in understanding disability.

Turning towards a postmodern conception of disability means that it can be talked about in many different ways (Goodley & Runswick-Cole, 2012). Dominant narratives of disability can fix disability identities, whereas a postmodern perspective implies that these identities are multiple and more fluid. Identities arise and fall away through language (Butler, 1993). In 1986, Brisenden pointed towards this idea, and questioned

whether a person could truly be defined by their disability. It is possible that disability as an entity or experience cannot be delineated and defined. Instead, it might be that disability experiences reveal themselves in fragments that do not come together, or coalesce in sensible and coherent ways (Estefan, 2008). This implies that those who engage with people who experience disability need to be more attentive to how disability experiences move dynamically within and between family life (Symeonidou, 2009).

By working with experience that is particular--and by considering that experience as knowledge for practice—practice can be, in some sense, liberated from the constraints of disciplinary knowledge that prescribes certain responses to certain groups of people. If knowledge about disability is not universal or objective knowledge (including knowledge for practices in health and social care) then, useful knowledge may be located in subjective experience and knowing. Postmodern thought helps researchers to understand that disability is a social construction, sustained through discourse (Goodley & Runswick-Cole, 2012). As an extension of this idea, the experiences of people with disability are shaped and constrained by patterns of talk, the language that is used to describe, direct, interact with, and care for people with disability.

This research is an inquiry into disability experiences. Experience implies that something is happening, being apprehended, and in social contexts this experience happens between people. Often, attention (socially, or in research) is directed towards the object (or subject) of investigation rather than the observer or researcher. A postmodern perspective disrupts this one-way gaze and draws attention to the ways both the observer and the observed are implicated in experience. The experience of disability is, then, “not so much as a matter of the capacities and limitations of bodies but more about what we

expect from a body at a particular moment and place” (Garland-Thomson, 2005, p. 524).

This expectation is a transaction between people with disability and those with whom they engage. While the social model of disability has been a preferred lens to describe disability (Stamou et al., 2016), this model is perhaps too simplistic to open up and explore subjective experiences of families with disability (Goodley & Tregaskis, 2006).

Despite the capacity of postmodern thinking to shift and challenge dominant perspectives, discourses, or narratives it is not an antidote to dominant narratives of disability. Postmodernism makes no promise of a “better” understanding (Crotty, 1998). Instead, it reveals contradictions, inconsistencies, and ironies in systems of thought and action (Donovan et al., 2017). In doing so, postmodernism makes possible different thinking, speculation, and even practices that, in turn, take on their own complexities and tensions.

In the context of disability studies and experiences, postmodernism poses some problems. While postmodern perspectives of disability might serve to question what have been seen as common-sense categories, interactions, provisions, and interventions for people with disability, it also risks contributing to isolation (Symeonidou, 2009).

Although disability can be thought of as an imprecise, vague, or even unhelpful, umbrella term (Brisenden, 1986), it has also served to bring people together to form a collective identity (Galinsky et al., 2013). Belonging to a collective provides opportunities for people to come together for support, for identity building and reinforcing experiences (Estefan & Roughley, 2013), and to pursue material benefits or advance political platforms (Galinsky et al., 2013; Symeonidou, 2009). Disability has been a useful term for families seeking healthcare and support services (Anastasiou & Kauffman, 2013;

Stamou et al., 2016) by making it easier to talk about certain pathologies and access treatment, services, and funding (Goddard et al., 2000).

To extend the postmodern perspective, disability as an experience and language practice is a complex dialectic. It is, on one hand, a category that does not hold; there is no singular disability, but rather a multiplicity of disability experiences. In this way, disability acts as a constraint, disciplining possible disability identities (Foucault, 1978). Yet, being able to name oneself disabled, part of, or allied to the disability community can confer individual, relational, material, and social benefits (Galinsky et al., 2013). In this research, postmodernism sensitized me to the complexities of language, identity, patterns or systems of talk (Cole, 2019; Lupton, 1992; 2003), contradictions and distinctions, and towards a more dialectical sensitivity. The consideration that postmodernism gives to difference provided a stepping-off point into feminist theory, which also contributes to the theoretical frame for this research.

### ***Acknowledging Feminist Influence in the Research***

Although I have not positioned this research as feminist research per se, I cannot ignore that aspects of this study are informed by feminist ideas. To this point, I have argued that disability is an experience characterized by difference. The argument is, however, more complex than simply stating that different people have different experiences—that there is a “natural” and “to be expected” variation in how people experience disability. Experiences of disability intersect with numerous other aspects of life. Intersectionality (Erevelles & Minear, 2010) is a term derived from feminist thinking that contributes to the perspective that human beings do not just objectively see the world and that which it contains. We see the world *as* a person who is situated, embodied, and

participating in personal, institutional, and social narratives (Clark, 2013) such as race, gender, class, sexuality, the body, genetics, and social and institutional oppression (Clark, 2013; Hall, 2011). Intersectionality focuses social inquirers towards stories of living with disability as sites for understanding the intersections that comprise identity and experience.

Although this is not an intersectional feminist study, the concept of intersectionality sensitizes narrative researchers to look sideways (Clandinin & Connelly, 2000). Looking sideways is a narrative practice that involves thinking with many dimensions of a person's story to live by (a narrative term for identity) and attending to stories that illuminate disability experience without centralizing it. In postmodern thinking, this practice might be thought of as looking towards and attending to the margins (Rimmerman, 2012; Whittle et al., 2017) for insights about a particular phenomenon or experience. In doing so, it becomes possible to tell stories that resist or challenge dominant narratives of living with disability. Razack (2006) referred to this resistance as an attempt to "interrogate the space between the knower and the things known" (para. 5). People with disability and their families are well positioned to offer rich insights into diverse experiences. I am seeking to integrate into knowledge for practice stories of experience that may be hidden or subordinated (Garland-Thomson, 2005). In doing so, it perhaps becomes possible to come to know disability as a part of ordinary human experience rather than an experience that is abject and marginal (Whittle et al., 2017).

Inquiring into ordinary experiences in the context of disability seems like an important and necessary step to counteract or resist marginalizing narratives of disability.



Feminist critiques of disability illustrate how disability is “configured as helplessness, weakness, and incapacity, all conceptually related to the ways women have been seen throughout history” (Hirschmann, 2013, p. 650). Of note, feminist scholars have paid significant attention to the influence of the male *gaze*—acts of depicting women as sex objects—on cultivating representations of women’s bodies so as to please a presumed heterosexual male viewer (Eaton, 2008). In the case of the male gaze, the female body is being produced in service of men. This production of the body occurs through the man who creates an image, the man who participates in the image, and the man who consumes the image (Devereux Herbeck, 2004; Narine, 2010).

Similarly, disabled bodies can be thought of as produced: cultivated in particular ways, by particular people, for particular purposes. The review of the literature in Chapter Two explores, for example, the ways that disability is talked about, by whom, and some of the resultant effects on people’s experiences and identities as well as service provision. Research that inquires into stories of families living with disability might be well positioned to offer useful illustrations of these dynamics as they are taken up in experience. This seems like an important objective for research, given that people with disability are often understood to be functionally or epistemologically inadequate (Fricker, 2009; Magee & Milligan, 1996). That is to say, their experiences as well as their knowledge about self, other, and experience cannot be relied upon as sources of knowledge for practice. This study proceeds from the perspective that experience is a legitimate source of knowledge (Caine et al., 2013; Clandinin & Connelly, 2000; Dewey, 1938). What happens for people, how experience unfolds, and the often hidden and unspoken dimensions of experience contain rich insights for understanding.

### **Methodological Foundations for this Study**

This research draws upon aspects of narrative inquiry (Clandinin, 2013; Clandinin & Connelly 2000; Connelly & Clandinin, 1990) and narrative analysis (Holstein & Gubrium, 2012; McAllister, 2001; Riessman, 1993). Like Clandinin and Connelly (2000), I reflected upon a series of philosophical and methodological approaches, arriving at a beginning point in which I could engage with research participants in a meaningful way. I did this through various readings and realized that this work warranted an integrative approach that drew on the ontological-relational commitments of narrative inquiry (to represent voice and experience), and the analytic practices of narrative analysis to explore new ways of understanding stories. The combined approach in this research makes room for depth of engagement with stories of experience, and an analytic practice that attends to disability as a socio-cultural and intersubjective experience (Clandinin & Raymond, 2007).

The idea that experience is a legitimate source of knowledge for how to live well in the world is derived from the pragmatic theorizing of John Dewey (1859-1952). Dewey (1938) understood experience as transactional: something that happens between people, over time. As such, knowledge derived from inquiry retains that transactional feature. That is to say, knowledge is returned to experience and action, rather than becoming something more abstract or transcendental (Caine et al., 2019) such as theory.

With experience as a starting point for research, narrative inquirers inquire into people's lives and tell stories of their experiences. This inquiry enables the researcher to begin to tell a story about experiences: about how life in a given context is lived. For narrative inquirers, human beings are in the world through the stories that we live and tell

of self and each other (Clandinin & Raymond, 2007). In narrative inquiry, experience is understood as a storied phenomenon that occurs within a metaphorical three-dimensional narrative inquiry space (sometimes referred to as the narrative *commonplaces*) comprising temporality, sociality, and place (Caine et al., 2019; Clandinin 2013). The stories told in Chapter Four attend to the *when*, *where*, and *with whom* of the commonplaces.

### ***The Place of Story in Research***

Humans are social beings and practiced storytellers. For most people, stories begin to shape how we understand the world during childhood. Children's stories are entertaining and instructive; children dwell within and learn from stories. As young people, we also learn about our sense of self, family, family history, and identity through stories that are told and sometimes handed down through generations. These stories shape how we live, how we understand ourselves. The stories influence relationships, choices, and our memories and reflections (Lessard et al., 2018; Clandinin & Connelly, 2000). Put another way, stories are lived as well as told (Caine et al., 2019; Estefan et al., 2016).

Just as stories can be thought of as a living text, they are also a rich source of data about living. Stories represent "efforts to explain life events; to sustain and/or protest certain images of self; to justify behaviours; and to come to terms with illness, crisis, or transition" (Sandelowski, 1991, p. 25). When people tell stories, it happens in ways that are analytically interesting. For example, stories are often told in a sequence, from beginning, to middle, and then an end (McAllister, 2001). Stories contain and describe characters as well as the actions of those characters. Storytellers make decisions about what stories to tell and how their stories are told (Malhotra & Rowe, 2013). Stories are

organized along certain plot lines, such as comedy or tragedy (Anastasiou & Kauffman, 2013; Goodley & Tregaskis, 2006) as well as other plots that speak more to nuanced experiences such as in the case of health and illness (Frank, 1991; 2013). In this way, storytelling is communicatively useful for the sharing of information and experience (Hydén & Antelius, 2011) and analytically helpful for exploring and theorizing experience (Sandelowski, 1991).

Story living and storytelling are transactions between people. As well as being told, stories are also heard, interpreted, and re-told (Caine et al., 2019). Audiences make judgments about and decisions based upon stories they are told; people make sense of stories based on their own interpretations, comparing and contrasting a story with their own experiences (Hydén & Antelius, 2011). Both storyteller and listener engage in meaning-making prior to, during, and after sharing a story. Stories are, then, rich data for research inquiry and for ongoing knowledge translation.

**Narrative Inquiry.** Narrative inquiry is a longitudinal, relationally driven approach to research. Narrative inquirers engage in lengthy fieldwork alongside participants in order to explore their storied experiences in depth (Caine et al., 2019; Clandinin, 2013). Narrative inquirers tell their own stories as part of the research as a way to attend to the relational context in which knowledge emerges (Lessard et al., 2018; Clandinin, 2013). Staying attentive to a relational view enables researchers, as well as consumers of the research, to engage in *world-traveling*, a conscious effort to venture to the world of the other in a way that resists assumptions, the presumption of knowledge, and arrogant perception (Lugones, 1987). In this research, I have drawn upon relational principles of narrative inquiry in two ways: first by including aspects of my own story as

a way for readers/knowledge users, including research participants, to make judgments about my part in the parade I have presumed to study (Clandinin & Connelly, 2000); second, I have told the participants' stories in a way that helped me, and I hope helps readers/knowledge users to travel to participants' worlds and engage with their stories in advance of opinion, judgment, or presumption.

In narrative inquiry, story and experience are understood as being synonymous. Stories tell of our experiences and also influence and shape experiences and identities (Bruner, 1991; Polkinghorne, 1988). The practices of storytelling are, thus, implicated in the conduct of narrative inquiry research. Narrative inquirers describe narrative inquiry as both phenomenon and method (Caine et al., 2013; 2019). That is to say, story is the phenomenon being explored and also the means of exploring it. In this dissertation, I tell participants' stories of experience as well as something of the story of the research, in order to show the relationships, tensions, complexities, inconsistencies and ironies, between story, experience, and knowledge for practice.

In order to engage in successful narrative inquiry research, narrative inquirers adopt an "intentional, wide awake" (Clandinin, 2006, p. 47) approach to the inquiry. Researcher and participant are both active members in the exchanges that result in data (Smith-Chandler & Swart, 2014), meaning that data are co-constructed (Connelly & Clandinin, 1990; Sakellariou et al., 2013). In this current research, I explored and clarified meanings with participants during interviews, allowing room for different understandings to emerge, be spoken about, and clarified. I remained attentive to these negotiations of meaning as I worked analytically with and made meaning of participants' stories.

**Narrative Analysis.** There is a tension between thinking about story as a living text and story as a unit of analysis. For narrative inquirers, a story cannot be reduced to a research transcript because to do so separates analytic and interpretive thinking about experience from the stream of experience itself (Caine et al., 2013). Put another way, it is important to return to the life being lived as we attempt to make sense of that life. Techniques of narrative analysis call for a different view in which story, as a discrete unit of data about experience, is its own site, rich with analytic and interpretive potential. These tensions are not irreconcilable; indeed, Clandinin (2013), Clandinin and Connelly (2000), and Estefan and Roughley (2013) have provided insights into how narrative analytic approaches can offer useful insights into the stream of experience, when incorporated in narrative inquiry research.

The narrative analysis approaches that were used in this current research were informed by two theoretical perspectives. The first perspective is that of the narrative commonplaces of temporality, sociality, and place (Caine et al., 2019; Clandinin, 2013). These commonplaces provide a way to think about the constituent elements of experience and story. Temporality refers to the role that time plays in the telling of stories of experience. For example, experiences happen in certain times, across time, and are made possible in certain times and not others. Sociality refers to the social dimension of experience, or the interplay between self and other(s). Place attends the role that place plays in making possible and organizing experience.

The second theoretical perspective that informed the narrative analytic dimensions of the study was that offered by McAllister (2008), who undertook a postmodern narrative inquiry to explore how she was making sense of a story told to her by a nursing

student. McAllister described the impetus for her inquiry as her own dissatisfaction with her interpretations of the student's experience. This experience of feeling unsettled or knowing there was more to be inquired into pushes a researcher beyond surface interpretations, to consider the complexities of experience, language, and representation.

Because stories provide a way for people to make sense of their experiences, a narrative analytic approach attends to plot, characterization, and the sequencing of stories to develop helpful interpretations of experience and phenomena (Bruner, 1991) in particular contexts. Narrative researchers "...attend simultaneously to 'small' and 'big' stories" (Phoenix, 2013, p. 74). The storyteller provides their subjective version of events (small stories) while the researcher-as-audience might then bring these happenings into focus alongside dominant narratives (big stories; Phoenix, 2013). A person's stories are an interpretation of experience offered in light of dominant narratives (Kramer-Kile, 2012; Streubert & Carpenter, 2011). Attending to stories in this way centralizes and decentralizes characters and plotlines, enabling a story to be thought about from different perspectives, revealing tensions, complexities, ironies, inconsistencies and alternatives. From a postmodern narrative perspective, McAllister (2008) argued that it is important to "be astute to a story's inconsistencies, tensions, or struggles, because they ...reveal that all is not as simple as it may seem" (p. 392). If one aim of narrative research is to help others to travel the world (Lugones, 1987), asking critical questions about stories can open up dimensions of that world that are important. In doing so, it becomes possible to consider the ways that experience is "endowed with meaning" (Sandelowski, 1991, p. 165).

*A Postmodern, Narrative Study of Families and Disability.* Over time, people and families with disability have been subject to the persuasiveness of medicine, science, and the health and social care services that are informed by them. People with disability are placed (willingly or otherwise) into categories that can activate services and support while also calling forth stigma and marginalization. In her 2008 work, Riessman cautioned that stories are “always tentative and cannot provide certainties” (p. 17). In the context of researching and practicing with people and families with disability I argue that tentativeness and uncertainty offers alternatives for experience and identity.

In a complex world, such as that of a person or family where disability is present, singular stories will no longer do. Today, people live in a world characterized by difference, in which alternative identities and practices are emerging. In stories of disability and family experience, no one truth is revealed, and people’s experiences speak of the social, and institutional stories in which their family experiences are embedded. Therefore, I hold stories as being: (a) sources of subjective knowledge about the world; (b) a counterpoint to the idea of objective truths about disability; (c) an account of a storyteller’s past and an expression of an imagined future (Bateson, 2007; Clandinin, 2013); and (d) open to multiple intersections, interpretations and readings because stories are told alongside other stories, upon complex interpretive landscapes.

Each of these perspectives on story and disability leads to implications for the conduct of a narrative study with families who experience disability. In the forthcoming section, I describe the methods enacted in this study, paying attention to context, recruitment of participants, data collection, data analysis, ethics, and rigour.



## **Research Methods**

Fieldwork for this study occurred in Calgary, Alberta during the summer of 2019. The study was reviewed by the University of Calgary Conjoint Health Research Ethics Board (CHREB). Ethics approval was received in May 2019 (CHREB; REB18-0870). Once ethics approval had been received, advertisement and recruitment began.

### ***Recruitment and Participants***

Participants for this study were recruited through a Calgary-based non-profit organization that serves families with disability. A recruitment poster was placed at the offices of the organization (See Appendix A.3) and a social media post was shared on the organization's social media news feed (See Appendix A.4). Email and telephone contact details were provided so potential participant families could contact me. In a first screening conversation, I asked potential participants about their circumstances as well as questions to determine whether they fit the inclusion criteria of the study.

My intention was to recruit families who have a member with disability. My use of the term, "family" was intended to recruit people related either through biological or legal ties, and/or those people who choose one another to be part of their support system. For this study, I looked to the participants to define who was part of their family.

The inclusion criteria for this study were: (a) the family had a child or sibling with disability, or the respondent was affected by disability themselves; (b) the person with a disability and family members needed to be able to communicate using verbal or written English; and, (c) participants must live in the Calgary metropolitan area. Exclusion criteria were: (a) people not living with a family member with a disability (child, siblings, or parent); or (b) individuals who did not, themselves, have a disability; (c) non-family

caregivers (e.g. paid or volunteer support person) or supportive roommates. No exclusions were made based on type of impairment or degree of affectedness. In total, 11 potential participants contacted me in response to the advertisements. Of these 11, six responded to my initial follow up. Of these six respondents, one did not respond to any subsequent follow up and five went on to sign consent/assent forms and participate in an interview conducted at the family's preferred date and time, and at either the University of Calgary or in their family home.

During initial recruitment communications with the five families, one respondent from the family initiated communications with me. In the case of each family it was the mother who responded. The mothers confirmed their willingness and the willingness of their family member(s) to participate in the study. For families with multiple members interested in participating, I offered the options to interview them individually or together with one or more family members at the same time. The mothers expressed that their other family members would participate as a group or the mothers expressed this to me in future communications after checking with the other members. With their voiced preference, I conducted the interviews with a group of two to five family members present and participating. A description of the composition of the families interviewed, including details on which family members participated in the interviews can be found in Chapter Four.

### ***Data Collection***

Five interviews were conducted in total with two or more participants from a family present for each interview. While interviewing only two family members might not constitute a "complete" family perspective, there were instances where interviewing

all family members together was not feasible or practical. For example, in two cases, the child member of the family was non-verbal and unable to participate in the formal interview process; in another interview, the 18-month-old child was present but did not contribute to the interview.

I used a semi-structured approach to the interviews (Caldwell, 2014; Jovchelovitch & Bauer, 2000), using broad, open-ended questions as a guide (See Appendix B). Semi-structured interviews offer the opportunity to collect data that is relevant to the study question, while allowing participants the opportunity to expand or diversify into areas of experiences that they consider relevant (Bold, 2012).

All research interviews were conducted face-to-face. Each interview lasted between 60 and 90 minutes and was audio recorded and transcribed verbatim by an experienced research transcriptionist. As well as participants' talk, transcripts included reference to affective data such as laughter, changes in mood and tone reflected in the participants' voices. Each transcript was read alongside the audio recording to check for accurateness and completeness. I also made notes on transcripts where I recalled from the interviews that sarcasm or irony was being used.

### ***Data Analysis***

Individual transcripts were read from beginning to end and scrutinized for language conventions that indicated a story was being told. For example, some stories began when I asked participants for a specific recollection. At other times, participants moved into storytelling in response to conversation and these moments were signalled by the use of devices such as, "I remember when..." and, "that reminds me" (McCormack, 2004; Riessman, 1993). Having located the beginning point of storied segments in the

transcripts, I looked for the development of characters and an overall narrative arc. The narrative arc was found by paying close attention to how the story was unfolding, moments of tension, and resolution (McCormack, 2004). In rare instances, these stories were told in an uninterrupted fashion. At other times, participants began a story, changed topic in response to another idea or recollection, or became distracted by something happening with another person in the room. They then later returned to the story they had been telling. As I worked with transcripts, I had to be attentive to where stories were left off and picked up, as well as to the layering effect of participants going back and forth between different stories in the course of an interview.

Once storied segments had been isolated in the transcripts, they were highlighted and extracted. Stories that were told in narrative segments were pieced together and examined as a whole (Riessman, 1993; 2008). I then followed Sandelowski's (1991) process in which a researcher "select[s] and temporally arrange[s] events to give them coherence and unity" (p. 26). That is to say, segments were put together in a way that enabled the story to make sense without changing participants' intended meaning.

I then read individual stories from the transcripts of each participant in turn. I made notes about what I was noticing in each of the stories, according to the frameworks of narrative inquiry and narrative analysis. Specifically, I attended to the narrative commonplaces of temporality, sociality, and place (Clandinin 2013), and to statements or insights that were novel, unexpected, or surprising to me in order to stay open to the possibility of world traveling and resisting any premature arrogant perception (Lugones, 1987). Throughout this process, it is important that the researcher preserve the complexities of the story and value the emotive command of the story's message. This

process was described by Bold (2012) as looking through a “window on the tensions and issues” of the story (p. 133). To achieve this, Riley and Hawe (2005) emphasized attention be paid to “broader social forces” acting on the story (p. 227).

As I engaged in this process of back and forth between the stories, attending to the temporal, social, and situated aspects of stories, I started to think about how the storied segments could be recomposed into a narrative that was both faithful to participants’ experiences and provided a coherent narrative for further interpretation. I noticed I was trying to tell the story of each family in the context of disability in a way that kept the family themselves whole and central, as authors of the work. I returned to the idea that postmodern inquiry often addresses partiality and fragmentation and decentering the author. I was aware that, at that point in the analysis I was dealing in parts and fragments of stories. As a researcher gathers details and explores nuances, she also organizes fragments of stories for analysis and reflection (Sandelowski, 1991). As I sought to resolve the tension, I was experiencing between faithfulness to experience and maintaining a postmodern lens, I was drawn to a methodological paper in narrative inquiry that discussed the purposes of *fictionalizing* in narrative inquiry (Caine et al., 2016). This paper proposed *blurring the boundaries* and *creating “As If worlds”* (p. 217) as narrative practices that offer the chance to engage with stories more deeply.

Blurring aspects of data is not uncommon in qualitative research. For example, researchers use pseudonyms for people and places, as well as alter other kinds of identifying information. According to Caine et al. (2016), the purpose for this kind of blurring is ethical: to take steps to protect participants’ identity. Although I had attributed pseudonyms to participants and families, I was aware some of their experiences were

sufficiently nuanced to make them potentially identifiable. In the aforementioned article, Caine et. al. (2016) discussed a research study in which a narrative inquirer created *composite stories* because to tell individual stories could make participants identifiable and working with those stories individually would have meant omitting rich detail. The creation of a composite story is, then, a means to care for participants and also for the story that is being told (Caine et al., 2016). This type of narrative practice blurs the boundaries between participants and their experiences yet remains faithful to the purpose of bringing others into the hidden worlds of research participants.

I placed participants' stories alongside each other, thinking about them in relation to each other. While doing this, I made analytic notes alongside the stories, and keywords were used to identify narrative conventions that were being used by participants to speak about their experiences (See Appendix C). As I worked through individual stories and considered them alongside each other, I grouped stories together in a way that showed aspects of temporality, sociality, and place (Caine et al., 2019; Clandinin, 2013), plot, and characterization (Riessman, 1993). As stories were inserted, removed, and repositioned in relation to one another, a composite story of family life with disability began to emerge.

The creation of *As If worlds* involves the use of imagination, to create a fictional context in which participants' stories and the researcher's experience of those stories can come to life. According to Caine et al. (2016), although As If worlds are fictions, they grow from the experiences of participants and researchers. In this way, the As If world becomes another layer of analysis, a kind of "layering" or deepening of insight into experience (Caine et al., 2016). In Chapter Four, three stories are presented, each of which is a composite story derived from data collected in the study. *The Morris Family* is

the first of these stories, in which I draw upon the experiences of all the families in this study, to evoke experience of family life.

As I was reading and rereading the families' transcripts, I noticed that I was being drawn back to the voices of the mothers in the stories. As a woman myself, the stories from the women interviewed especially resonated with me. In my experiences working with families with disability, I developed close, personal relationships with the mothers of the clients with whom I worked. As a woman, registered nurse, and disability advocate, I am curious about how specific roles are taken up and performed by mothers. This is not to dismiss fathers contributions, or to imply that they do not take up meaningful roles in families. The fathers in this study actively participated in the interviews they attended (in only one interview, the father was unable to attend due to work commitments). In the interviews, fathers spoke to how they were very involved and attentive to their children's and family's needs. Although the fathering role is also an important one in families with disability (and a direction for future research), it was the mothers' drive to do best for their children that particularly stood out for me.

The second story, "*To Our Healthcare Team*" is told in the form of a letter written by a mother to those from whom her family have sought care and support. This letter, also written from the standpoint of the As If world, reveals something of the frustrations and deliberations of parents as they navigate complex healthcare systems and practice. "*To our Healthcare Team*" is a pastiche in which I have imitated a style of writing for its capacity to generate feeling (Austin, 2013). The style of this letter is informed by the scholarship of Joy-Ruth Mickelson, whose seminal narrative inquiry addressed the experiences of mothers whose sons had been labeled by the school system

as “behaviour disordered” (Mickelson, 2000). The story *Conversations Between Mothers* tells also of an As If world in which the women of the study gathered together in conversation, discussing their experiences.

In understanding how these stories can be drawn together, there is a distinction to be made between narrative analysis and analysis of narrative. Narrative analysis involves creating descriptions of events, creating a story by attending to unfolding plot; analysis of narrative involves reading across the stories to determine themes or patterns (Creswell, 2007; Polkinghorne, 1995). In keeping with narrative inquiry methodology, I have not characterized the writing of the stories in Chapter Four as thematizing. Instead, these stories are intended to be read as part of participants’ broader stream of experience (Caine et al., 2019; Clandinin, 2013). As other narrative inquirers have commented, when stories are placed alongside each other, it makes it possible for them to come into conversation with each other (Smith et al., 2018). Thinking about stories in this way means that they are not reduced simply to a unit of analysis (such as plot, theme, characters) as might happen in some types of narrative analysis (Holstein & Gubrium, 2012), but viewed more holistically in relation to each other. In this way, it becomes possible to balance an attentiveness to experience with the analytic objectives of the research.

In Chapter Five, I extend the analytic objectives of the research by presenting a discussion that contrasts conventional and postmodern readings of the stories in Chapter Four. To do this, I draw upon the postmodern critical questions posed by McAllister (2008, p. 393), namely: (a) What meanings are produced in the story?; (b) What meanings are standard?; (c) What truisms are sustained?; (d) What meanings are obscured?; (e) what voices in the margin can be heard?; (f) what resistances (usually



concealed) are revealed? (g); What gaps remain that may suggest other stories are needed? (h); and, What does this reading illuminate about the experience?

### ***Research Ethics***

The proposal for this research was approved by CHREB prior to commencement of the study. All participants provided consent and/or assent to participate (Appendix A). Consent was gained from participants over the age of 14 years of age and who have their own guardianship. For those participants under the age of 14 years, assent was gained from the participant and consent was gained from their guardian. Only those that provided consent or assent and who signed the consent form approved by CHREB were included in the study. Participants were notified that they may withdraw from the study at any time without penalty. They were informed that participation was voluntary and that they may withdraw from the study at any time without penalty.

Participants were made aware that every attempt would be made to safeguard their confidentiality. Participants were made aware that due to the sometimes-particular nature of stories of experience, there was a chance that they might be identified. In order to address this, I invited participants to select pseudonyms in place of their own names. Also, where possible (and within the bounds of fictionalization in narrative inquiry) I changed names of organizations and affiliations that might have identified a particular participant.

This study involved the telling and hearing of stories of experience. Although the sharing of experiences can be cathartic, the telling of stories can also be difficult, especially when speaking of experiences that are complex, traumatic, or oppressive (Estefan & Roughley, 2013; Razack, 2006). Razack (2006) expressed that although there

exist risks, "...the chance to speak, to enter your reality on the record, as it were, is as irresistible as it is problematic" (para. 28). As such, exploring sensitive topics required me to be aware of emotions that might arise and to remain sensitive to the psychological safety of participants (Razack, 2006). Participants were made aware they had a number of options, from pausing an interview and resuming, reconvening at a later date, or ending their participation in the study. Although none of the participants requested it, they were made aware I had prepared a list of support services for should they have felt they needed ongoing follow up.

In this study, all of the families asked that their interview be conducted with two or more family members present; meaning that, aside from myself as the researcher, multiple family members were present in the interview. This required extra attention and sensitivity; there were times when family members were interviewed while the person with disability was present, and also times when the person with disability was sharing their experience in front of other family members. I worked to be considerate to the sensitive nature of the discussions that were likely to take place during the interviews by assuring them that: (a) they could steer the interview in any direction they chose; (b) they were not obligated to speak to any particular topics or aspects about life with disability; and, (c) they could to share only those aspects they felt comfortable sharing.

Families with disability have interdependent relationships (Caldwell, 2014). It was important, also, for me to be sensitive to the family cohesiveness during the interview. In preparation, I turned to the American Association on Intellectual and Developmental Disability's report on interviewing people with disability for guidance (Tassé et al., 2005). The authors suggested the following considerations when

interviewing people with disability: treat the person in an age-appropriate manner; keep language simple and concise; maintain usual tone, appropriate volume of voice, and speak clearly; look and speak directly to the interviewee; and ensure sufficient time for their response and ask for clarification if needed. For persons with hearing and language impairments, Tassé et al. (2005) also encouraged other interview considerations as follows: For persons with limited verbal expression, I offered questions with short answers to encourage their participation in the interview; and for people with hearing impairments, I spoke clearly and steadily, turning directly towards them to allow them to lip-read, if appropriate. As needed, I also encouraged them to utilize alternative means to communicate including communication devices, if preferred.

I made an effort to build rapport with the interviewee as a way to establish trust (Caldwell, 2014), and “set the stage” for the interview (Tassé et al., 2005, p. 6). I introduced myself, shared a bit about my interests and research, then asked some surface level questions about their day and what activities they enjoy doing. I also asked each interviewee what word or words they prefer me to use to describe their impairment, if they would like me to do so at all. This allowed interviewees to declare their preference and allowed an opportunity for me to modify my interview questions and verbiage to meet the interviewee’s preference. Through deliberate and pointed attention to the agency of the interview participants, I worked to mitigate subjugation of interview participants.

By having a family member present for the interview, each family member could share the information they desired alongside the support, facilitation, and potential constraints of the other family members present. I noted when some interviewees would refer to another family member as a way to supplement and validate what they were

saying. Caldwell (2014) described how family members can serve as “confirmatory sources of information” for one another (p. 489). That is to say, family members rely on one another to confirm their perspectives and accounts of experience. I followed this back-and-forth process in the interviews and interjected where I felt I needed to clarify that I understood their experiences in the way they intended to convey them.

Caldwell (2014) also warned about the potential detriment of interviewing families with disability together. For example, family members might provide proxy responses, “speaking for” the person with disability. This risks barring one person’s social participation in the interview (Caldwell, 2014), potentially misrepresenting their experience. As Goodley (1999; as cited in Caldwell, 2014, p. 491), “disability research *with* participants can fall into research *on* participants...” which creates ethical concerns and conflicts with the intended research. It was critical that I worked to mitigate this while still having the family members present for the interview, as per the request of the person and their family. I worked with the family to make space for the person’s expression by offering support, asking for clarification, and redirecting the interview back to the person as needed to keep them central during their interview.

### **Research Rigour**

There are a number of ways that research rigour is evaluated. What constitutes rigorous research differs, depending on the study design. In qualitative research, rigour pertains to the degree to which the research adheres to the processes and conventions of the method, whereas trustworthiness refers to the “quality and truthfulness” of the findings (Cypress, 2017). There is, however, a relationship between these terms in the sense that rigorous research conduct increases confidence that the findings and

recommendations are trustworthy (Given, 2008). That is to say, findings, interpretations, discussion and recommendations are sensibly linked to the data and analysis.

Most often this is achieved through the creation of an *audit trail* (Lincoln & Guba, 1985) that traces decisions made at key points in the study. For this study, I have reviewed the literature to arrive at a researchable question for an identified knowledge gap in the literature. I have described the narrative research approach used for this study, and provided examples of data, in the form of stories, to support the subsequent analysis and discussion of those stories. One of the hallmarks of good qualitative research is demonstrating deep and insightful interactions with data (Maher et al., 2018). In Chapter Three, I offered an account of the engagement with data as I composed composite stories of experience of families with disability. In the appendices to this dissertation, I have included examples of how the stories were composed in order to show a transparent process of moving from raw data to data for further analysis. Discussion and recommendations made in light of data and linked to existing literature.

In postmodern, feminist research it is necessary to take a reflexive and relational approach to inquiry. I have done this in the following ways: In Chapter One, I wrote about my own background and experiences in order to help a reader make judgments about my influence on this work. In subsequent writing, I have maintained a first-person writing style in which I have also narrated key decision-making moments in the study and how these were informed. I have done this to show the theoretical deliberations that contributed to the findings and discussion. In writing this dissertation I have sought to fulfil a relational obligation to participants, to show something of the depth and complexity of life as it has been lived for them in the context of living as a family with

disability. Together, these approaches were intended to demonstrate that my intention was not to impose myself upon participants and their experiences, but to move alongside them in ways that help their stories to be told and thought about.

## **Conclusion**

This chapter has outlined the theoretical, methodological, and practical dimensions of this research study. I have described and defended a combined narrative inquiry/narrative analytic design in order to inquire into and analyse the stories of families with disability. The procedures involved in this research and considerations of ethics and rigour have been discussed. In the forthcoming chapter, I present three stories that are the product of the research process described in this chapter.

## CHAPTER FOUR – STORIES OF FAMILIES WITH DISABILITY

In this chapter, I present three stories, composed from interview data. The stories are: *The Morris Family*, “*To Our Healthcare Team*,” and *Conversations Between Mothers*. Each of the stories in this section helps explore the richness of families’ experiences in the context of living with disability. In Chapter Five, I offer conventional narratives and postmodern reading of these stories.

In the previous chapters, I have identified that much insight is needed regarding ordinary experiences of family life in the context of disability. The first story, *The Morris Family*, is, thus, an account of daily family life. This story is composed from stories told by all study participants and written from the perspective of one fictional family’s voice. A dominant motif in the stories of all families was that of “family first.” That is to say, the families centralized their family life a priority over work and social life. As I wrote the composite story of the Morris family, I took care to represent the family first sentiment faithfully.

The second story is written as a letter entitled, “*To Our Healthcare Team*.” All families told stories of involvement with health and social care providers. As I read and re-read the transcripts to locate stories of experiences, health-care-related stories were prominent. That the families told these stories to a registered nurse is perhaps unsurprising. Of note, though, was that the families’ stories possessed the quality of a singular voice. Clandinin and Connelly (2000) argued that we dwell in each other’s stories. Aspects of experience, sentiment, interaction, and relationship from one family’s story were reflected and refracted in the stories of the others. “*To Our Healthcare Team*” is written from the perspective of a mother of a child with disability. The letter tells of the

complexities and tensions that arise in the midst of overlapping familial concerns and the provision of health care.

The third story, *Conversations Between Mothers*, is a story about the experiences of mothers in families with disability. As I read and re-read the interview data, I noticed how the mothers' stories possessed a conversational quality. That is to say, when placed alongside each other the stories read as a sharing of experiences that said something about how mothers come to understand and negotiate their roles as women, mothers, and partners in families with disability. I wrote *Conversations Between Mothers* by placing mothers' stories alongside one another and arranging them to create a dialogue. Throughout this story, I use interpretive signposts as a way to underpin the mothers' conversations.

### **Composition of the Families Interviewed**

In this section, I review the composition of each of the five families that I interviewed for this study. In particular, I provide the role each person takes up in the family, and the ages of the children (see Table 1). In this study, all five families were white, presumably middle class, heterosexual, married couples with two or more children.

The first family interviewed was a blended family made up of a mother and her biological 14-year-old daughter from a past marriage. The father had a biological 17-year-old son from a past marriage. Together, the couple have a 12-year-old daughter. All three of their children have impairments and all three participated in the interview, between completing their chores. Aside from the mother and father, the 17-year-old participated the most in the interview out of the siblings. This interview took place in the family's living room of their home.



The second family interviewed was a blended family made up of a mother, her biological 17-year-old daughter from a previous marriage and her 11-year-old son from her current marriage. The mother has a genetic impairment that was passed to both of her children, although her son is more affected by this impairment. The father of the 11-year-old and stepfather of the 17-year-old was not present during the interview as he was working. The interview took place at the University of Calgary, at the family's request.

The third family interviewed was a married mother and a father. Their two sons, aged 11-years-old and 4-years-old were both asleep in their beds. Their 11-year-old son has a severe impairment that meant that he would not be able to participate in the interview should he have been awake. The interview took place in the dining room of their family home.

The fourth family interviewed was a married couple and their two biological children, aged 7-years-old and 4-years-old. All four of the members of this family participated in the interview, although their 4-year-old daughter moved from the backyard deck, where the interview was taking place, into the grassed area of the yard to play. Their 7-year-old son with an impairment stayed for the duration of the interview and participated throughout.

The fifth family interviewed was a married couple and their two biological children, aged 6-years-old and 18-months-old. Their 6-year-old daughter has a severe impairment that precluded her from participating directly in the interview. She and their toddler son were both present in the living room during the interview with both parents.

Table 1.

*A summary of the composition of each of the families interviewed<sup>15</sup>.*

	Family 1	Family 2
Adults residing in current household	Mother (✓) Father (✓)	Mother, mild impairment (✓) Father (X)
Children - Biological descent, sex, age, affectedness of impairment (if present)	Paternal side, Son, 17, impairment (✓) Maternal side, Daughter, 14, impairment (✓) Daughter, 12, impairment (✓)	Maternal side, Daughter, mild impairment, 17 (✓) Son, 11, impairment (✓)

  

	Family 3	Family 4	Family 5
Adults residing in current household	Mother (✓) Father (✓)	Mother (✓) Father (✓)	Mother (✓) Father (✓)
Children - Biological descent, sex, age, affectedness of impairment (if present)	Son, 11, severe impairment (X) Son, 4, (X)	Son, 7, impairment (✓) Daughter, 4 (✓)	Daughter, 6, severe impairment (X) Son, 18-months (X)

### Story One: The Morris Family

The Morris family is a blended family. Parents, Bonni and Jim have a biological son together and a daughter from Bonni's previous marriage. Bonni and Jim met in 2010 and were married in a large ceremony filled with extended family. While both Jim and Bonni went through challenges in past marriages, they entered their marriage hopeful and committed to one another.

Bonni's daughter, Madison, is "the easy child." Aside from a handful of pre-teen outbursts in the last year or so, she has always been a fairly even-tempered child. Bonni and Jim recalled how, at parent-teacher interviews, they heard only positive feedback about Madison's performance at school. She enjoyed extracurricular activities and riding her bike around the neighbourhood after school. Madison helped around the house and she seldom needed a second reminder to go to bed when it was time. She willingly helped

<sup>15</sup> The check mark (✓) signifies who participated in the interview, while the (X) signifies who did not participate. Included here is also the biological descent (maternal or paternal, if the child is only biologically related to one parent in the household), sex, age, and impairment (mild means that the person is mildly affected by their impairment and they were not considered to be the person by which discussions about disability centred).

with her brother and seemed not to tire of pushing him in his tumble form chair around the house. Bonni and Jim described that parenting her was simple and predictable.

Bonni and Jim could not remember a time when their son, Callum, was “easy” in the way they experienced with Madison. Callum, who is now 9 years old, had always had a short fuse. He quickly tired of activities and became frustrated with others easily. Bonni and Jim recalled experiences of Callum’s difficult behaviours; at a mall or grocery store, a small change to a routine would lead him to lay on the floor, release high-pitched screams, and throw anything he could reach.

These “meltdowns,” as Bonni and Jim described them, intensified as Callum grew older, and it started to take longer for him to “bounce back” after them. Some days were “just bad days” for him whereas other days went by a little more smoothly. The family was always mindful about keeping him to his routine, keeping a leisurely pace and limiting outside demands placed on him. The family avoided certain places where Callum might become heightened, like noisy places or places with too many children. Bonni and Jim were very aware that, if things went wrong, it could ignite a meltdown from which it could take Callum hours to recover.

Bonni recalled a time when she went against her better judgement and agreed to Madison’s request to have a friend over to the house. Madison and her friend chatted in the living room while Callum played with his trains off to the left. Bonni watched from the kitchen as an animated Madison told a story to her friend. As she was telling her story, Madison twirled around, knocking a few of the train track blocks. Bonni remembered seeing her daughter freeze and her eyes quickly turning to her brother. Madison raced for her bedroom to try to escape her brother’s usual hitting and scratching.

Bonni heard Madison's friend ask, "why is your brother like that? Can't you just ask your parents to make him stop?".

Bonni and Jim were conscious about how having a brother like Callum affected Madison and her development. They were aware that Callum could be unpredictable and took a lot of their attention. Madison noticed and was, at times, frustrated by it. In Madison's words:

*I have to say lots of stuff to get him to play with me. I tell him, "I will do anything to play with you." He sometimes plays with me--he goes on the trampoline with me and plays cards sometimes--but he always makes me play his games. He never plays my games. He saves all his niceness for everybody else.*

In spite of Callum's outbursts, Madison continued to offer to play and include him. Bonni and Jim felt that having to accommodate her brother was not fair to her. Jim said:

*She got hurt a lot. I was worried he was gonna seriously hurt his sister. I remember thinking that a lot. If she disturbed his play, he'd hit. He'd just resort to a hit. Even if she touches a toy he's not even playing with. He gets really aggressive and impulsive. He's still like that. He will shout, "I need her to leave and she's not leaving!". He just acts out.*

Bonni and Jim made adjustments to their schedules and roles in order to have one-to-one time with Madison. Jim would also schedule her to spend the day at her dad's house or with her grandparents for the day. They felt it was important that she have time to "just be a kid."

It was not just the children's social lives that were affected. After Callum was born, Bonni and Jim had many friends and family with whom they no longer spent much

time. After a visit or two at somebody's house, there would be an incident that would involve Callum. Bonni and Jim noticed that invitations became less frequent, and when they were invited to an old friend's or family members' homes, it would be a "no kids" gathering. It was not lost upon them that when they arrived at some of these events, other children were present. Jim reflected upon this shift in their social lives, saying:

*We know we're not invited to certain social events or gatherings because our family is a lot. We could sense it all along, this judgment on us and our kid. We spent the whole time following our kid around like, "Oh! No! Don't do that! Not here...please, not here."*

Bonni and Jim reflected on other times they felt like they were not accepted by others around them. They noticed, during their visits with family, Bonni's sister would be constantly "on" Callum. They noticed, she was constantly "after him," trying to loudly redirect him and making passive-aggressive statements about how "his parents" needed to "do something" about how Callum was behaving:

*Our [extended] family doesn't get it. We found that out recently. Well, we knew, but it was said...clearly said. It came out that...it just looks like bad behaviour. What's so frustrating, is that she [Bonni's sister] has no idea. The lack of support...it changes your perspective on how you view that person.*

After this visit, Bonni and Jim talked about the effect it had on their sense of who they were as parents and how they were managing. They spent the next few weeks reminding one another of the ways they were doing the best they could for their family. Their experiences reinforced for them their need for continuing support. Bonni stated:

*I go see a counsellor every now and again when I feel myself getting really burnt out, and he reminds me that caregiver burnout is a thing and offers ways to practice self-care. Cause some days, I'll just wake up, and I'll look at Callum, and I'll just...wanna cry, because it's just not fair, and then other days, I wake up, and I'm like, "let's just go have a good day and do our thing."*

Jim had been seeing a counsellor since before Callum was born. Bonni pointed out that Jim had always been the “pessimistic” one since they met and after they first married, before Callum was born. Bonni described how she saw Jim had “found optimism” as they learned to face different challenges as a family. Jim shared how seeing a counsellor was helping him:

*I stay pretty even keeled most of the time. I just think, there is no point in taking negatives out of everything 'cause...it's not gonna get us anywhere. Our situation is what our situation is. So, why not look for any bit of good we can find out of it and just, try to find things to look forward to? It's not like it never affects me, but I saw a counsellor much more regularly than [Bonni] did, for possibly a lot of reasons related to this, but, just for a whole bunch of other stuff too. Since then, I've found ... when I get myself down, I can get myself back out on my own. And a lot quicker these days. I don't tend to get stuck on and dwell in things as much as I used to. I'm more the one who's there, like, "it's okay, son."*

As their counsellors help them work through the more difficult moments, Bonni and Jim recognize the limitations in some people's understanding of their circumstances. They choose to seek out those people who they say “get it”:

*Honestly, I notice that the people we have hung out with or, like, who we end up socializing with, have kids like ours. We connect with other parents whose children are going through the same thing. Sometimes it's just nice to hear someone... someone, just, living the same experience you do. Like, I have a few wonderful friends who are super-good, but they don't live my life and I don't live theirs. There're some things... they just don't get.*

Jim also found support through an online group for fathers of children with complex needs. He talked about spending late-night Fridays reading some of the men's posts and noticing how he empathized with them:

*Now I'm part of this group for dads, 'cause dads are... different. Dads are supposed to be the strong ones...they're not supposed to need to talk with somebody. This dad group is essentially just a bunch of dads who get frustrated and post, and then they have fifty other dads to be like, "I get what you're going through." It provides a support system of other people just as frustrated as you are. They want the same answers that you do, but they can't get 'em either.*

Over time, Bonni and Jim encountered new parenting complexities. They grew increasingly aware that it was difficult to find solutions to problems with Callum. When Callum began school, Bonni received phone calls on many days from the school, asking her to come and take Callum home. The school told Bonni that Callum was a danger to the staff and the other children. He hit other children, threw chairs, and behaved in other ways that were a concern to the school. Bonni attended many meetings with Callum's teachers and the principal. At one meeting, the school told her that he would not be allowed to attend a planned field trip for his class. Callum did not understand why he was

being excluded and this further aggravated things for the family. Although Bonni described being able to respond to the circumstances and Callum's needs in that moment, she noticed how she also needed to feel support from Jim. She said:

*My husband was super-busy with work and so I was alone. It was just me. And then I told him, "I need you here," and, after that, he was with me at every meeting.*

That night, after talking with Bonni about her need for support, Jim resigned from his job. He started a consulting business, which gave him the freedom to attend every meeting with Bonni. In Jim's words:

*We've had to look for employment opportunities with more flexible schedules. My wife has had to basically find a job that would work around the needs of our family. My job was very rewarding for me, but it demanded all of my attention. I'd come home and work would still be on my mind. I needed to support our family. I was trying to find the best way to be around and help out not just at home, but at school...at everything. So, I am self-employed.*

Even though having Jim present was an important source of support for Bonni, Bonni continued to find her interactions with Callum's school personnel difficult. She described feeling misunderstood and even "uncared for" in interactions with the school. She felt little empathy or concern from the school, beyond their concern with the disruptions that Callum caused:

*People just didn't understand the stress of having a child like him, the stress from how the staff described him when I picked him up...they always had something*



*horrible to say. Once again, we were called to this meeting and I knew it was gonna come to this, but they ended up kicking him out.*

Jim, the past pessimist, encouraged Bonni as they lived through the process of engaging with the complexities of Callum's schooling. He supported her as they learned to take things one day at a time:

*We think short-term, like, "Okay, well, what do we gotta deal with tomorrow? What do we gotta deal with this week? What do we gotta deal with this month?". Next year is a whole different picture. We don't really need to think about it much. Let's just wait and see where we are. Our situation is what our situation is. We're just, normal people. We have, just, different challenges.*

As they searched for insights, advice, and support to parent Callum, Bonni and Jim sought out professional advice from specialists. Callum was tested for a variety of disorders. Bonni and Jim were told that he had attention deficit hyperactivity disorder and oppositional defiant disorder. They initially welcomed the diagnoses in hopes it would help others understand Callum's needs. Despite the diagnoses, no further support seemed forthcoming and Callum's behaviours continued:

*His coping strategy was fight-or-flight. And a lot of times he was a flight risk. He would leave the classroom and then someone would chase him, so then he'd book it out the doors, and through the courtyard. And that became risky.*

Bonni and Jim felt they had to push for their concerns to be seen as important or urgent to the specialists, and to have access to more services. They also wanted the specialists to understand they needed more information about Callum's diagnoses. Jim shared:

*Our child had been struggling for years, and we'd been fighting with the fact that he'd been struggling for years. It was exceptionally difficult. Then the specialist says, "well, it's just really complicated." I wish they would have said, "Y'know what, we are kind of confused. Let's see what we can work on together. Let's build his capacity." I don't want him to be a rubber tube floatin' down the river. I want him to have a paddle and a rudder.*

With Callum being kicked out of school, Bonni, Jim, and Madison felt the need for a change of scenery. To accommodate the new and changing rhythms in their family life, Bonni and Jim considered moving to a new city. They heard that funding and support for families with disability was better in Alberta. They asked themselves, could life be different in Alberta? The possibility of things being easier was enough for them to pack their home and move provinces. Callum started at a new school. Equipped with a growing repository of experience, Bonni knew not to get discouraged and to keep pushing for Callum's success:

*I met with the school board to discuss some of the challenges that we were facing coming into Grade 1. And that we felt there was a significant need to meet the teacher, in advance, to form a relationship 'cause forming that relationship was one of the key things vital to our son's success. We were reassured, but then we met the teacher the day before school started. We got push-back right away. The resource teacher came outside on the first day and said, "I think we need to talk...". They suggested I bring Callum later in the day. I said, "aren't all the kids tired the first day?". Because this isn't our first rodeo, as soon as we heard, "your child needs to go to a locked program," we met with the higher ups. I was*

*like, this isn't right, with everything I know about inclusion. That's when we found this school and Mrs. Morgan. Mrs. Morgan was amazing with him, she had ten years of working with kids like Callum. The extra experience and training make a huge difference. It's the idea of connection, and she built that with Callum. When he would run, she would say, "Callum, we're gonna start this activity and we really miss you, and we were wondering if you're gonna come back for it?". She said she didn't even turn around and he was back in the room.*

Having Mrs. Morgan was a turning point for Bonni and Jim. As they built up their confidence from the successes with Mrs. Morgan, they also found a new team of specialists. Soon after that, the new team agreed upon a diagnosis of autism spectrum disorder for Callum. This new diagnosis created forward momentum. Callum's diagnosis served as a "lens" or "filter" through which others could view and make sense of Callum's behaviours. Knowing more about the diagnosis of autism spectrum disorder also helped Bonni and Jim to communicate to others what Callum's needs were. Bonni and Jim felt a shift in their circumstances from mostly struggling to what felt like "gaining ground" on their situation. Callum's teacher seemed to "get it":

*He'd literally just been drowning, slowly but surely. Before, he wasn't showing any desire to learn. Within a few months at the new school, he was reading above his grade level. The difference was in the approach.*

Mrs. Morgan encouraged Callum to develop new ways of communicating; to express himself with words instead of his hands. She was also helping him learn to remove himself from places and interactions that could become problematic for him. Bonni noted:

*He's praised for how well he can express his emotions now, but that's one thing we worked on a lot. But it also comes with high expectations. Because, yes, he can articulate it really well now, but when he snaps, he's not thinking anymore. It takes time before he's put back together and he's able to rationalize and think.*

While Bonni and Jim made progress with parenting, supporting, and advocating for Callum, they were also concerned about how all their attention, directed at Callum, affected Madison. This was a difficult subject for them both as they tried their best for both of their children, even though Callum was the one who received much of their attention:

*I mean, this is just her life. She doesn't know any different. At first, we didn't think she understood what was going on. I remember, a while back, she was in her stroller, and we were dropping her off at her grandparents' house, then I had this emergency with Callum. I was trying to drop her off quick so I could get back to Callum. She usually just goes off with them, but this time, she completely freaked out. I just didn't even think about it, and then I'm like, "oh my goodness. She just saw my worry and panic and suddenly I was about to abandon her." Like, she's never been much of a cuddler, but some nights, she needs a cuddle and then she will be like, "Okay, I'll go back to bed." ... [Finding that balance] is constantly developing, the older she gets.*

Madison spoke about how she saw the family's situation. She shared how she felt being Callum's sister and how her parents' attention is occupied:

*I don't really think about it. I'm used to it. It doesn't take long. I've been doing it for forever so... I mean, I don't need that [attention] so it would be pointless for my parents to come to my school every week. There'd be nothing to say.*

As Madison grew, Bonni and Jim noticed Madison was also building capacity in herself as a result of having Callum as her brother:

*Madison's very compassionate. At school, she seeks out kids that are kinda like Callum. And plays with kids who are like Callum, which is really good, you know? She has a lotta tolerance for...that. I think having a brother like Callum has helped her on problem-solving skills, because, yeah, she's pretty adaptable. Doesn't matter what we do, she sees the silver lining.*

Jim added that finding activities that both children could “excel at” has been helpful to keep their daily rhythm. Jim shared a final insight into the times he feels his family is indistinguishable from any other family:

*When I've got the kids active, like dirt-biking and fishing, participating in things that they're comfortable with, where there's no external demands being pushed on them. I say, “let's get on and ride and have fun.” When we're out like that, people don't seem to know any different. They don't know any of our emotional struggles 'cause we're just all out there having fun and engaged.*

### **Story Two: “To Our Healthcare Team”**

“To Our Healthcare Team” is a composite story written as a letter. The letter is written by Leah, a mother of a child with disability. Leah explores experiences her family has had with healthcare teams. She details some of the complexities and tensions that arose within these relationships.

*To our healthcare team:*

*I wanted to write this letter in hopes of giving back in some small way. I wanted to share what it's been like for us these past few years. I know this might be hard to read - it was hard to write! I know this letter won't necessarily be something that helps our family, but if it helps other families down the road, that's good enough for us.*

*Let's start by saying, our family feels so lucky to have each of you on our team. I know your job can be a thankless one, so I start this letter by saying thank you. Thank you for taking time for the small things, like always greeting our girl, Holly, when you greet us, for making sure not to treat her like a piece of furniture in the room. These small things are big things for us. By caring for our girl, you care for us too.*

*You'll want to know; we have come a really long way as a family. And her! How far she has come! Now that Holly's doing better, we are all doing better. This is all thanks to the hard work done to get us here. Our family would not be where we are without this team.*

*I look back at us a couple years ago. Things were harder back then. Holly didn't have the diagnosis yet and we didn't fully understand what was going on with our daughter. Then, we got the news all at once very, very early on. By the time we sat down to actually take stock of it all, we were months in. I didn't know how to be a mum, let alone how to be Holly's mum.*

*You told us to be prepared for anything but how could we have prepared for this? We were introduced to disability practically before we were even*

*introduced to her! It felt like we were expected to just know how to be and what to do. So, we did all the research and we read all the books. We learned it all. We were at Holly's side every day. Still, every day was a letdown. Just when it felt like we had a hold of things, we were reminded that it's her that sets the pace. It just doesn't seem fair for her to be saddled with all this. She didn't do anything wrong. The stress of it is polarizing. It stresses all your relationships, creates cracks in them, and breaks open any existing cracks even more.*

*Some of these cracks have been very painful. Do you know, I used to hate Holly's birthday. I couldn't celebrate like other families could. As the day approached, it was a reminder of where she is and where she is not. I used to compare her to other kids her age. Then, when she regressed, things worsened for me. I internalized a lot of shame and guilt. My emotions were magnified but I concealed them from others, kept them secret. I often wondered, "Why can't I do this?". I guess, unconsciously, I thought I could make it go away...that we could somehow escape it. Forget fight or flight; it was flight-or-flight-faster. It was easier to keep everyone out and sometimes, it still is. But that's anticipatory grief. My husband got me out of that negative cycle. It's funny because he used to be the negative one! Now it's just a random Tuesday that I have a bit of a breakdown, but I can pick it up quicker these days.*

*Another crack I find it hard to ignore is the one that has arisen between us at times. Do you remember how determined we were near the end of Holly's last admission? She finally started to stabilize out and we got everything in place to go home. Then, it came out that a few of you were actually trying to stall, even*

*prevent us from taking her home. You have no idea how hard we work at being parents, and to have you say that?*

*After everything we have been through, don't you think we understand how these things work? We did everything you asked us to. We don't need you changing the map on us now. It feels like you're missing the whole point: that we know what's best for our family. We know our kid better than anyone else. We defer to you because you're the experts. You're the experts when it comes to genetics...to cardiology. Sure, you're the experts when it comes to all things medical, but don't for one second think that you are the expert when it comes to my child. That is where you defer to me.*

*As frustrating as it was to have people in your position doubting us, it wasn't the first time. We said, "we know what we're doing" and off we went. Because it's personal for us. We've had some big chapters in our lives. Yes, we know it's unknown and yes, we know it's going to be hard. We get it.*

*As I think about closing this letter, here's my take-away from these thoughts I've laid down and I hope they are your take-away thoughts, too. Your world is not our world. You can never truly know our world, but if you ask us, if you include us, we can bring you a little closer to our world. I will end this letter by saying, should you ever find yourself in our shoes, don't feel sorry for yourself. There's no reason to. Know that you can do it. We've managed to do it and we lead a pretty good life. It's not easy, but it's not impossible.*

*Signed,*

*Holly's mum, Leah.*



### **Story Three: Conversations Between Mothers**

To sit and share stories of experiences is a way of creating connections, giving, and receiving support. Sharing experiences in this way tells us about common and distinct aspects of our stories and helps to generate understanding and insight. This story is told as a conversation between five mothers: April, Beth, Leah, Bonni, and Brianna. In composing this story, four *conversational threads* became prominent. The threads are: *Under the Microscope*; *Not Knowing*; *Ableism and Labels*; and *Priority Shifts*. As I looked across the mothers' stories, I noticed how each of them described feelings of scrutiny, insecurity, being subject to social dynamics, and making adjustments to family life. As I thought about these stories alongside each other (Clandinin, 2013; Caine et al., 2015) I became attuned to the "conversational" nature of the segments when they were laid out next to each other. I found this to be particularly interesting and chose to further explore how these excerpts might come together to form a conversation and what the characteristics of this conversation might be.

As I wrote this story, I imagined the women gathered in a social space, perhaps a coffee shop, perhaps one of their homes. I see them drinking coffee, legs crossed or tucked underneath them on a sofa. I see them engaged with each other and sharing. Whereas the previous stories are composite stories, *Conversations Between Mothers* retains the individual characterization of the women who were in the study. Their words appear here as they were in their original transcript.

### ***Under the Microscope***

In this conversational segment, the mothers share their experiences of being *under the microscope*. They shared times when others judged them and times when they perceived that others were judging them:

*Bonni: People are like, "Control your kid!" ...Except it's my kid they're talking about. You gotta laugh or cry!*

*April: What are we supposed to say to them? I'm sorry for being us?*

*Bonni: One time, when we were leaving a store, I had one kid under this arm and the other one under this arm. There's staring, and someone's layin' judgement - it feels like everybody in the store and the parking lot and the next four blocks are watchin'. I'm just like, "I got this! Leave me alone! I'm completely aware of the situation that's going down!". People just don't understand the stress of constantly being under a microscope!*

*Leah: I know I'm being judged more. When my daughter first got her wheelchair, when we would go out, I felt like I had to smile and be friendly with everyone. I felt like people were judging me based on how polished I am. If I looked cross or cranky, I felt like I'd be judged: 'Oh, that poor, poor dear. She's got this special needs kid. Look at all that she has on her plate - that must be why she's not wearing make-up.'*

*April: You don't need to add extra shame on top of everything!*

*Leah: Like the one guy in Home Depot who came to talk to me and asked if he could pray for us...It feels like I'm letting down the special needs community by feeding some stereotype of the tired, sad mom who's overwhelmed.*

*April: It's like, 'I feel so sorry for you' - That's terrible. We don't want that.*

*Leah: It was almost a little victory when I finally let myself go out when I'm just looking like garbage and scowling at people. I was like, "I've finally reached the point that I don't care."*

*Bonni: This is us - take it or leave it! When I see moms of other kids, like, melting down, I say, "I see you. I've been there." I want them to know: "You got this, momma."*

### ***Not Knowing***

As much as being under a microscope implies a level of scrutiny and detail, being *under* the microscope means it is hard, in many ways, to see into and gain insight into one's circumstances. There were times when the mothers experienced feelings of insecurity and uncertainty. In exploring these feelings, the mothers reflected upon significant past milestones:

*Brianna: It all started for us with my pregnancy. We went for that detailed ultrasound, and that's kind of where...it was much more than, "I'm gonna have a girl." That's when we found out about her heart condition...we were getting these diagnoses and these probabilities... Now, while all these moms are sad, sending their kids off to kindergarten, like, "I'm gonna miss my baby!"—I'm, like, "Can*

*she even? Are we even gonna be able to get her to kindergarten?” It’s just very different.*

*Leah: We didn’t have any sort of clear picture of what...what life would look like for our daughter, so we were kind of prepared for anything from a mild disability – maybe just like some learning difficulties – up to, like one doctor mentioned, the possibility of two-hundred seizures a day, practically a vegetative state. Not knowing was...infuriating.*

*Bonni: My son had the umbilical cord wrapped around his neck. His oxygen levels were low, so I had an emergency C-section. Like, when he was born, the doctor said to me, “His birth weight is low– what did you do? Did you drink? Did you smoke?” I was like, “No! I took my prenatal vitamins! I didn’t do anything that would cause his birth weight to be low.” I guess, I hear these stories about traumatic births and how that affects development... and with his diagnoses... I really wonder...*

*Beth: When we found out that my son’s condition was genetic, they tested me and found out I... had it too. And then they tested my daughter, and she also has it. I didn’t know but I still passed this on to both of them; it just happened. That is the gift that I have given them... Sometimes I wonder, if my son didn’t have this syndrome, how would that be? I get that that’s guilt. I get that that’s unreasonable. But that doesn’t mean I don’t feel it.*

*Brianna: We don’t know the future. We don’t want to put her in a box, and say, this is all she’s going to be capable of, but at the same time, we can’t be naïve*

*about her future. If she does live to adulthood... We know that's gonna look different.*

*Beth: As my son becomes an adult, hopefully he's independent and living on his own 'cause I'm not gonna be there to do that stuff for him, right? I can only teach him the tools and, and I mean I'll obviously always be there to support him.*

*Brianna: We have a townhouse that we rent out, and we hope that maybe one day, if she can live on her own... I mean, we know that holding down a full-time job, and supporting herself is... probably not gonna be a possibility for her... but right now, we are already making preparations... preparing for all possibilities. It's both preparing for the worst-case scenario and the best.*

*Beth: It's like, my whole life has revolved around my children... when my kids go off independently, where does that leave me? And that sounds so selfish, but how hard is that transition going to be for me? I think I'll probably be okay because I'm aware that it's gonna be hard for me. Doesn't mean it's gonna be easy.*

### ***Ableism and Labels***

Although the application of a diagnosis was one remedy for not knowing, the mothers were ambivalent about the application of diagnoses and labels to their child.

*Beth: I have this love-hate relationship with the word, "disability". Having that label gets you things, but then having that label also doesn't get you things. Like, if I use the word "disability," then my son gets the accommodations he needs, but then, at the same time, people assume he can't do things. There's two problems with it: when people first meet him, they notice his disability and will assume that he's not as capable as he is.*

*Then, when they get to know him, they realize how capable he is but then they forget that he needs accommodations.*

*April: If you're gonna have a disability, it needs to be physical because if people can't see it, it doesn't exist. Having an invisible disability <sup>16</sup> is the worst...literally the worst thing in the world. Our daughter has a learning disability. She had been struggling for years, and I'd been fighting with the school about the fact that she'd been struggling for years. We fought for that diagnosis, then suddenly when it was written down on a piece of paper, we got a worker that comes a couple days a week and so much funding. Before it was written down for the school to see, she had been drowning...steadily drowning in her classes for years.*

*Beth: Hopefully over time, it will be easier to be heard, so, there'll be less negative experiences.*

*April: Even my friend, after her son got diagnosed with autism, she was actually super-frustrated with the amount of help she was offered because she had fought for it for so many years and gotten nowhere. And the moment the magic word came in, suddenly doors were opened to her that she had been fighting for for years.*

<sup>16</sup> An invisible disability is the disablement that a person experiences due to an impairment not obvious to the layperson in some or all settings. Examples of impairments that are invisible to others could be a learning impairment in reading, visual impairments in dim or dark settings, chronic fatigue or chronic pain syndromes.

Leah contrasted April's and Beth's experiences, emphasizing how she worked to overcome the label that others put on her son based on his physical disability. Leah concluded the conversation by offering some insights to how she focuses on the *normal*:

*Leah: Our daughter has a neurological disorder which causes seizures and hypotonia. She's not very interactive...I mean, She can't walk, she can't talk, she can't...she can, if we put something in her hand, she can hold onto it, but she can't manipulate it. So, for us, we try focusing on the normal...the commonalities instead of the abnormal. When children come up to her at the playground, I say, "She can't climb the monkey bars with you, but she can play catch with you!" Rather than just thinking about what she can't do, let's talk about what she can do.*

### ***Priority Shifts***

The experiences of the mothers reveal a kind of *looking back* and *looking forward* as they occupy spaces of not knowing. The mothers also reflected upon how they made changes over time to meet the changing needs of their family. They spoke about times they felt challenged by their role as the mother of a child with disability:

*April: A couple of years ago now, I ended up being off work for a month on stress leave. It wasn't just work stress; it was life stress.*

*Leah: One day it's just kind of overwhelming, and the next day it's not. I find it, like, waxes and wanes. Some days, I'll wake up and I'll look at her, and I'll just...wanna cry...because it's just not fair. And then other days, I wake up and I'm like, "Well, today we're goin' to the zoo."*

*Bonni: I remember we had, like, a little episode through the summer where we were having a really hard time. My husband just got a new job and he was really overwhelmed and was working 'til, like, seven-o'clock at night and trying to figure this all out. And I was trying to be there for everybody, y'know? I realized that I wasn't really right. I went to the doctor and I had postpartum depression. That's when we decided I would stay home for a year and my husband started his own business. We needed the flexibility to be there for our son.*

*Beth: It takes a priority shift in families like ours. Like it's either, you're in it together, or you're not. I don't think there's that polarization in other marriages.*

*Bonni: It can go both ways- It brings you together, or it just rips you apart.*

## **Conclusion**

This chapter has told three stories that are composed from research transcripts from interviews with families with disability. Together, the three stories--*The Morris Family*, *"To Our Healthcare Team,"* and *Conversations Between Mothers*--offer narrative insights into the everyday experiences of families and family members with disability. In the forthcoming chapter, I apply a postmodern comparative reading of the stories, in order to explore how the contrast between conventional and postmodern readings of the stories can help to generate new insights into family experiences with disability.



## CHAPTER FIVE – ANALYSIS OF THE STORIES

What can be told only begins to suggest all that is wrong.

--Frank, 2013, p. 99

In this chapter, I discuss the stories *The Morris Family*, “*To Our Healthcare Team*,” and *Conversations Between Mothers*, drawing upon conventional and postmodern narratives. The conventional reading is framed by dominant narratives that intersect with disability. The postmodern reading engages the stories in a more metaphorical and playful way, revealing different layers to the stories. The postmodern reading attends more closely to fragmented aspects of narrative and the potential value of these fragments for understanding in practice.

This chapter begins with the description and application of three dominant narratives to the stories: *The Chaos Narrative*, *Deficit Canon*, and *Paternalism*. I then apply a postmodern lens to the stories, showing limitations associated with conventional understanding. I offer three postmodern readings from the stories: “*To Have a Paddle and a Rudder*”; *Turning Points*; and *Different Sides of the Same Coin*. Because postmodernism is a response to the dominant narratives of modernity (Crotty, 1998; McAllister, 2001), the conventional narratives are addressed first before speaking to other, worthwhile stories of living in the margins (Rimmerman, 2012; Whittle et al., 2017). From this comparative reading, stories of living with disability can be taken up in new ways and alternative meaning-making from the stories becomes possible (McAllister, 2001).

## Conventional Narratives

In earlier chapters, I wrote about dominant narratives. Dominant narratives are the *big stories* that produce and reinforce power and privilege through a commanding storyline (Bacon & Lalvani, 2019; Phoenix, 2013) that confers authority on some to speak, while others are silenced. Dominant narratives act in a way that reproduces relationships of knowledge and power (Bacon & Lalvani, 2019) which means that some knowledge and experiences become privileged and others are treated as marginal. Dominant narratives act upon people, families, communities, and societies in ways that permit them to be taken as common sense, or their own truth. Put another way, dominant narratives have a quality of “taken for grantedness” that can make them difficult to question. Dominant narratives are thus, in many ways, familiar. Because a dominant narrative seems like common sense, challenging it can seem and feel like heresy. Alternatives to a dominant narrative might be difficult to argue for because alternatives lack the apparent stability, coherence, and continuity of stories that are more well established and authoritative (Estefan, 2008). While dominant narratives are big stories, they are also pervasive in a way that makes it difficult to detect where and how they are operating (Clandinin, 2013). In other words, these narratives are so common that they can “conceal” other, alternative ways of reading stories and experiences (McAllister, 2001, p. 392).

Dominant narratives mean that some disability experiences are more knowable and sayable than others. While conventional narratives create a sense of “shared lessons and resonate as true” for some (McAllister, 2001, p. 392), more recent literature contests the capacity of the single voice of dominant narratives to make room for less

conventional, more novel *small stories* (Phoenix, 2013). By applying a postmodern lens, subjective, multi-faceted, transactional sources of knowledge that feature in small stories can be tended to.

### ***Living in the Midst of the Chaos Narrative***

Chaos stories are among the most difficult to tell, hear, and understand. Chaos stories contradict the usual trajectory of stories; they have no clear beginning, no sense of an end, and they have no recognizable plot (Frank, 2013). The *chaos narrative* is difficult to hear because “it imagines life never getting better” (Frank, 2013, p. 97). Without some sort of “happy ending” or at least reparation, chaos narratives foreground and emphasize troubles. The chaos narrative moves back and forth between often impossible situations and circumstances without offering any sense of unravelling or resolution of complexity. (Frank, 2013). When people are caught in chaos narratives it can be difficult to manage circumstances or make sense of or meaning from experience. As a result, people living a chaos narrative of disability can struggle to gain coherence in experience.

When reading the stories in Chapter Four, there are moments where chaos is revealed. The Morris family moved to Alberta with the hope of accessing better services, but this did not eventuate for some time. Madison was a helpful and supportive sister to Callum, but just when the family felt they were “*gaining ground*” with Callum, Madison acted out more in response to further diminished attention. A chaos narrative shows movement but also reveals struggles with progress, forward momentum, or resolution.

The chaos narrative suggests that, despite encouragement to the contrary, it does not always get better. In her letter to healthcare providers, Leah said:

*...we did all the research and we read all the books. We learned it all. We were at her side every day. Still, every day was a letdown.*

In *Conversations Between Mothers*, April similarly shared how her life was not getting better:

*One day it's kind of overwhelming and the next day it's not... some days I'll wake up and I'll look at her, and I'll just...wanna cry...because it's not fair. And then other days, I wake up and I'm like, 'Well, today we're goin' to the zoo.'*

A chaos narrative makes it difficult to see past aspects of experience in these stories that position disability as troublesome, unrelenting, and perhaps impossible to resolve.

Chaos stories are difficult to tell and can be uncomfortable to hear (Frank, 2013). Chaos stories can create discomfort because they can be “too personal, too embarrassing or too frightening” (Smith & Sparkes, 2011, p. 39) and they tell “how easily any of us could be sucked under” (Frank, 2013, p. 97). In other words, they are stories of vulnerability and instability. For the mothers in the *Conversations Between Mothers*, in times of *Not Knowing*, the mothers exposed vulnerabilities and personal stories. Bonni shared that Callum *had the umbilical cord wrapped around his neck during a traumatic birth*. Her physician asked what she had done to cause her son's low birth weight. Although Bonni was able to defend herself to the physician, she later reflected on whether she may, in fact, be to blame for Callum's impairment.

Beth's story of her child's genetic impairment has no clear beginning. She (and at least one parent before her) carried the gene she passed to her son. Although she did not know she carried the gene that she passed to her son, she tells a story that betrays guilt that is difficult to resolve. She said, “*that is the gift*” she has given both of her children.

Bonni and Beth's stories are unsettling, uncomfortable, and very personal. For each of them, there is no "happy ending."

One of the advantages of narrative research that inquires into stories of experience is that stories are often told retrospectively. Frank (2013) argued that stories of living chaos can only be told at a distance (Frank, 2013) because in the midst of it there is no coherent way to organize the story. He went on to say that chaos, in the moment, can only be lived (Frank, 2013). It is in reflection and retrospection that stories of chaos can be told. Bonni reflected upon her living chaos during "*a little episode through the summer where [the family was] having a really hard time.*" She expressed the feeling of "*overwhelm*" that she experienced that summer. With distance from the experience, she realized she "*wasn't really right*" and learned that she had postpartum depression. Leah similarly shared a story of her living chaos when her daughter was first born. She shared that not having "*any sort of clear picture of what life would like*" for her daughter was infuriating. With some distance between then and now, both Bonni and Leah, were able to speak to experiences resonant with the chaos narrative.

Chaos narratives reveal vulnerabilities. Frank (2013) described these vulnerabilities using a metaphor of a wound. He explained that words can only circle the experience (wound) but could not ever fully move into it:

*What cannot be evaded in stories...is the hole in the narrative that cannot be filled in...cannot be sutured. The story traces the edges of a wound that can only be told around. Words suggest its rawness, but that wound is so much of the body, its insults, agonies, and losses, that words necessarily fail. (p. 98)*

In *Conversations Between Mothers*, there is a “telling around” of the experience of Brianna’s vulnerability in *not knowing*. Brianna spoke about how “*things all started*” when her ultrasound “*was much more than I’m going to have a girl.*” In this story, Brianna spoke around her experience; she did not share what specific “*things all started*” at that ultrasound appointment. Perhaps, here, she was trying to tell something that was untellable, too vulnerable to assign words.

### ***Deficit Canon, Readings of Living in Deficit***

Chaos narratives render experiences with disability as unsteady, uncomfortable, and vulnerable. A similar narrative that can be applied to the stories in Chapter Four is the *deficit canon*. Stories of deficit read that disability is the root of the problem for families with disability. As such, much research can be read as informed by deficit canon because it is disability (as deficit) that is central to researchers’ or writers’ endeavours.

In a literal sense, deficit refers to characteristics of a person that are deficient, dysfunctional, defective, inferior or incomplete<sup>17</sup> (Dinishak, 2016) while canon is a collection of socially influential works or ideas (Bates, 2013). According to Bates (2013), the term canon describes the most important and influential texts in a given time or place. As a composite of works, canon determines knowledge that is worthy of attention (Bloom, 1995), as well as what is valued or “accepted” across a given storyline or fictional world. For example, there is scholarship about Tolkien’s writing and its relationship to the canonical *fantastic*<sup>18</sup> of the twentieth century (Shippey, 2000;

<sup>17</sup> Note that, like the medical model of disability, the deficit canon equates disability and impairment. Since the canon does not consider the social aspects inherent to disability, I will use the term disability in this section.

<sup>18</sup> Fantastic is a literary mode that arose in response to the dominance of positivism. It foregrounds the ambiguous, marvellous, and other-worldliness.

Whitehead, 2008) as well as other debates about more recent fictions such as the science fiction worlds of Star Trek and Star Wars (Geraghty, 2005; Kies, 2011). The literary canon regulates, creates rules and norms, and becomes a “yardstick” for evaluating other literary works (*Literary Devices*, n.d.), legitimating what belongs in a collection of knowledge.

Disability as deficit is a common narrative in academic literature and other non-scholarly commentary on disability (Dinishak, 2016). Influential deficit stories in the literature have, over time, bound people with disability to narratives of ill health, sickness, difference, and deficiency (Sutherland et al., 2009). The person with a disability becomes an “object of fascination,” whereby the person, their behaviour, attitudes, and condition are conflated and totalized as being in deficit to an idealized, able-bodied norm (Goodley & Runswick-Cole, 2012, p. 62). Leah’s account of being “*introduced to disability practically before we were even introduced to [our daughter]*” says something about the power of deficit narratives to cover over other stories such as those of new motherhood. In Leah’s story, deficit was centralized by the healthcare team more than other aspects of her new experience. Later in her letter, Leah wrote again about disability as deficit when she said, “*I couldn’t celebrate like other families could. I hated her birthday. As the day approached, it was a reminder of where she is and where she is not.*” In composing her story in this way, Leah draws upon her experience of being different because of something “less than” an ideal.

In a practical (or practice-oriented) sense, the deficit canon makes disability a site for intervention. Where a health deficit exists, providers are expected to respond. Therefore, health and social care providers routinely intervene in the lives of people

living with disability (Goodley & Runswick-Cole, 2012). Intervention is not always a solution to deficit, however. Diagnosis, for example, can clarify the nature and severity of deficit, but diagnosis alone cannot resolve it. Nonetheless, diagnosis activates services that can reduce burdens associated with care (Goodley & Runswick-Cole, 2012). Before Leah's daughter was diagnosed, she was in a state of confusion. Leah's family "*didn't fully understand what was going on with [their] daughter.*" Receiving a diagnosis replaced ambiguity with some clarity (Harry & Klingner, 2007).

Although it might be expected that families might resist living according to a deficit narrative, this is not always the case. The deficit narrative has become powerful by being taken up in institutions of medicine and health and social care practices. Put simply: to receive care, deficit must be demonstrated. As April illustrated:

*[My daughter] had been struggling for years, and I'd been fighting with the school about the fact that she'd been struggling for years. We fought for that diagnosis, then suddenly when it was written down on a piece of paper, we got a worker that comes a couple days a week and so much funding. Before it was written down for the school to see, she had been drowning...steadily drowning in her classes for years.*

With the diagnosis, she now had all the services and resources she needed; once her daughter's deficit was substantiated, ambiguities about what would happen for her daughter were (at least for the time being) resolved.

Many authors have found the use of a deficit-based lens problematic (Dinishak, 2016; Goodley and Runswick-Cole, 2012; Harry & Kingner, 2007; Sutherland et al., 2009). Deficit stories have the power to reduce a person to a diagnosis (Harry & Kingner,



2007), undermining personhood and agency for families with disability (Sutherland et al., 2009). The deficit canon opens up the lives of families with disability to critique and action by interventionists, such as health and social care providers. Although deficit stories make room for an account of social and cultural factors that cause or contribute to disability (Harry & Kingner, 2007), dominant narratives of deficit remain individual rather than social. Inquiry that sets out to foreground how social and cultural factors give rise to disability are less influential than the more authoritative narratives derived from the application of positivist science. Sutherland et al. (2009) warned that when people think about disability as a deficit, they “turn away” and make invisible the institutionalized negativity and the complexities of the experience of disability that cannot be described by deficit (p. 704). The deficit narrative is a “phenomenon of missing discourses” (Sutherland et al., 2009, p. 703); it emphasizes certain (deficit-based) aspects of experience, while overlooking other, more nuanced aspects of subjective experience.

The stories in Chapter Four show that, even in the midst of difficulties, there are positive, beneficial, and adaptive relational, familial, and social experiences. The deficit canon makes little room for pleasure or joy (Goodley & Runswick-Cole, 2012). It overlooks adaptation and successes that happen in discreet and local contexts (Dinishak, 2016; Goodley and Runswick-Cole, 2012; Sutherland et al., 2009), keeping attention focused towards problems. To illustrate, below is a summary of The Morris Family story, using a deficit narrative.

***The Morris Family: In Deficit.*** The Morris family is made up of Bonni, Jim, and their children Madison (from Bonni’s first marriage) and Callum. Madison shares only 50% biology with her half-brother, Callum. Callum has autism, Madison does not. She is

smart, performs well in school, and is compassionate, flexible, and adaptable. Madison has lost social and academic opportunities because of the attention and resources Callum needs. Madison mostly copes well, but her life is difficult because of her brother's autism.

Callum's disability means his parents and sister have to make significant behavioural and social adjustments around him. Callum is routine-oriented but can also be unpredictable. He prefers playing alone with toy trains, a long-standing preoccupation. When Callum does join family activities (like family dinner), his engagement is poor, likely due to comorbid attention-deficit hyperactivity disorder.

Callum has autism and it remains unclear how far he will develop. Callum is unlike Madison in that he does not learn information quickly. He is also not able to apply information without repetition. To contain Callum's behaviour, Callum needed to be separated from the other children in his classroom. Callum's school staff felt that Callum was too much of a challenge to join in on field trips as he was not successful at these times in the past. In time, Callum was usually removed from school as he was too difficult to manage.

Bonni and Jim struggle to maintain friendships, partly due to Callum's behaviours. There have been similar family tensions. Bonni and Jim have felt powerless. Bonni has spent much of her time managing Callum's high needs and Jim had to leave his job to assist in caring for Callum. Bonni and Jim both sought counselling to talk about their mental health, specifically, their feelings of frustration and carer burnout. They have described numerous burdens associated with caring for Callum.

Bonni and Jim looked to health care providers to help explain what was wrong with Callum. He was diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder and, later, autism spectrum disorder. Equipped with this new diagnosis, Bonni and Jim enrolled Callum into a new school in a new province. The diagnosis helped get services and they found a teacher able to manage Callum and teach him how to manage some of his emotions and behaviours. Equipped with this new diagnosis, the Morris's finally felt they were gaining ground.

***Paternalism, Readings of (Dis)order in Relationships***

In this conventional reading, I discuss how what I refer to as the paternalistic narrative shapes understanding of the ways relationships between families with disability (the patient) and health and social care providers (the provider) are meant to occur. The paternalistic narrative confers authority upon providers and expects patients to submit, to varying degrees, to that authority (Hagerty & Patusky, 2003; Rees et al., 2007). The paternalistic narrative therefore serves to create and maintain order to the provision and receipt of health and social care. Order is achieved when the parties act in their respective dominant and subordinate roles (Hagerty & Patusky, 2003).

The idea that a paternalistic narrative influences health care is not new. Health and social care providers have a history of paternalistic relationships with patients (Hagerty & Patusky, 2003; Rees et al., 2007). On the surface, the paternalistic narrative implies that the provider and patient engage in a relationship with a shared goal to restore and maintain health for the patient (Rees et al., 2007). While this is not an unreasonable aim, the paternalistic narrative prescribes that relationship as the provider imparting their knowledge and expertise upon, while the patient is a dependent recipient of that expertise

(Rees et al., 2007). The paternalistic narrative imbues providers with expertise and patients with expected characteristics of deference, gratitude, cooperation, and even compliance (Rees et al., 2007). When patients resist the conventions of the paternalistic narrative, they take risks. As Leah described in her letter, when she and her husband wanted to take their daughter home from hospital sooner than was recommended:

*Then, it came out that few of you were actually trying to stall,  
even prevent us from taking her home...*

*We said, 'we know what we're doing' and off we went.*

This was a particularly difficult moment for Leah and her family. This illustrates something of the nature of relationship breakdowns within a paternalistic narrative. The paternalistic narrative prescribes that, for patient-provider relationship success, both the provider and the patient must fulfil these role expectations and responsibilities (Hagerty & Patusky, 2003; Holmström & Röing, 2010; Rees et al., 2007). In another interview, a father shared times when their providers did not seem to be acting in their best interest. He shared about a time when the provider-patient relationship broke down:

*Well, the other joy of it is- let's say that you're a doctor...  
you're aware of the fact that as soon as you put a particular label on someone,  
all of the funding comes with it.*

*And so, you start guarding it like it's pirates' treasure.*

*The doctor's like, 'I wanna see a little bit more', so we're like, 'this child's five and non-verbal.'*

*'Rebook in three months' doesn't help anybody.*

In this excerpt, the father shows how he and the provider did not seem to share the same goal. He speaks to the provider guarding the family from obtaining what they sought in the appointment, in this case, his daughter's diagnosis. The father further explored how their providers did not perform their role in the relationship:

*The entire goal is for them to put as much of it as they possibly can on us.*

*And if we break,*

*then they try to glue the pieces back together.*

*It's, like, a puppet game.*

*It's like...watching a dog fight.*

*Let's throw them in the ring*

*...and we'll see who comes out on top.*

This abrupt expression from the father tells of his frustration with the provider-patient relationship. It tells of how, when the family accepts the recipient-of-care patient role, the paternalistic narrative can become self-reinforcing by perpetuating the view that the family is the likely reason as to why the relationship is not functioning.

For the father above and for Leah, it felt like providers acted upon, rather than alongside the family and their needs. In the letter, Leah shared how the provider-patient relationships did not meet her expectations:

*We defer to you because you're the experts....when it comes to genetics...to cardiology...*

*but don't for one second think that you are the expert when it comes to my child.*

*That is where you defer to me.*

The paternalistic narrative challenges who we see as the expert and when. In the stories shared in Chapter Four, I framed the mothers' voices more prominently than the fathers.

Alongside my own sense of being drawn to mothers' voices, this was also a reflection of how the mothers took up roles as leaders and navigators for the families. This seems to challenge the "doing for" or "acting upon" that sustains paternalistic narratives, in which women are expected to take up more passive roles (Farkas & Leaper, 2016). Instead, the mothers in this study took up active roles in their families as leaders, navigators, and advocates, and were supported in these roles by their partners. As one father put it:

*For my wife. it's a little bit different...she's all about advocacy.*

*It really sticks in her jaw for a while.*

*Advocacy is borne out of frustration and anger.*

*She is a natural-born advocate. She doesn't let stuff slide, which I love about her.*

The paternalistic narrative assumes women as primary carers, but the experiences of some families in this study were in contrast to this. Two of the families considered the father to be the primary, hands-on carer for their child with disability, while one family shared this primary caring role. The other two families saw the mothers as the primary carers. For three of the families, the mothers shared how they started as primary carers and found the role of carer and navigator to be overwhelming. The mothers turned to their partners to flex their role within the family. For two of these three families, this meant that the father quit his job as an employee and turned to self-employment to be available and have flexibility to meet his family's needs. For the remaining family, the mother wanted to stay home, so the father shifted from staying at home to working full-time to support the family. As Bonni said in *Conversations Between Mothers*:

*And I was trying to be there for everybody, y'know? I realized that I wasn't really right.*

*I went to the doctor and I had postpartum depression.*

*That's when we decided I would stay home for a year and my husband started his own business. We needed the flexibility to be there for our son.*

In any given episode of care, the paternalistic narrative dictates who leads and who follows. Patients who transgress these relational expectations have been labeled oppositional, uncooperative, and non-compliant (Vivian, 1996). The paternalistic narrative makes the stakes high for patients seeking care (Scarlett & Young, 2016). As Leah's story shows, transgressions of the rules for provider-patient relationships can complicate the receipt of care that is helpful and effective (Vivian, 1996). In *"To Our Healthcare Team,"* Leah initially acted in a subordinate role as patient by expressing her thanks to them for their care, direction, and pragmatic support. Later in her letter, Leah adopts a different tone, in which she more strongly asserts her concerns at how she was positioned. This choice can be read as a bold and assertive choice, but one is also left to wonder whether it was entirely wise.

*The Morris Family* story reveals how the paternalistic narrative can fail both patients and providers. Jim shared, *"Then the specialist says, 'well, it's just really complicated.' I wish they would have said, 'Y'know what, we are kind of confused. Let's see what we can work on together. Let's build his capacity.'"* The Morris' left this meeting without what they needed from their health and social care provider. Their story shows they sought direction and what they wanted, apart from a diagnosis, was an open acknowledgement of not knowing from the provider.

A conventional reading of the stories in Chapter Four helps to compare the experiences of families to what is already known about disability experiences. What is notable is that, under these circumstances, the families' stories service existing

perspectives. That is, their stories can be used to substantiate and illustrate existing theory and commentary, even though they also challenge various health and social care practices. The conventional reading serves as an illustration of current experiences and practices and also as a call to action to explore alternative narratives that reveal the richness and texture that exists in families with disability.

### **Postmodern Readings**

...the ‘self’ is not a unitary, but a fragmented being.

--Manchón, 2000, p. 469

A postmodern reading is a departure from the conventional. From a postmodern perspective, stories that seem to be straightforward and direct are more complicated and multi-layered (McAllister, 2001). Postmodern readings therefore replace coherence and certainty (or apparent clarity) with uncertainty and generative ambiguity. A postmodern reading moves away from the authority of “objective” knowledge and towards more alternative subjectivities and experiences (Crotty, 1998). Postmodern readings move away from the big stories and tend to the smaller, local, and particular stories lived and told in and about daily life. A postmodern perspective means many different stories can be told, and that any given story may contain multiple and seemingly ill-fitting meanings (Alvesson, 2002; McAllister, 2001). Some aspects of stories are personal and even temporary in their relevance (McAllister, 2001), but they are nonetheless influential in how life is composed and spoken about. Surfacing more personal, local, and “unstable” meanings makes possible different understandings that might resonate with others in similar circumstances (McAllister, 2001; Clandinin et al., 2018). A postmodern reading is



disruptive and challenges the order and explanatory authority of conventional narratives like the Chaos Narrative, Deficit Canon and Paternalism.

***“To Have a Paddle and a Rudder”***

In the Morris Family story, Jim invokes a metaphor of sailing in order to explain something they hoped to achieve for Callum:

*I don't want him to be a rubber tube floatin' down the river.*

*I want him to have a paddle and a rudder.*

Lakoff and Johnson (1980) suggested that the use of metaphors is helpful in sharing experiences that might be difficult to relate to; they described how metaphors help to make things that are strange seem familiar, and to render things that seem familiar, more strange. Metaphors “...can give new meaning to our pasts, to our daily activity, and to what we know and believe” (Lakoff & Johnson, 1980, p. 128). Metaphors help to make sense of and relate experience to others. Metaphors, then, are both a subjective truth (they offer insight into experience) and the means of linking that truth to a network of language in which different people operate.

Jim's statement about wanting his son to have a paddle and a rudder helped him to share important sentiments about his hopes for his son. Jim wants Callum to be equipped in his daily life: for him to know where to go and to have what he needs to get there. In a conventional, perhaps literal sense, a paddle is a tool that Callum might use to propel himself forward. A rudder is a means for Callum to steer as he gains forward momentum. With a paddle and a rudder, he has a greater chance to get where he is going. Jim uses the paddle and rudder metaphor to make his own experience of parenting, and worrying about, Callum accessible to others. It would be easy to skate over the surface of Jim's

metaphor, drawing only from it that he wants Callum to have the resources to live well. Metaphors can, however, provide deeper insights into how the world is perceived and the ways one acts and relates to others within the world (Rees et al., 2007).

The paddle and rudder metaphor makes knowable more about the relationship between Jim and Callum. It says something about Jim's hopes for success for Callum in his future. At certain times, paddling is easy amid a gentle current, at other times it can be harder to maintain direction forward momentum. Perhaps Jim understands that Callum will navigate both easy and difficult waters in the future and he wants him to be able to maintain stability, be equipped, and possess ongoing capacity for self-sufficiency.

When a person uses a rudder to steer a vessel, this involves (to greater and lesser degrees) the exercise of choice. At times, some directions are taken out of necessity and for survival. At other times, people choose directions because they are pleasing, rewarding, or even unknown and challenging. The paddle and rudder metaphor says something about Jim's hopes for Callum to be able to steer his own direction, even in the face of challenge or adversity.

A person who steers a vessel on water is only ever partially in control. The natural environment, as well as others who are along for the ride, are always considerations. In the context of living with disability and negotiating disability services, people arguably experience poor weather conditions and turbulent waters. Callum is still vulnerable to the environment around him. As a person living with disability, his claim to be able to steer may not go uncontested. Others, such as health and social care providers can act like winds of change, influencing (subtly or not) the directions he is able to take and the time it might take to reach a preferred place.

It is important, then, that health and social care providers, as well as family, work to build rather than diminish Callum's capacity. On a personal life journey such as Callum's, providers as well as families can act as harbingers of disability. Just as the first frost of a season heralds the onset of winter, those who (with good intent) go before Callum to smooth the waters also signal that disability soon will follow. Perhaps, then, Callum, too, might need to learn how to work his rudder in a way that takes advantage of and resists the "current" of family support and health and social care intervention.

### ***Turning Points***

The telling of stories in one way that people create continuity in experience. That is to say, stories tell of things that happen alongside other things that happen (Clandinin & Connelly). Although stories convey a sense of the passing of time, the sense of continuity that is created is, for postmodernists, an illusion. Instead, the passage of time, and experience that happens within that time, is populated with the events that are more random, but pieced together in storytelling as people try to make sense of what is happening. Nünning and Sicks (2012) argued that the randomness of experience is not necessarily a dramatic experience; they suggested "change takes place by means of gradual transformations, consisting of continuities and discontinuities" (Nünning & Sicks, 2012, p. 1). *Turning points* are subtle moments or more profound ruptures in experiences that can be located through retrospection (Nünning & Sicks, 2012, p. 2). Turning points, when explored, reveal themselves as unusual experiences that can lead in unexpected directions.

The families' stories reveal interesting turning points in their experiences. Nünning and Sicks (2012) described turning points as "an explicit and sudden rupture, or

as a gradual re-vision of perspectives” (p. 2). Turning points happened for the families in moments that were both ordinary and profound. Some turning points happened in discrete moments and others emerged over time.

Leah described a turning point for her when she described how she “*reached the point*” that she no longer cared what others thought of her personal appearance while out in public:

*I’ve finally let myself go out when I’m just looking like garbage.*

Leah’s statement here reveals something of the scrutiny she felt as an object for public consumption. As a woman and mother of a child with a disability, Leah refused to be unseen because of the judgment and assumptions (whether real or imagined) that she felt from others.

*When we would go out... I felt like people were judging me based on how polished I am.*

*“Oh, that poor, poor dear... Look at all that she has on her plate-  
that must be why she’s not wearing make-up...”*

*It feels like I’m letting down the special needs community by feeding some stereotype  
of the tired, sad mom who’s overwhelmed.*

This turning point reveals the multiple layers of personal stories. This is a story of parenting a child with a disability, but it is also a story of women and of a society that judges and evaluates women based on their appearance. As such, this is not a singular story, but an intertextual (Kristeva, 1989; McAllister, 2001) telling of the complexities of negotiating different aspects of identity alongside the pragmatics of parenting. Through this story, Leah shows her capacity to resist, but her expression of feeling like she’s

letting others down also conveys something of the power of dominant social narratives to impose identities like “the good mother” (Smith et al., 2018).

Thinking about this turning point for Leah calls into question whether it is possible to access her subjectivity, who Leah “really is.” Leah’s story is told alongside and organized by other narratives of disability, women, and mothers. Leah grapples with social norms and describes an act of resistance that draws attention to her as the subject of the story. Perhaps, though, by adopting a postmodern practice of decentering the subject (Beetz, 2016) it is possible to open up the possibility of a broader critique and discussion about how multiple storylines coalesce within individual experience and shape and disrupt identity.

Other turning points were identified by the families. They storied times when tensions ran high between parents, challenging their relationship and pushing them to make a *priority shift*. These times were charged with emotions and required the parents to make adjustments to the ways they care for themselves, their child, and their marriage. April identified “*life stress*” as a precipitating factor while Bonni described “*overwhelm*.” The building up of life stress resulted in turning points for the families where they made space for new opportunities like changing places of employment, staying home with their child, and choosing to prioritize their family.

Another turning point was shared by Leah in the letter to her healthcare team. Unsettled in the early years of her daughter’s life, Leah shared that they “*have come a really long way as a family*.” Titchkosky (as cited in Mercer, 2003, p. 238) stated that “disabled people learn that they must assimilate an outsider view of [disability] in order to be rehabilitated.” Leah’s story says something about how this also works for families,

in that they reached a turning point realizing they needed to first subscribe to the medicalization of disability and accept care in the way it is offered.

The assimilation of the outsider view involves acceptance and compliance with dominant narratives. These narratives privilege the knowledge of health and social care providers, but healthcare is not “unambiguously beneficent” (Bury, 1997, p. 2), nor are providers necessarily the most knowledgeable about a family’s needs or circumstances. “Expert” provider solutions to family problems are “a product of an intelligent and a rational approach” (White & Taket, 1994, p. 734). The expert is seen as a specialist in a particular set of knowledge, using “reason and science” to enlighten people with solutions (White & Taket, 1994, p. 735), but the participants’ stories also reveal providers’ solutions or interventions as sometimes disconnected and dispassionate.

Perhaps one answer lies in yielding some of the certainty and authority of dominant narratives, to stories that are more local and particular. As Bury (1997) stated, it might be helpful to:

...transform modernity’s reliance on expertise and the ‘docile’ body into a more fragmented and less authoritative scientific voice on the one hand, and a more active and sometimes resistant stance of the lay person on the other. (pp. 11-12)

In a story of both cooperation and resistance, Leah assimilated herself into the world of healthcare. She balanced the demands of mothering, caring, and navigating the complexities of Holly’s health as she became more and more “fixed” by and within the healthcare setting. Leah worked to “cut the cord” between the healthcare team and Holly to reclaim her position as carer of and expert about her own child. Although the choice to discharge and leave the hospital care environment was one of “sudden rupture” (Nünning

& Sicks, 2012, p. 2), the decision to leave against medical advice was a more subtle turning point, perhaps a growing recognition of her own expertise.

### *Different Sides of the Same Coin*

I have used the phrase “different sides of the same coin” to refer to times when families turn away from some aspects of their experience while also leaning into other, sometimes conflicting aspects. When it came to diagnosis, Beth explained:

*It gets you things,*

*but then having that label also doesn't get you things.*

Beth's family leaned into diagnosis on the one hand because it enabled services and funding. They were also cautious of the social implications of receiving a diagnosis. *Different Sides of the Same Coin* shows something about how turning points are not simply a transition from one thing to another, or from one state to another. Instead, turning points can involve complex negotiations, compromises, new tensions, and choices about where and upon whom to focus attention. Bonni shared a story about Callum that showed new tensions in one of Callum's turning points:

*He's praised for how well he can express his emotions now,*

*but... it also comes with high expectations.*

The high expectations Bonni referred to reveals multiple layers of their family's story. There are high expectations *on* Callum and also high expectations *for* Callum. These expectations are applied differently by different people in Callum's world, and with expectations comes the caution in Bonni's words: that the expectations create a new, different kind of unease.

In this story, then, there are what Fairfield (2001, p. 226) referred to as different “modes of subjectivity” at play. Callum and his family are changing in relation to each other, learning more, and “being” together differently as they continue to engage with school and health and social care providers. The individuals and the family unit are not encapsulated. Jim, for example, is not just Jim. He is “dad Jim,” “husband Jim,” “husband Jim who is Madison’s dad,” “dad Jim who is Callum’s advocate,” “discussion board Jim who needs support,” and “supportive husband Jim” to name just a few of the many permutations of Jim’s modes of subjectivity.

Similarly, for Bonni, there are different sides to the coin of being a mother. Mothers have distinct roles in families. The lived experience of a mother is singular--it is her experience--yet it also contributes to shared experiences as part of the broader social construction of motherhood (Caesar, 1995). Bonni said:

*When I see moms of other kids like, melting down, I say,*

*“I see you.*

*I’ve been there.”*

*I want them to know: “You got this, momma.”*

In this part of her story, Bonni is both a mother of a child with disability, who struggles with her own son’s meltdowns and difficult behaviours. She is also able to recognize the capacity of herself and others to respond and manage in complex situations involving a child’s behaviour.

Bonni’s experience here shows how intrapersonal and interpersonal dynamics are rarely one thing or another: this or that. Bonni is not simply coping or not coping, but instead she occupies a more dialectical position in which she experiences many states. A



dialectic can be thought of as the state (or tension) created by opposing forces (*Merriam-Webster*, n.d). One notable dialectic that has been written about in relation to mental health provision is *acceptance and change*<sup>19</sup>. This dialectic is revealing in that it relates to the complexities and tensions that arise when a person might need to experience self-acceptance while simultaneously making conscious effort to change (Cunningham et al., 2005; Meyers et al., 2020). When applied to health and social care, dialectical perspectives can reveal interesting insights into identity, personal and social practices, and provider responses.

The experiences families in this study described suggest they live within a dialectic of resilient vulnerability. Resilience is a trait that enables coping and recovery from adversity and it applies to individuals as well as to other social entities and units such as families and organizations (American Psychological Association, 2012; Miller et al., 2010). On the surface, resilience is a desirable attribute because it can help buffer against a variety of stressors and adversity. The concept is, however, also problematic because resilience can be equated with positivist, Western ideals of capable, well, and “resilient” individuals (Hutcheon & Wolbring, 2013). In other words, resilience theories do not account well for context and difference (Hutcheon & Lashewicz, 2015).

The families in this study (as family units) and family members (as individuals) are neither entirely vulnerable, nor resilient. The families showed fragments of vulnerability in stories of raw moments when their experiences of living in the margins or

<sup>19</sup> I use this example to illustrate a dialectic because it is a clear description of a tension. I do not intend to imply any relationship between experiences of disability and mental health problems.

being marginalized became overwhelming. Yet, within these moments, it is possible to locate resilient individual and family practices that were sustaining and reinforcing for them. These practices are shown in the stories as moments of meaning making or making sense of experience, another way of thinking about resilience (Antonovsky, 1979; Meyers et al., 2020) as well as a resistance to non-acceptance or misunderstanding they encountered. The families' stories say something about how they work to overcome and build resilience alongside that vulnerability.

The narrative practice of looking sideways or, in postmodern terms, decentering the subject, opens up a different perspective on families' experiences: that their resilient vulnerability/vulnerable resilience was composed alongside engagement with services (health, social care, and education) that were also vulnerable. The families stories help to resist the idea that services are obvious sites for support and building resources. In many instances, the stories show services to be unhelpful, lacking insight, and limited in their capacity to care and understand. As such, the families' stories leave us with the discomfort of knowing that answers to disability-related questions and solutions to disability-related problems might not lie in expected, authoritative places but, instead, in the very local, particular, and ordinary experiences of people, engaged in living with, or in the context of, disability.

## **Conclusion**

In this chapter, I have contrasted conventional readings of the families stories, drawing upon dominant narratives, with a postmodern reading of the stories that emphasises multiplicity of meaning and identity. Postmodern readings are disruptive and emphasize fragmentation of experience and identity. As such, they open up experiences

but do not attempt to create coherence, settle, or pacify the anxieties this may cause in a reader. In this chapter, the postmodern reading offers different insights, but they are not definitive or complete. Even so, they represent an opportunity to think in new ways, and to surface experiences that may have resonant capacity for others (families with disability and those who care for them) in similar circumstances. In the next chapter, I conclude this research by exploring what knowledge might be taken from this research and applied in future practice and inquiry.

## CHAPTER SIX – CONCLUSION

In this chapter, I summarize the findings and discuss the implications arising from the current study. I discuss these implications in terms of health and social care practice, ongoing inquiry, and the structural and institutional factors that shape disability experiences. I address the strengths and limitations of this study and conclude by making recommendations for practice, policy, and research.

Stories shape and also tell of experiences. Stories make some understanding possible, credible, and believable and other understanding less so. This was a narrative study, designed to evoke experience. The intent for this research was to show something of the worlds of families living with disability and also to analyze that experience in ways that help to challenge and expand insights and understanding. Families with disability live amid dominant storylines that provide a boundary or scope for how and what can be told about their experiences. A postmodern challenge to dominant narratives reveals more novel aspects of family life in the context of disability. Such a challenge is one means to assist health and social care providers to explore experience, consider alternative ways to understand the experiences of families with disability, and to venture into the complexities of life that might be covered over by more dominant narratives.

In this research, I set out to explore the everyday experiences of families living with disability. The existing research that informs health and social care are helpful in understanding the health outcomes that families with disability experience as well as the times that families with disability access care (i.e., times of distress, when disability is complex) and what general approaches to care that they find effective (i.e., coordinated,

empathetic, ongoing). However, the existing research lacks a depth of insight into the particularities of life with disability.

Three composite stories were written from interview data and read against dominant and postmodern narratives. The comparative reading shows family life with disability is multifaceted, multi-layered, and involves the negotiation of family amid competing relationships and subjective identities and experiences. The influence of dominant narratives of disability, health, and social care make the richness and complexity of family life difficult to apprehend. The conventional reading revealed the ways that chaos, deficit, and paternalism organize the telling of stories and the experiences of participants.

The discussion in Chapter Five offers insights for health and social care providers by revealing something else that lies underneath stories of chaos, deficit and paternalism. The particular, local, or “small” stories being lived in the midst of dominant narratives are powerful and suggest that health and social care providers find ways to explore these stories more deeply, to not settle for a surface reading. By interacting with the stories that families tell, health and social care providers can question the ways they have come to understand disability through their experiences in their lives and in their training. Being able to participate in narrative retrospection alongside families might mean that providers can engage families in more meaningful ways, inquire alongside families into their experiences and needs, and offer care that is sensitive and responsive to complexity.

### **Implications**

The findings in this study emphasize the less conventional, novel stories that families with disability tell. As health and social care shifts towards more individualized,

subjective, and equal (power sharing) relationships (at least in intent), families with disability will be expected to become more active participants in their care. While this study suggests that families possess knowledge, skills, and attributes to participate in this kind of model of care, the expertise of the family is also a challenge to dominant stories about the legitimate authority of providers. As families become more involved in power-sharing relationships, providers will need to cultivate wakefulness to why patient participation might appear or be interpreted as resistance. It will also benefit providers if they are able to intentionally look to families' stories as legitimate and valuable sites for knowledge for how to practice.

At a practice level, some of the implications of this work are that providers may benefit from considering alternatives to problem or deficit narratives. Providers might approach care in a way that is non-pathologizing and looks for new possibilities and means to inquire into the experiences of families with disability.

Through storytelling, patients can share with their health and social care providers sites of tension, provocation, pleasure, and joy. In other words, stories offer context for behaviour and action and can serve to clarify relationships and actions in caring contexts. Knowledge gained from patients' stories can reveal gaps in care, limitations to existing policies, or offer insights into the need for new policies and practices. Narrative research provides fertile context to "stimulate policy inquiries" as well as to propel advocacy and discussion about policy effectiveness (Fadlallah et al., 2019, p. 18).

There are political implications to narrative research. As is the case with this study, stories of experience challenge historical, traditional, and conventional stories. Storytelling disrupts authority of grand narratives, showing the possibility of local and

contextual difference and diversity. Although I have used the term *disability* in this study, the research has also shown that disability experiences can be as diverse as they are alike. Where diversity and difference can be shown, it becomes possible to activate resources and advocacy to meet the needs of those whose stories have been hidden, marginalized, or obfuscated.

### **Strengths and Limitations of the Study**

This research is a narrative study, drawing upon principles and practices of narrative inquiry and narrative analysis. This narrative study proceeds from the perspective that experience is a legitimate source of knowledge (Dewey, 1938). I drew on the ontological-relational commitments of narrative inquiry to study and faithfully represent experience, and the analytic practices of narrative analysis to explore new ways of understanding stories. The combined approach in this research makes room for depth of engagement with stories of experience, and an analytic practice that attends to disability experiences in novel ways.

In narrative inquiry research, researchers inquire into people's lives and tell stories of their experiences. Through a longitudinal, relationally driven approach to research, narrative inquiry approaches enable the researcher to co-construct stories of experience. However, there exists a tension between thinking about story as a living text and story as a unit of analysis. For narrative inquirers, stories cannot be reduced to a research transcript. To do so separates analytic thinking about experience from the experience itself. That is, narrative inquiry finds importance in returning to the life being

lived alongside the research efforts to make sense of that life. Techniques of narrative analysis call for a different view than narrative inquiry. Narrative analysis sees each story as its own site, rich with analytic and interpretive potential but does not reconcile this in the same way that narrative inquiry does: it does not return to the life being lived to make sense of it.

In the writing of the dissertation, I sought to maintain something of the relational obligations of narrative inquirers, by attending closely to participants' experiences and writing the composite stories in a way that enables the richness of their lives and experiences to be shown. Similarly, I drew upon tenets of narrative analysis to engage with the participants' stories before taking a postmodern perspective on the stories in order to look beyond the obvious.

As in any qualitative study, the study findings are not generalizable to all people and families with disability. As found in the study, the experience of life with disability is varied between cultural contexts and understandings. Different families' stories can be read in conventional and postmodern ways, but these readings will not necessarily come up with results that are consistent with that I have found in this study. In this study, for example, the families interviewed were all white, presumably middle class families. This study does not specifically address the intersections between race and disability, nor did any other families represent other minority groups such as those in the gay, lesbian, and transgender community. The results of this study should thus be read according to this limitation. What the study does is it brings attention to specific experiences across life



with disability that these particular families expressed. It brings to light, in a different way, the social phenomenon of disability and critiques sweeping assumptions that might be made about living with disability.

Although it was not my intent to represent only white, presumably middle class married couples with children, I am aware that aspects of the research process influenced sampling and recruitment. Because of funding limitations for this study, one of the inclusion criteria for the study was that the family must write and/or speak fluently in English. This likely contributed to the singular family type that expressed interest in participating in the study. Requiring fluent written and verbal use of the English language was likely to limit the participation of families with more diverse ethnicities and cultural backgrounds. Another consideration is that families from more diverse backgrounds might view and understand disability in different, sometimes unfavourable ways. As discussed earlier in this dissertation, some non-Western cultures do not have terminology to describe “disability”; instead, describe their particular impairment. Increased cultural sensitivity through such means as availability of translation and transcription services, for example, might lower the barrier to entry for families with more diverse backgrounds to participate in studies like the current one.

Another aspect that might have inadvertently influenced sampling and recruitment was my choice to include a photo in my recruitment poster and social media post (See Appendices A.3 and A.4). My chosen photo features a school-aged child with two young women leaning into his wheelchair. With one of the women facing towards the camera, it can be determined that she might be a sibling to the young boy in the wheelchair; both

her and the boy are smiling widely and appear to be of Asian or Eurasian descent. My intent with this photo was to catch the attention of passersby in a way that would make the poster and the content in the poster (i.e., impairment/disability, family, etc.) immediately recognizable. Inadvertently, the content in this photo, alongside the title caption of “Do you have a child or a sibling with a disability, or do you have a disability?” was likely to attract families of younger children with disability (i.e., under the age of 18 years), rather than families who have an adult child with disability or even a parent or other extended family member with disability. While the sample of families that were recruited provided rich data, more inclusive recruitment posters might have attracted families with a more broad age range and different family compositions and relationships to the person with disability.

Another potential limitation to the study was that I interviewed family members together. Interviewing in groups of two or more people risks some of those participants veiling their responses, choosing not to share, or modifying responses to please the other people present. I interviewed in groups in order to sustain a conversational interview that facilitated storytelling. The families also wanted to participate in the interviews together. While there were tensions around interviewing together, including that others could “speak for” their fellow family members or that hearing stories of a sensitive nature can be difficult, interviewing them separately was against their wishes alongside other barriers. In the interviews I conducted with both parents present, the mothers and fathers participated in the interview together for four of the five interviews (one father was working at the time of the interview), in what I would consider more equal contributions.

In this study, the people with disability that participated in the interviews had what might be considered more mild impairments (notedly, a mild impairment does not mean that they experience their disability any less than somebody whose function is more severely affected by their impairment). Those with more mild impairments did not require assistive technologies; however, as four of five of the families were in their home environment, they could access their own assistive devices if required.

There were barriers to participation for the children, including their age (too young to participate); they were not immediately available (i.e., they were sleeping or lacked interest in the interview itself); or their impairment made it not possible for them to participate (i.e., children with severe intellectual impairments who could not make use of assistive technologies for expression, as per their parents' accounts). For one family member with more severe impairments, I was unable to include her in the formal interview, however, her parents and I engaged her in play throughout the length of the interview.

The application of a postmodern lens can be problematic. While postmodernism offers the possibility of deep inquiry into stories of experience, it does not assure a satisfying or neat conclusion to inquiry. A postmodern lens looks beneath surface interpretations, but what it shows can leave an experience of feeling unsettled and less sure about the topic than before. In health and social care, it is an uncomfortable experience when some of the taken-for-granted aspects of practice are forced to yield to less certainty, new options, and an enduring sense of having to question. While this experience has been referred to as a kind of *analysis paralysis* in relation to decision making (Langley, 1991), it is also somewhat more existential. It calls into question how

and why providers do what we do, and what it means to be a health and social care provider in the context of disability services.

### **Recommendations**

Several recommendations arise from this research. First, for health and social care providers in practice, this research represents a caution that providers, as well as families, are subject to the influence of dominant narratives of disability. As such, it is necessary to reflect and remain sensitive to how some of the common sense and taken-for-granted stories influence practice. Dominant narratives are a sociocultural phenomenon, meaning they might influence providers long before any education about or exposure to disability occurs. It is necessary to be cautious and intentional that we live and tell stories of disability alongside those we serve, rather than for or about them. For learners and those new to disability care, should find opportunities to work alongside people with disability and their families as a way to become more sensitized to the differences between peoples' experiences and the dominant stories that are told for and about them. This practice could be taken up at differing levels of professional and lay education.

This study revealed opportunities for further inquiry and research. Other opportunities for future research might be a study of how providers' understandings of life with disability might contribute further to the ways that dominant narratives influence conceptions of an enactment of health and social care practices. For example, a future study, such as a discourse analysis, could examine the ways that health and social care providers might unknowingly or unintentionally contribute to the barriers of access to health and social care for families with disability. This could provide further insights into the tensions between what providers want to achieve and what they are able to do.

Another topic of interest for many of the families in this study was resource availability and accessibility. Given my registered nurse identity, the families presumed that I was interested in learning about gaps in services and the types of resources families would benefit from. Although this was not an area that I was specifically intending to study, it undoubtedly would be valuable research. Future research on the gaps that families experience when accessing services, as well as research on how optimal service delivery might be structured are recommended. This knowledge could be targeted to policy-makers, funding bodies, and others involved in service development.

Another recommendation for future research is to further explore the experiences of fathers and the roles they take up in families with disability. In this study, fathers took up meaningful and involved roles in their children's and family's life, but in the overall literature their experiences are under-represented. In this study, fathers demonstrated great attentiveness and care for their children and reflexivity to the needs of their family over time. Further research into fathers' experiences and the ways that fathers take up roles in families with disability would offer more scholarly depth to understanding the experiences of families with disability by adding the voices of fathers.

### **Epilogue**

This study is not meant to be any kind of “final word” on daily life for families with disability. It is also not the final word for me. Inasmuch as the hybrid narrative approach used in this study can be understood as a limitation for generalizability, writing and thinking with the stories in Chapter Four has enabled me to deeply engage with experience in ways that are postmodern, playful, and yet respectful of participants’ stories and confidentiality. Doing this has helped me to think differently, to reflect upon and challenge some of my own assumptions and practices. Through the sharing of my experiences, the participating families’ stories, and my experience of conducting this study, I hope this research is able to work similarly for others.

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## APPENDIX A: CONSENT AND ASSENT FORMS, RECRUITMENT POSTER

### A.1. Consent Forms



#### CONSENT FORM

**TITLE:** “Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability”

**INVESTIGATORS:** Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053  
Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

Note that this document uses “investigator” and “researcher” interchangeably.

#### **BACKGROUND**

IN the past, when a person was diagnosed with a disability, it was thought they were ill or sick. More and more, people are viewing people with disabilities as healthy, but there is still little information about the disability experience as a whole. We also know that disability is often felt by the person’s entire family. In this study, we want to know more about the ordinary and everyday experiences of people with disabilities and their families. The information gained in this study can help health and social care professionals care for families in the ways that families want.

#### **WHAT IS THE PURPOSE OF THE STUDY?**

We want to know more about the ordinary and everyday experiences of people with disabilities and their families. We want to know how these experiences compare to other ways of looking at disability. Sharing experiences of disability can help us change how health and social care practitioners care for families.

#### **WHAT WOULD I HAVE TO DO?**

You will be asked to participate in one 60-90 minute interview with the investigator. In the interview, we will ask you about your own and your family’s experiences of disability. We will ask you questions, and you can speak about other topics that are important to you. The interview will be audio-recorded, then a transcriptionist will write out the conversation we had. We will ask you to review this transcript. You can add or clear up anything as well as ask to remove anything from the transcript if you wish.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

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### **WHAT ARE THE RISKS?**

We do not foresee there will be any physical risks of participating in this study. While talking about your experiences, you might recall stressful, worrying, or embarrassing moments. Talking about these experiences might leave you feeling worse than you did before you began the interview. We expect that any distress you might experience in the interview to be transient. In the event you experience distress in the interview, the researcher will offer to:

- Pause the interview and resume after a break;
- Stop the interview and reschedule to a later date; or
- Stop the interview and you may withdraw from the study if you wish.

In the event that you experience stress after the interview, we can give information about counselling and supports. Some of these will be free of charge.

### **WILL I BENEFIT IF I TAKE PART?**

If you agree to participate in this study, we do not expect there will be an immediate direct benefit for you. Over time, we expect this research might help develop services. You might find you benefit from this service development. In studies like this, other people have said that having the opportunity to talk about their experiences is a rewarding and enjoyable experience.

### **DO I HAVE TO PARTICIPATE?**

Your participation in this study is voluntary and you are under no obligation to participate. You can withdraw from the study at any time. There is no penalty or consequence of withdrawing from the study. You can withdraw from the study in one or more ways. First, by writing to the researcher (by email or letter). Second, by speaking with the researcher (in person or on the telephone). Third, by stopping contact with the researcher. If we do not hear from you, we will attempt contact twice. You are under no obligation to respond to these attempts if it is no longer welcome. If we do receive a response when contacting you a second time, we will assume you have withdrawn from the study and we will make no further contact.

In certain circumstances, the investigators might withdraw you from the study. If we have reason to believe that your participation is putting you or another person at risk, we will withdraw you from the study. If new information that might affect your willingness to take part in the study, we will tell you as soon as possible.

### **Withdrawal of study data**

You can withdraw some or all your data (in the form of a transcript) at any time, until data analysis has begun. If you decide you want to withdraw all their data, you must inform the researchers by email or letter, or in person or on the telephone. Once data are being analyzed, you may no longer withdraw your data from the study.

In the event that you withdraw from the study, we will ask to keep and use the data we collected from you. You do not have to agree to this. If you withdraw from the study without contacting the researchers, we will include your data in the study unless asked not to.

#### **WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

We will not ask you to do any more than described in this document.

#### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

We will provide an honorarium of \$20 in the form of a Second Cup gift card as a token of appreciation for taking part in the study. You can choose to have the interview at home or at the University of Calgary in the Faculty of Nursing or across campus. We will reimburse parking costs.

#### **WILL MY RECORDS BE KEPT PRIVATE?**

Your identity along with the data collected during your time in this research study will be held and used by the investigators in this study only. We will store all electronic files (audio recordings and Word documents) as password protected files on a secure server. We will store all hard copies in a locked filing cabinet in the office of the principal researcher. Note that authorized representatives from the University of Calgary and the Conjoint Health Research Ethics Board may review your study records for quality assurance purposes.

We will make every effort to remove information that identifies you (for example, names, the names of places, services, etc.) from transcripts. Where possible, we will replace these with pseudonyms. You can choose a pseudonym for yourself and/or your family. You can review your transcript and tell the researchers anything you think might make you identifiable to others. Where it does not affect the analysis or truthfulness of the research, we may change minor details about your experiences to protect your confidentiality. You should be aware that these measures do not provide an absolute guarantee that others cannot identify you or your family.

Once the study is complete, the researchers will store this signed consent form and de-identified transcript in a locked cabinet in the office of the principal investigator at the University of Calgary. The researchers will delete the voice recording of your interview and any electronic versions of your transcript.

The pseudonym I have chosen for myself is: \_\_\_\_\_

The pseudonym I have chosen for my family name (if applicable) is: \_\_\_\_\_

**IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?**

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the University of Calgary, Alberta Health Services, or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

**SIGNATURES**

Signing indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care or position with the organization we were connected by. If you have further questions concerning matters related to this research, please contact:

**Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053**

**Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312**

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

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### **PEDIATRIC CONSENT FORM**

**TITLE:** "Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability"

**INVESTIGATORS:** Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053

Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

Note that this document uses "investigator" and "researcher" interchangeably.

### **BACKGROUND**

In the past, when a person was diagnosed with a disability, it was thought they were ill or sick. More and more, people are viewing people with disabilities as healthy, but there is still little information about the disability experience as a whole. We also know that disability is often felt by the person's entire family. In this study, we want to know more about the ordinary and everyday experiences of people with disabilities and their families. The information gained in this study can help health and social care professionals care for families in the ways that families want.

### **WHAT IS THE PURPOSE OF THE STUDY?**

We want to know more about the ordinary and everyday experiences of people with disabilities and their families. We want to know how these experiences compare to other ways of looking at disability. Sharing experiences of disability can help us change how health and social care practitioners care for families.

### **WHAT WOULD MY CHILD HAVE TO DO?**

Your child can take part in one 60-90 minute interview with the investigator. Based on your child's specific needs and condition, we can shorten the length of the interview. In the interview, we will ask your child about their or their family's experiences of disability. We will ask your child questions, and your child can speak about other topics that are important to them. The interview will be audio-recorded, then a transcriptionist will write out the conversation. We will ask your child to review this transcript. Your child can add or clear up anything as well as ask to remove anything from the transcript if they wish.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

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### **WHAT ARE THE RISKS?**

We do not foresee there will be any physical risks of participating in this study. While talking to us, it is possible that your child might remember stressful, worrying, or embarrassing moments. We hope they don't, but your child might leave feeling worse than they did before they began the interview. We expect that any distress your child might experience in the interview to be transient. In the event your child experiences distress in the interview, we will offer:

- Pause the interview and resume after a break;
- Stop the interview and reschedule to a later date; or
- Stop the interview and your child may withdraw from the study if they wish.

If your child feels stressed after the interview, we can give information about counselling and supports. Some of these will be free of charge.

### **ARE THERE ANY BENEFITS FOR MY CHILD?**

If you agree for your child to take part in this study, we do not expect there will be an immediate direct benefit to them. Over time, we expect this research will help develop services. You might find your child benefits from this service development. In studies like this, other people have said that talking about their experiences is rewarding or an enjoyable experience.

### **DOES MY CHILD HAVE TO PARTICIPATE?**

Your child's participation in this study is voluntary and they are under no obligation to take part. You or your child can withdraw from the study at any time. There is no penalty or consequence of withdrawing from the study. You or your child can withdraw from the study in one or more ways. First, by writing to the researcher (by email or letter). Second, by speaking with the researcher (in person or on the telephone). Third, by stopping contact with the researcher. If we do not hear from you or your child, we will attempt contact twice. You or your child are under no obligation to respond to these attempts if it is no longer welcome. If we do receive a response when contacting you a second time, we will assume your child has withdrawn from the study and we will make no further contact.

In certain circumstances, the investigators might withdraw your child from the study. If we have reason to believe that your child's participation is putting them or another person at risk, we will withdraw your child from the study.

If new information that might affect you or your child's willingness to take part in the study, we will tell you and your child as soon as possible.

### **Withdrawal of study data**

Your child can withdraw some or all their data (in the form of a transcript) at any time, until data analysis has begun. If your child decides they want to withdraw all their data, you or your child must inform the researchers by email or letter, or by speaking with the researcher in person or on the telephone. Once data are being analyzed, your child may no longer withdraw their data from the study.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

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In the event that your child withdraws from the study, we will ask to keep and use the data we collected from them. Your child does not have to agree to this. If your child withdraws from the study without contacting the researchers, we will include your child's data in the study unless asked not to.

**WHAT ELSE DOES MY CHILD'S PARTICIPATION INVOLVE?**

We will not ask your child to do any more than described in this document.

**WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?**

We will provide an honorarium of \$20 in the form of a Second Cup gift card as a token of appreciation for taking part in the study. You or your child can choose to have the interview at home or at the University of Calgary in the Faculty of Nursing or across campus. We will reimburse parking costs.

**WILL MY CHILD'S RECORDS BE KEPT PRIVATE?**

Your child's identity along with the data collected during their time in this research study will be held and used by the investigators in this study only. We will store all electronic files such as audio recordings and Word documents on password protected files on a secured server. We will store all hard copies in a locked filing cabinet in the office of the principal researcher. Note that authorized representatives from the University of Calgary and the Conjoint Health Research Ethics Board may review your child's study records for quality assurance purposes.

We will make every effort to remove information that identifies your child (for example, names, the names of places, services, etc.) from transcripts. Where possible, we will replace these with pseudonyms. Your child will be able to choose a pseudonym for themselves and/or your family. Your child can review their transcript and tell the researchers anything they think might make them identifiable to others. Where it does not affect the analysis or truthfulness of the research, we may change minor details about your experiences to protect your confidentiality. You and your child should be aware that these measures do not provide an absolute guarantee that others cannot identify your child or your family. Once the study is complete, the researchers will store your signed consent form and de-identified transcript in a locked cabinet in the office of the principal investigator at the University of Calgary. The researchers will delete your child's voice recorded interview and any electronic versions of your child's transcript.

The pseudonym I have chosen for myself is: \_\_\_\_\_

The pseudonym I have chosen for my family name (if applicable) is: \_\_\_\_\_

**IF MY CHILD SUFFERS A RESEARCH-RELATED INJURY, WILL WE BE COMPENSATED?**

If your child suffers injury as a result of taking part, no compensation will be provided to you by the University of Calgary, Alberta Health Services, or the researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

**SIGNATURES**

Signing below indicates that you understand to your satisfaction the information related to your child's participation in the research and agree to their participation. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You and your child are free to withdraw your child from the study at any time without jeopardizing your or your child's health care or position with the organization you heard about us through. If you or your child has further questions concerning matters related to this research, please contact:

**Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053**

**Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312**

If you or your child has any questions concerning your or their rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

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 Participant's Name

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 Signature and Date

---

 Investigator/Delegate's Name

---

 Signature and Date

---

 Witness' Name

---

 Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

Version number 2, May 10, 2019

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## A.2. Assent Forms



### ASSENT FOR THE YOUNGER CHILD (7-10 years old)

**Title:** “Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability”

**Investigators:** Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053

Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312

We want to tell you about a research study we are doing. A research study is a way to learn more about something. In this study, “investigators” are also called “researchers”. We want to meet you to learn more about you because you have a disability, or you have a family member who has a disability. We want to know what this is like for you.

If you agree to join this study, here are some other things you should know about what we want you to do:

- We will give you the questions we will ask before we meet with you.
- We will meet about 1 or 1.5 hours. If you want to talk for a shorter time, we can do that instead.
- We will meet you at your home or the University of Calgary. It is up to you where we will meet.
- Your parent/guardian can come with you to our meeting. They can wait outside the room we talk in, or they can come with you into the room while we talk.
- We will audio record our meeting using a voice recorder. After our meeting, we are going to make notes on what we talked about and let you read them. You can change anything you would like while we are talking.

This study will not hurt your body. Sometimes, when you talk about things that are sad or that made you worry, you can feel anxious. We hope you don’t feel anxious while talking with us, but if you do, you can either:

- Take a break;
- Stop the talk and ask to meet at another time; or
- Stop the talk and not meet again.

If you feel sad, worried, or anxious a few days after talking with us, tell your parent/guardian. We gave them some phone numbers to call if you need some help to feel better.

Some people like to talk about what it is like being them. If you are one of those people, you will probably enjoy talking with us. Some people might not care as much so those people might not find that talking to us was helpful.

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This study might find out things that will someday help other children who have a disability, or who have a family member with a disability. What you tell us might help other people learn what children like you or what families like yours feel like.

This study will help us learn more about what it is like to have a disability, or to have a family member with a disability. You don't have to join this study. It is up to you. You can say yes, or you can say no. It is okay to change your mind later. If you want to stop, then all you have to do is tell us or have your parent/guardian tell us you want to stop. No one will be mad at you if you don't want to be in the study. Nobody will be mad at you if you say yes now then want to stop later.

Before you say yes or no to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. You can tell the researcher that you have a question.

We will also talk to your parent/guardian about this study. You can talk this over with them before you decide.

If you have any questions about this study when we are not together, please call or have your parent/guardian call the principal investigator, Dr. Andrew Estefan at (403) 220-8053.

Would you like to take part in this study? (place a check mark beside yes or no).

\_\_\_\_\_ Yes, I will be in this research study. \_\_\_\_\_ No, I don't want to do this.

_____	_____	_____
Child's name	Signature of the child	Date
_____	_____	_____
Person who received assent	Signature	Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A signed copy of this assent form has been given to you to keep.



### **ASSENT FOR PERSONS UNDER GUARDIANSHIP / ASSENT FOR THE OLDER CHILD (11-17 years old)**

**Title:** “Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability”

**Investigators:** Principal investigator: Dr. Andrew Estefan, Faculty of Nursing, (403) 220-8053

Co-investigator: Suzanna (Sue) Crawford, Faculty of Nursing, (403) 918-0312

#### **What is a research study?**

A research study is a way to find out new information about something. Young people don’t need to participate in a research study if they don’t want to participate.

#### **Why are you being asked to be part of this research study?**

In this study, one of the “investigators” (also called a researcher) wants to meet you to learn more about you because you have a disability, or you have a family member who has a disability. We want to know what this is like for you. The researchers will meet with between 4 and 8 people during this study.

#### **If you join the study what will happen to you?**

- We will ask you to sit with us and talk about what it is like to have a disability or what it is like to have a family member with a disability.
- We will give you the questions we will ask before we meet so you know what we will talk about.
- It will take about one hour or one and a half hours to talk to you about this. If you want to talk for a shorter time, we can do that instead.
- We will meet you at your home or the University of Calgary. It is up to you where we will meet. If your parent/guardian drives you, we will pay for parking your family car.
- Your parent/guardian can come with you and wait outside the room we will talk in, or they can come into the room while we talk.
- We will use a voice recorder to record our talk. Afterwards, we are going to make notes on what we talked about and let you read them. You can change or remove anything you want.

#### **Will any part of the study hurt?**

This study will not hurt your body. Sometimes, when you talk about things that are sad or made you worry, you can feel anxious. We hope you don’t feel anxious while talking with us, but if you do, you can either:

- Pause the talk and start again after you take a break;
- Stop the talk and make a time to meet again at a later date; or
- Stop the talk and not meet again.

Ethics ID: REB18-0870

Study Title: Expressing Disability: A Narrative Analysis of Experiences for Families Affected by Disability

PI: Dr. Andrew Estefan

Version number 2, May 10, 2019

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If you still feel anxious a few days after talking with us, tell your parent/guardian. We gave them some phone numbers to call just in case you need some help to feel better.

**Will the study help you?**

Some people like to talk about what it is like being them. If you are one of those people, you will probably enjoy talking with us. Some people might not care as much. They might not find that talking to us was helpful.

**Will the study help others?**

This study might find out things that will someday help others who have a disability or who have a family member with a disability. We might be able to help them by sharing your stories to help other people learn what families like yours need.

**Do your parents know about this study?**

We will talk to your parents about your participation in this study as well. You can talk this over with them before you decide.

**Who will see the information collected about you?**

The information collected about you during this study will be kept safely locked up. Nobody will read it except the people doing the research. We will not tell your parents or anyone else, unless you want us to tell them. One other time that we might have to tell somebody else what you said is if something you said makes us think you or somebody else is in danger.

In this study, we don't need to use your name. In fact, when we take notes after our talk, we will be changing a few details about you, like what community you live in. This is to make sure other people can't easily tell who we talked to. We will also delete the voice recording we took while we talked to you after we take some notes on it.

**What do you get for being in the study?**

To say thanks for talking with us, we want to give you a \$20 Second Cup gift card. Since we are meeting at the University of Calgary, parking can be expensive. You can tell your parent/guardian that we will pay for parking while we are talking.

**Do you have to be in the study?**

You don't have to be in the study. No one will be upset if you don't want to do this study. If you don't want to be in this study, you or your parent/guardian can tell us in person, on the phone, or by email. You can take time to think about whether you would like to be in the study.

### A.3. Recruitment Poster



## Do you have a child or sibling with a disability, or do you have a disability?

We invite you to take part in a research study about the experiences of families who have a member with a disability. If you would be willing to participate in a 60 – 90 minute conversational interview—and you meet the criteria below—the researchers would like to hear from you.

To be eligible for participation in this study, you must:

1. Be the parent/guardian or sibling to a person with a disability, or be a person with a disability;
2. Be able to communicate in either spoken or written English; and
3. Live in Calgary, Alberta.



To express interest in participating, or to inquire about this study, please contact:

**Sue Crawford, co-investigator/researcher, Faculty of Nursing, University of Calgary**

[Suzanna.crawford@ucalgary.ca](mailto:Suzanna.crawford@ucalgary.ca) or 403-918-0312

*The University of Calgary Conjoint Health Research Ethics Board has approved this research study.*

Ethics ID: REB18-0870

#### A.4. Social Media Post



**Do you have a child or a sibling with a disability, or do you have a disability yourself? Do you live in Calgary?**

If so, University of Calgary Faculty of Nursing researchers invite you to take part in a study about the experiences of disability within families.

If you would be willing to participate in a 60-90 minute conversational interview, please

**contact the researchers at**

**[Suzanna.crawford@ucalgary.ca](mailto:Suzanna.crawford@ucalgary.ca) or 403-918-0312.**



The University of Calgary Conjoint Health Research Ethics Board has approved this research study.  
Ethics ID: REB18-0870

**APPENDIX B: INTERVIEW QUESTIONS**

- How has disability altered your/your child's/your spouse's/your other children's experience?
- How does disability impact you/your family? How does having a family member with disability impact you/your family?
- What tensions does disability present for you/your child/your spouse/your other children?
- What capacities has disability resulted in for you/your child/your spouse/your other children?
- Tell me about the times when you notice the presence of disability more? When (if ever) does disability seem to “disappear” for you?
- When have been the times where you have most felt the impact of having disability within the family?
- Can you tell me about some of the tense times in your family's life?
- Have you noticed ways that your family has grown or adapted or developed in response to disability?

## **APPENDIX C: CREATING COMPOSITE FAMILY STORIES**

### **C.1. Writing The Morris Family**

The inspiration for The Morris Family came from the experiences of the fourth family that I interviewed. This family's stories stood out to me because of the ease in which the parents revealed their vulnerabilities and how their son, although quite young to be interviewed at age 6, worked to share with me all the things he has learned from his parents, teachers, and support worker. This was also a momentous interview for me and for the family because this was the first time that the parents shared their own story in front of their son.

After writing down the larger "turning points" for this family in particular, I realized that the other families also expressed similar experiences that could be drawn into the story to build a composite family's experiences. Upon reading and re-reading the transcripts, I noted ways to fold in each of the families' shared experiences into the story. Figure 1 is an example of the process I followed. I copied the excerpts from the original transcripts into these larger turning points, numbering each of these stories based on the chronological order of the transcript that the excerpt came from. Through repeated readings of the story and comparing it to the original transcripts, I checked for anything that might inadvertently misrepresent the participants' experiences. I then made the necessary changes. Careful not to alter the emotive command of the story, or any material facts, I made small changes to some of the excerpts to unify the story.



Figure 1.

*An example of how I wrote a portion of The Morris Family story. The comments reflect which family members of which family that the excerpt was borrowed from.*

<p>Mrs. Morgan encouraged Callum to develop new ways of communicating; to express himself with words instead of his hands. She was also helping him learn to remove himself from places and interactions that could become problematic for him. Bonni noted:</p> <p><i>He's praised for how well he can express his emotions now, but that's one thing we worked on a lot. But it also comes with high expectations. Because, yes, he can articulate it really well now, but when he snaps, he's not thinking anymore. It takes time before he's put back together and he's able to rationalize and think.</i></p>	<p><b>Sue Crawford</b> Excerpt from the mother in family #4.</p>
<p>While Bonni and Jim made progress with parenting, supporting, and advocating for Callum, they were also concerned about how all their attention, directed at Callum, affected Madison. This was a difficult subject for them both as they tried their best for both of their children, even though Callum was the one who received much of their attention:</p> <p><i>I mean, this is just her life. She doesn't know any different. At first, we didn't think she understood what was going on. I remember, a while back, she was in her stroller, and we were dropping her off at her grandparents' house, then I had this emergency with Callum. I was trying to drop her off quick so I could get back to Callum. She usually just goes off with them, but this time, she completely freaked out. I just didn't even think about it, and then I'm like, "oh my goodness. She just saw my worry and panic and suddenly I was about to abandon her." Like, she's never been much of a cuddler, but some nights, she needs a cuddle and then she will be like, "Okay, I'll go back to bed." ... [Finding that balance] is constantly developing, the older she gets.</i></p>	<p><b>Sue Crawford</b> Excerpt from the mother in family #5. Gender of the child changed from female to male to match the story.</p>
<p>Madison spoke about how she saw the family's situation. She shared how she felt being Callum's sister and how her parents' attention is occupied:</p> <p><i>I don't really think about it. I'm used to it. It doesn't take long. I've been doing it for forever so... I mean, I don't need that [attention] so it would be pointless for my parents to come to my school every week. There'd be nothing to say.</i></p>	<p><b>Sue Crawford</b> Excerpt from the older sister in family #2.</p>



## C.2. Writing “*To Our Healthcare Team*”

Figure 2 is an example of the process I followed to write the narrative, “*To Our Healthcare Team*”. From each of the five interview transcripts, I highlighted stories of times when families worked with care providers. I emphasized stories where the service providers were health care providers and looked for ways to include stories about working with social care providers like school staff and support workers. I copied the excerpts into a single document then numbered each of these stories. In a comment associated with the excerpt number, I pasted the original excerpt so I could refer to the original quote as needed (See Figure 2).

Stories with similar topics and tone were matched together and separated into paragraphs. I then added bridging words to promote the narrative flow of the letter. Careful not to alter material facts or the emotive command of the story, I made small changes to some of the excerpts to unify the letter as one voice. I read and re-read the letter, referring to the original, transcripts to preserve the voice of the participants as much as possible.

Figure 2.

*Example of how I wrote paragraph 2 of “To Our Healthcare Team”. The left shows the final writing excerpts and the right shows the original excerpts from the transcript data.*

“*To Our Healthcare Team*” – Version A, para. 4

I look back at us a couple years ago. (2)  
 Things were even harder back then. She didn’t have the diagnosis yet and we didn’t really understand what was going on. (4)  
 Then, we got it all at once, very, very quickly on. (17)  
 By the time we sat down to actually take stock of it, we were months in. (15)  
 I didn’t even know how to be a mum, much less being her mum. (13)

**Sue Crawford**  
 Interview #2: If I look back at us a couple years ago, as a family, we have come really long way. And him. The fact that now he’s doing better, we all do better.

**Sue Crawford**  
 Interview #4: It was harder because we didn’t have the diagnosis; we didn’t fully understand what was going on.

**Sue Crawford**  
 Interview #3: We got it all at once, very, very quickly on.

**Sue Crawford**  
 Interview #3: By the time you sat down to actually take stock of it, you were six months in.

**Sue Crawford**  
 Interview #3: “I didn’t even know how to be...a dad. Much less, y’know... [being his dad].”