

MATERNITY ROLLS/ROLES: AN AUTOETHNOGRAPHY ON AN EMBODIED  
EXPERIENCE OF PREGNANCY, CHILDBIRTH, AND DISABILITY

by

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## **ABSTRACT**

As a woman with a spinal cord injury who uses a wheelchair, my thesis is an autoethnography that is based largely on the journals I have written in over the last twenty years, and in particular the journals I kept while I was pregnant and giving birth to my two children. Disability is a pervasive ideology that informs many of our cultural ideas of self and other, what constitutes acceptable and celebratory bodies, political stances, public policy, and language. Much of the literature that examines the female bodily experience excludes the stories and experiences of women with disabilities. Because the body with disabilities is often seen for what it can not do, taking on the role of mother can give the body a different value, status, and worth. I feel that my lived experiences as a woman with a disability experiencing pregnancy and childbirth offers insights and understanding into what it is already known about women's bodies. I display multiple levels of personal and cultural consciousness while connecting to the larger understandings of the culture of pregnancy, childbirth, and disability.

**DEDICATION**

To Patrick and Chelsea  
For giving me a story to tell

And for Darrell  
Because this is his story too

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## PROLOGUE

The word was born in the blood  
Grew in the dark body, beating,  
And took flight through the lips and the mouth...

(Neruda, 2001, p. 5)

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## CHAPTER 1: INTRODUCTION

During the time that I wrote this thesis, I participated in a Life and Health Sciences Research Day held for graduate students at the University of Saskatchewan. Each participant displayed her or his research in poster form and had the opportunity to give a five minute speech to a team of judges. All posters and presentations were evaluated and prizes were awarded at the end of the day.

I had not anticipated how few numbers of qualitative research projects were present at the event, but nevertheless when it was my turn to speak about my own project, I believe I did so with confidence and enthusiasm. At the end of the day when I was awarded second place in my category, I suspected that the award was a reflection of my public speaking skills and less about the perceived quality of my research. After all, my judges were honest – although they were genuinely intrigued by my story, they could not see the scientific significance. One judge asked me, “Why didn’t you choose to write an autobiography or a memoir and skip the academic exercise altogether?” Thinking about how emotional the writing, remembering, and reflecting process has been, I laughed and answered honestly, “I have asked myself that question many times.” What graduate student, after all, at some point does not question his or her decision to continue on the path of graduate studies that can be frustrating, difficult, lonely, and financially challenging? The judge then further pressed, “What is the point of doing this academic exercise if the work does not generalize and therefore does not apply to anyone else but you?”

Good questions. To answer his first query, I choose to persevere through the academic exercise because of my desire to create social change about how disabilities are

perceived and how women with disabilities can be seen as competent nurturers. My perseverance was grounded in the realization that there is no shortage of literature that examines female bodies, whether the writing is popular or academic (Weiss & Haber, 1999), much of the literature that examines the female bodily experience excludes the stories and experiences of women with disabilities (Wendell, 1996). Undoubtedly, discursive analysis of women's embodied experiences and pregnancy has been embraced by feminist scholars (Mullin, 2005). Still, feminist research has also neglected the embodiment issues, including pregnancy, of women with disabilities (Chouinard, 1999, 2005; Fine & Asch, 1988; Gill, 1997a; Wendell, 1996). "Disability has typically been left out of the politics and theorizing of gender" (Titchkosky, 2007, p. 8). Because feminist movements have focused attention on women's strength and celebrated the experiences of women's bodies that give pleasure, they have also overlooked embodiment differences, particularly disabilities (Wendell, 1996). The feminist movement has made efforts to include many other "differences" into their activism, but continually neglects women with disabilities, choosing rather to see this group of women as having diminished societal value (Gill, 1997a). Feminist research has also focused on the objectification of women's bodies as sources of exploitation, but has undervalued and repeatedly excluded the female body with disabilities, and bodies that are not traditionally considered sexual, competent or physically strong (Wendell, 1996). "Until feminists criticize our own body ideals and confront the weak, suffering, and uncontrollable body in our theorizing and practice, women with disabilities and illnesses are likely to feel that we are embarrassments to feminism" (Wendell, 1996, p. 93).

As a graduate student beginning her studies, I had read about qualitative inquiry to give myself a solid grounding in methodologies and I began to have a desire to influence higher learning. I also came to recognize that it is important that people with disabilities are active in research processes since research in the area of disability has often been done by “outsiders” - those who do not share the disability experience (Bredahl, 2007; Peters, 1996; Titchkosky, 2007). I realized that I had a desire to reach and inform doctors, nurses, and students of the health sciences with my story so that they could re-think the way they practice medicine. As my thesis progressed, I remained committed to the writing through a desire to contribute to the larger conceptual and theoretical understandings of disability in our society. I felt strongly that my personal story, while interesting, also had bigger points to make, and I tried to make those points by contrasting my stories against a social environment that tends to be ableist.

To answer my judge’s second question, I believe that my story is not just about me. First of all, disability is a pervasive ideology that informs many of our cultural ideas of self and other, as well as what constitutes acceptable and celebratory bodies, political stances, public policy, and language (Garland-Thomson, 2002). Autoethnography allowed me, as Deborah Reed-Danahay (1997) explains, to write a self-narrative that placed those stories within a social context. And although my story will not be exactly the same as another non-disabled woman’s or even another female paraplegic’s story, by intertwining my story with larger theories and understandings of disability it can inform others about the ways in which disability is seen, heard, felt, and experienced.

I also think that my thesis could reach further than the circle of women with disabilities and could help to inform anyone about what it is like to live with vulnerabilities, injuries, weakness, pain, interruption, and compromise. Becoming sick, injured or in need of medical intervention and even possibly hospitalization is a situation experienced by almost everyone. Despite our efforts for optimum health, strength, fitness and longevity, all bodies experience vulnerability and even disability at some point in their lives. Disability, in all its varying forms and degrees, is a human experience that can affect anyone. As Susan Wendell (1996) asserts, the experience of disability, while often considered atypical, by necessity extends the range of possible human physical experiences in ways not available to the able-bodied human population. A more complete understanding of embodiment requires a thorough understanding of the bodily experience of disability. Wendell further argues that in order to grasp the relationship of consciousness to the body, it is essential to understand the embodied experiences of women with physical disabilities. Other disability academics agree. For example, Michael Berube (2002) argues that the subject of disability “will be central to human existence for as long as humans have bodies – and embodied minds to theorize them with” (p. x). Tonya Titchkosky (2007) writes, “I hold that the problematic of ‘embodiment’, of fleshy life, of our being embodied beings, can be grasped through an analysis of how we give meaning to disability within everyday life” (p. 12). Moreover, as Rosemarie Garland-Thomson states, “disability is the most human of experiences, touching every family, and – if we live long enough – touching us all” (2002, p.5). Perhaps, then, my research is not as unique as it seems.

## **My Story**

My research begins with my story.

I am a 38 year old white, heterosexual woman who is married, the mother of two children, and living in a house in a quiet middle-class neighbourhood. In many ways, my life seems like the quintessential picture of a nuclear family living what is considered by many to be a traditional life.

However, my life is not as conventional as it appears, particularly because I am also a paraplegic and I use a wheelchair for mobility. My disability dramatically changes the picture of tradition. To help you understand why this is true, I need to tell you the story that starts with me, a little blond-haired farm girl, an accident that changed everything, and how everything changed again when I grew up, became pregnant and had children of my own.

I have told a version of this story many times, during conversations with my son's teachers when I meet them at the beginning of each new school year, to strangers at cocktail parties, to each new doctor or medical professional from whom I seek medical advice, and to groups of people when I have performed a keynote speech at a conference, or given a guest lecture. The main details are basically always the same, the length may vary, and the level of disclosure inevitably varies depending on my comfort, level of trust, amount of courage I am feeling and emotional detachment from the story I am experiencing at the time. Much of this story has been captured on paper in my journals, some is filed away in hiding places in my own head. Some of the story exists in the song lyrics written by others that "speak to me," some is what I have heard my parents tell, and

some simply exists on my tongue. I have lived my life through, and I have been shaped by, this story. It needs and deserves to be written, read, seen, spoken, and heard.

### **Girl, Interrupted: The Accident**

Tell me the story  
'bout when you were young  
I want to hear it again  
Leave in the part  
Where the hero gets stung  
I want to savour it  
I want to play it again  
(Lennox, 2007, p. 8)

On a scorching afternoon on June 4, 1976, my mother gave me the choice between catching the school bus to go home to our farm after I was finished with my school day or waiting a few extra minutes for her to finish up her meeting with the Catholic Women's League that was happening across the street. Although I was only six years old I had enough sense to know that the long bus ride home would be uncomfortable, sweaty, and hot. I decided to wait for my mom. Besides, I did not want the older kids on the bus to tease me about what I was wearing like they had in the morning.

A few days earlier, a boy in my class told me that I was not like the other girls because I never wore dresses and that if I wanted to be pretty I had better start wearing some. So on this hot, sticky day, I wore a simple lavender gingham cotton dress and as I waited for mom to pick me up and take me home, I was impressed and surprised with how much cooler a dress was than my usual blue jeans. Nevertheless as my mom, sister, niece, and I drove home with all the windows rolled down in a wishful attempt to bring some relief the way only a cool breeze can on that kind of sweltering day, I lay down in the



backseat of our car and imagined of how good a cool lemonade would taste under the shade of our garden's crabapple tree.

My day dreams were interrupted by what I can only remember as chaotic mix of images: my mother's head cut and bleeding; of strangers talking in loud, urgent voices; the sound of my sister crying and of feeling pain and discomfort from a sheet of cardboard behind my back and shoulders that someone had laid me on. My mom was frantically looking around for her lost earring; meanwhile with a strange calmness I realized I could not feel my legs. When I told my mom this, she dismissed my words and explained to me that I was in shock.

The next thing I remember is a cold, brightly lit emergency room where I was again laying on my back and feeling extreme pain. When I overheard the doctor tell my mother that my dress would have to be cut off of me because he could not risk doing damage to my body while pulling it over my head, I screamed and cried. While I could not feel my legs, while I was experiencing excruciating pain in the places I could still feel, surrounded by strangers in a strange place and knowing instinctively that something was terribly wrong with me, my most prevailing thought was how I did not want that dress to be mutilated by a pair of scissors. I honestly remember thinking, "How will I ever be pretty again?" In my mind, that dress meant I was a girl. In that moment, the idea of losing that identity was somehow more tragic than what my body was experiencing.

### **Where's the Girl: Lowered Expectations**

And you've been down this road before  
Which is not to say you're bored  
Or that you shouldn't want for more

It's just your expectations  
Should be lower  
(Collins, 1994)

Perhaps my grief over the dress's destruction was a foreshadowing for how my identity as a female person would also alter. As a girl with a spinal cord injury who uses a wheelchair, I experienced a markedly different set of developmental, social and biological expectations than non-disabled girls my age seemed to experience as they grew up. For example, it was assumed that I would always need someone to look after me; that I would not live independently, that I would not be able to attract a man, date, marry; and certainly not have a sexual relationship, have children and be able to look after those children. Because my spinal cord was injured, and I became a paraplegic at a young age, I believe this expectation that I would live a socially and sexually barren life was even more poignant for me than for women who acquire their disabilities later in life. At age six, I had not yet, of course, developed sexually in either physical, social, or emotional ways. I was just simply too young.

Michel Foucault (1984) describes social forces, especially those associated with sexual identity, as strong influences on how we define who we are and how we present ourselves. While there are societal expectations of men and women that are "accepted" ways to perform gender, such as women as nurturers (Butler, 2006), there is also a gendered experience of disability that assumes to live with disability is to live without sexuality (Fine & Asch, 1986; Garland-Thomson, 1997; Mairs,

1996; Wendell, 1997). The asexual status that is often attributed to people with disabilities was, I believe, stronger for me than for other people who are injured after they have achieved their sexual identities, because, unlike people who experience spinal cord injuries later in life, I had no opportunity to develop an 'adult' construction of sexuality or the pre-pubescent or adolescent constructions of sexuality. After a spinal cord injury, sexual identities and adult social roles are often denied (Fine & Asch, 1988; Garland-Thomson, 2002; Gill, 1997a).

Having my spinal cord injured and becoming a paraplegic so early in life, I did not have many chances to achieve much of a sexual identity and there were no expectations from most of the adults in my life, such as family members, teachers, friends and neighbours, that I ever would. There were none of the comments that my peers received, like, "Heather will be a heartbreaker" or "Heather will be a good mommy someday." Growing up with the unspoken yet prevailing attitudes that I would not live a fruitful and productive life, that I would not live independently from my parents, or become anyone's employee, girlfriend, wife, or mother, became undeniably, consciously and subconsciously, ingrained in how I identified and saw myself. It was more acceptable and easier for me to see myself, and to be seen by others, as a "cute kid" which is a more androgynous and asexual label, than as a "pretty girl" which is decidedly more feminine and by consequence, sexual. I did not realize how much I had internalized the notion that to live with a disability is to live without sexuality until I became pregnant for the first time and my sexuality could no longer be denied by anyone, not even me.

August 18, 1996

I just don't know how to feel. I have to go to the bathroom a lot and every time I do, I expect to find the blood stains of my period, informing me that this whole thing has been a huge misunderstanding. It's not that I don't want this baby; I just can't believe it is happening. Could something this natural, this normal, really be happening to my body? My body that has never been my friend? The bottom line is this: I did not expect I was ever this female.

### **Home Girl**

saturated with negative images  
and a limited range of  
possibilities is strange (shad, 2008)

In the early months after my injury, it was suggested by my then rehabilitation doctor and the rehabilitation centre's head nurse that I would be better off living and going to school at the Children's Rehabilitation Centre in Saskatoon (an hour and a half drive away from my home), lest, in their opinion, I become too much of a physical, emotional, and financial burden on my parents. At the time, the construct of disability was primarily dictated by a "medical model" that saw disability as a pathological problem that resided in the "patient" and required the solutions of rehabilitation and medical intervention to correct his or her "deficiencies" (Gabel & Peters, 2004; Olkin, 1990). The scientific system that underlies the medical model has certainly brought about medications and other technologies that improve physical functioning for people with disabilities; however, many more difficulties for people with disabilities reside within the social contexts of disability (Gabel & Peters, 2004). This was definitely true for me and my parents. Whereas my parents and extended family wanted me back at home and found it relatively simple to add an outside lift to our house and renovate our bathroom to include grab bars, it was

considerably more challenging to weave me back into the social systems of school and our community where oppressive and negative stereotypes about disability were firmly ingrained. It was, for example, easy for me to make friends, especially with those who were curious about the wheelchair. But it was also difficult for me to retain those friends once my disability was noticed by other peers who chose to tease or make fun of me. I would quickly become someone who was a threat to my friend's social currency and I would be dropped.

Watching your child struggle socially is difficult for any parent and mine were no exception. At the same time, they also were without real-life examples of other people like me and like themselves. In other words, not only was I without expectations and social norms, so were my parents, and therefore they were also without imagination for what the rest of my life would be like. "There are so few role models...that parents often have no vision of what their children can become" (Olkin, 1990, p. 110). My paralysis and the uncharted territory of my new disability related needs seemed to overshadow everything else that I was or could imagine becoming.

### **It's a Girl Thing: Longing for Long Hair**

She still doesn't have what she deserves...  
She never really expected more  
That's just not the way we are raised...  
She's looking in the mirror  
She's fixing her hair  
(difranco, 1992)

In the fall that I returned to school after the accident, this time sitting in a wheelchair, wearing pants, and sporting a pixie cut, I remember expressing to my parents

that I wanted to grow my hair longer so that I could wear “pony tails like the other girls at school.” My mom, did not think this was a good idea, gently telling me that short hair was easier and that I had “enough problems without having long hair to look after too.” I was hurt then, but I do not blame her for feeling this way now. I do not doubt that if she had known how much it meant to me she would have let me grow my hair, but I did not push the issue. I remember feeling the need to protect my mother from further sadness very early after the accident. I also know that she was doing her best to care for me and that it must have been intensely difficult for her to do all the things for me that she was required to. I think about this long hair dilemma that my mom must have faced every time I now wash my own daughter’s hair and painfully have to comb through her tangles. Perhaps my mom was speaking to the exhaustion she faced being both my mother and my primary caregiver (she was, after all, responsible for all my physical needs at this point – from physical therapy, to lifting me in and out of bed, to transferring me in the bathroom and doing all my catheterizations) and combing through hair tangles was just one thing she could not add to her already long list of obligations. Or perhaps she was reluctant or even fearful to see me resemble a girl and all the complications that came with that (like boyfriends, dating) in addition to the identity of disabled, paraplegic, and needing a wheelchair.

I do not know the full extent of the explanation why my mom seemed to struggle with my identity as a girl, perhaps I never will, and perhaps it does not even matter anymore. It is difficult for her to talk about the accident and my childhood because she still bears personal responsibility for what happened. I do know that it was difficult for her to allow me to move through the rites of passage that other girls my age were experiencing. I

am sure it is difficult for any mother to watch her daughter move from child to adolescent, but although I know she was doing her best, I think it was especially hard for mine.

Without knowing what kind of a future existed for me, without any models or examples for her to look to for hope or inspiration, and with a deep sense of responsibility for my bodily care, I think my mom viewed me, at least at times, as weak, dependent, and helpless. She once confessed to me that she used to lie in bed and wonder what I would ever do without her. Fair enough. She had to do so much for me. She also had no idea what my future would be like. The only people with disabilities she had ever really been exposed to were elderly or in need of constant care. These characteristics are how people with disabilities are often seen (Olkin, 1990) and they are the opposite of how a mature, sexual person is seen, which is typically as strong, self-reliant, and physically competent (Wendell, 1996).

As an example to my resistance to the ideas of weakness and asexuality was when I was 12 or 13 years old, and aware of that other girls were starting to wear bras, I expressed that I wanted to wear one too. In my mind, this garment was a significant mark of a “real” girl. My mom was reluctant to purchase one for me, telling me that I “was not ready.” She was probably right – my body was likely not in need of one. However, afterward, I felt ashamed for asking and I did not mention it again, instead, however, I frequently left the Sears catalogue open to the bra section on the end of my bed, as a hint and subtle reminder. When she finally gave in to my unspoken pleadings and bought me a bra, it was not made of the shiny, satiny and stretchy material - that my cousins and friends were so proud of wearing. It was plain white cotton and I was disappointed.

### **It's a Girl Thing: My First Bra**

A Foucaudian analysis states that social forces, especially those related to sexuality, have an intense influence on how individuals represent themselves. Foucault (1984) would also say, however, that when these forces are exerted, resistance to the power of those forces may also occur. My desire for a pretty bra was much stronger than my sense of obedience towards my mother. In an act that resisted the power of my mother's act to provide me with the kind of undergarment that I thought exemplified prettiness and sexiness, I bought my own bra at the local Kresge's store with some saved birthday money. I chose it off the shelf then hid the small box it came in between a paperback novel and a chocolate bar. My anxiety that someone would catch me and tell me that I was not allowed to buy it made my breath come in short gasps, however, once I paid for it and hid it in the shopping bag, I relaxed a little. I had no idea how I was going to keep it as a secret from my mother once it was home in my dresser drawer. The entire act was worth it once I arrived home and put on that bra that was just like the one that the other girls were wearing. While my mom was trying to exert control over what she thought I should wear, and who she thought I should be, I was exerting a reciprocal power by demanding a part of my identity that I was desperate to claim. Perhaps I was also frustrated with how many times I missed out on the many social constructions that seemed to happen naturally for my female peers: I did not wear dresses, I did not wear my hair long, although I attended all my junior and high school dances, I was not the girl that anyone ever had a crush on, I very rarely danced with a boy, and I did not date. There were other more subtle markings of what it meant to be a girl – the way they moved, walked, stood, sat with their ankles crossed, and



danced. The purchase of a bra was something I could control, although the act came with the threat of shame and anxiety. But at the end of the day, I celebrated my approaching womanhood and developing body, albeit alone.

### **It's a Girl Thing: Dresses**

If I don't want to, I don't have to  
I don't have to wear a dress  
If you don't want to, you don't have to  
You don't have to wear a dress  
I can sit with my legs apart...  
(Halstead, 2001)

I chased my sense of feeling female for years, some days I think I still do. I still feel a twinge of displacement and a little bit of shame when I shop for lingerie. For me, symbols of femininity were tangible objects that were external to me and that made sense to a little girl: long hair, bras, and dresses. After that precious lilac dress was cut off of my small six year old body that day in the Emergency room, I would not wear a dress again for three years. By then, I was marking my ninth birthday at the Hospital for Sick Children in Toronto where I was a patient.

I had arrived at Sick Children's Hospital because my mom had read about the advancements that this hospital and its neurosurgeons were making towards spinal cord injuries research so she bravely picked up the telephone from her farm house kitchen in small town Saskatchewan and dialed one of the doctors in Toronto that she had read about. Astonishingly, the doctor told her to book a flight and bring me to the hospital and he would take me on as a patient. One of the first things the medical staff did for me was remove the indwelling catheter with the leg bag that was strapped to my calf and

subsequently taught me how to do independent, self-catheterizations, a process they promised me and my parents, that would add years to my life by ensuring fewer bacterial infections and less stress on not just my bladder, but also my kidneys and overall blood stream. But from a nine-year old's perspective, it also meant that the ugly, embarrassing, and smelly leg bag would be gone and because my legs would be free and bare, I could wear a dress again. I was excited about this idea! Dad went out and bought me a dress for the birthday that I celebrated as a patient and I remember the special event of unwrapping it in my hospital room at Sick Children's. Although I no longer have it (I wish I did), I can picture it vividly. It was buttery-cream coloured soft cotton with a lilac paisley trim. It even had a bow in the back. Dad admitted to me that no one would be able to see the bow when I was sitting in the wheelchair, but because both he and I knew it was there, that was good enough. I loved that dress. And I loved my dad for buying it for me and for somehow understanding that the dress could give me something I was missing: a sense of being ordinary, feminine, pretty and therefore in my mind, valuable, beautiful and whole.

Dresses continued to be an important symbol of my female identity into my adolescent years. For example, I desperately wanted to wear a dress to my first junior high school prom. Again, my mom was resistant, telling me that because I could not cross my legs nor keep my knees together while sitting in the wheelchair, that a dress was not the best option for me. There was an unspoken "girl" rule that to sit in a dress with your knees apart meant an increased potential for exposing something that best remained covered up. This risk of exposure of my private area, an area that is inherently sexual, only served to further confuse me. On one hand, I received the message that my disabled body rendered

me an asexual being, on the other hand, I was also being told that the dress could expose that which made me sexual. Nevertheless I still wanted a dress. I know mom sensed my disappointment and as she was a skilled seamstress, she offered to make me a “nice jumpsuit” out of whatever fabric I wanted. Eventually, however, I was either persistent or outwardly depressed enough that she gave in to my desire to look pretty and feminine and I wore a dress to my first prom, just like the other girls. Like the other significant dresses in my life so far, it was also a shade of lavender. It was also cut in the brazen style of the mid 1980’s. It was made of taffeta, had a fitted top and huge puffy sleeves that were in the “off the shoulder” style of the day. Underneath the shiny taffeta skirt of the dress, I duct-taped my knees together and I felt like a princess. It was not until I was in the girl’s bathroom midway through the dance that one of my female peers exclaimed that the back of my dress was so low that it revealed my surgical scars. There was no mistaking the shock and mild disgust in her voice. I was thunderstruck and then humiliated when her observation drew a crowd of girls surrounding and pointing at me and my scars that were peeking out from the top of the bodice.

The event was not the first time that I would be ashamed of my physically different body at school. Although many efforts were made to integrate me in the classroom with my non-disabled peers at school, I did not take part in many of the physical activities that boys and girls my age were involved in, including the physical education programs and no attempts to modify a program were made for me. Having to watch from the sidelines was a painful experience which was made worse in junior high (grades 7, 8 and 9) when I still did not participate, but was often required by the teacher to change out of my school clothes

and wear a gym uniform as I watched my non-disabled peers from the sidelines during physical education class.

### **Shooting Like A Girl**

At the same time, sport and physical activity were also activities that were integral parts of my family's life. Our visit to the Sick Children's Hospital in Toronto opened my parent's eyes to the benefits of physical activity. In particular, they were motivated to have me try swimming. Because they never did anything halfway, they researched, designed, and built an indoor swimming pool right outside my bedroom door and swimming became a daily activity for me.

Furthermore, both my older brother and my father were national team athletes in the sport of target shooting and I would often accompany them on trips to competitions, but just like all my other physical activity and education experiences, I was left to watch from the sidelines. Coincidentally, around this same time, my dad met a small motor mechanic who was a paraplegic. Knowing my dad's athletic history, he asked for some help in learning how to shoot. My dad provided him with equipment and some coaching. Once this fellow paraplegic started competing, Dad asked him if he knew of any young girls in wheelchairs who were involved in the sport. The answer was that there were not many, especially in Canada, but nevertheless inspired Dad to encourage me to try. As it turned out, I had plenty of skill that surprised everyone, especially me. I loved shooting and it was a boost to my confidence that I was good at a sport. The year was 1986 and I attended several matches that year in competition against my non-disabled peers. While at Nationals that year I was approached and encouraged by Olympic gold medalist, Linda

Thom, to try wheelchair sports. “You could be a Paralympic gold medalist,” she told me. I retorted, “I plan to be an Olympic gold medalist, actually.”

Despite my cheeky response, Linda’s views strongly influenced my dad, who, while he acted as my coach and worked with me daily, continued to entice me with ideas about coaching and travel. He took me to Calgary the following summer to compete at the nationals that included wheelchair shooting. This was my first-ever exposure to other wheelchair shooters and to other people in wheelchairs in general. To entice me to attend, my Dad had bribed me with promises of shopping and allowing me to drive around a big city. I was just terribly reluctant to involve myself with other people in wheelchairs. As Garland-Thomson posits, this reluctance I felt makes sense: “Our culture offers profound disincentives and few rewards to identifying as disabled” (2002, 22). I do not have an exact date for this journal entry because it was scribbled down in one of the many notebooks I was writing in at the time, but I know the story comes from that first introduction of wheelchair shooting:

These guys see me as just a girl. Before the match began, I even overheard one of them making the others laugh by asking them, “Can you shoot like a girl?” Well, I showed them how girls can shoot! I had a hard time getting into the range by myself and while bringing my equipment in I got stuck in the rain and was totally soaked before my first match. I was placed on the line right beside the current national champion, who looks like he has been shooting forever. He even had a beard for God’s sake. I bet he was thinking, “Who the hell is she?” as I unpacked my gear and my lucky teddy bear. The rain had pooled in my chair and left a puddle underneath me. How embarrassing, but it also showed how tough I am. And I beat him. Not by much, but enough.

I earned membership on the national wheelchair team from that day of shooting soaking wet on the line. A few months later I was invited to attend the 1987 World Championships in Los Angeles, California.

Despite the promise of traveling to California, I was still extremely reluctant to associate myself with other wheelchair users. As Carol Gill (1997b) contends in her theory of disability identity development, many people who have disabilities have internalized the societal fear and devaluation of disability and have been socialized to reject people with disabilities as having something in common with them. Gill argues that children with disabilities often communicate their wishes to feel like they belong by attending the same neighbourhood schools that ‘everyone else’ does. She also states that some people with disabilities will “vigorously avoid” (p. 42) contact with other people who have disabilities, especially activities that are primarily or exclusively for ‘the disabled’ since they have internalized the stigma and public fear of disability. Before I met the team I would be working with, I was no exception to this. I vividly recall how nervous I was the day we first came together as a team. That meeting happened at the Calgary International Airport on the way to the World Championships in California, which was our first competition as a team.

The first thing I noticed was that aside from me, my team was made up entirely of men who were all older than me (I was seventeen) and that many of them were the men who had been laughing at me a few months earlier in Calgary. It took a while for us to warm up to each other and for them to accept that I was part of the team. I remember how being the only girl on an all male team both helped and hindered my sexual identity

development. Because we were all wheelchair users, my disability was not my primary identification with my teammates. In the beginning of my shooting career my teammates did see me as female, but in a way that was a disadvantage. Because of my gender, I was an “added on” and reluctantly-accepted part of the shooting team, not a welcomed and included member of that team. Luckily for me, I was also intensely competitive, and so it was in that sporting realm that I felt considerable pressure to prove myself as a competitor to my teammates. Ironically, when I did this by winning a silver medal at my first world championships in 1987, my status shifted in the eyes of my teammates from the derogatory “girl” to the inclusive “one of the boys.” My teammates felt, I am sure, that there was no higher praise than to be labeled an honorary male. Because I had not felt like I had belonged anywhere before, being part of the team and described as “one of the boys” was an identification I accepted with open arms. I was used to not being seen as a girl and I was relatively comfortable with that. Additionally, the sense of community I received from being part of a team was invaluable. We all had different personalities, yet we shared a love of laughing, pranks, and telling jokes. We all adored our coach. We also shared similar body problems and it was a combination of these things and much more that created an environment where I felt safe, and as Carol Gill would label, “at home” (1997b, p. 43).

The fact that my team was all made up of other wheelchair users like myself, strongly shaped how I perceived having a disability and the meanings I gave it. Maurice Merleau-Ponty (1962) argues that this group involvement is a revolutionary act of combating the oppressive structures. Because of my involvement with these other people who had disabilities similar to my own, I created what Merleau-Ponty posits was a new

way of identifying myself through my lived-body and by sharing that activity through the interaction of other individuals who were undergoing a similar transformative experience. With this drastic change in the way I felt about myself and the sense of community that I was involved with, I made international competition a priority in my life and subsequently won two silver medals at the 1988 Paralympics in Seoul, Korea. I went on to win a bronze medal at the 1992 Paralympics in Barcelona, Spain.

Along with medals, I also won a shift in identity. The experience of high performance sport led me to see my body as having physical competence. Although Merleau-Ponty (1962) excludes the effect of differences, like gender and disability from his analyses of embodiment, his description of motility nonetheless fits well here. For him, motility is a belief that human subjectivity, or the ability to be insightful, perceptive, and discerning, is a process not located in the mind, but rather in the body and the ways in which your body moves in space is by consequence a new embodied experience. Since I was skilled at target shooting and was seen by my family members and coach as a strong and competitive athlete, I began to see my body in new, positive, competent, and empowered ways. My coach also had a powerful influence on both my emotional and physical confidence. The perspectives on my sexual identity, and the expectations that surround those perspectives, however, did not really change. Through sport I began to see myself as strong, and my body as skilled and physically competent, but there were still barriers to seeing myself as female.



## **Girl Meets Boy**

It was during this time that I also met, and eventually married my husband, Darrell. The story of how we came to love each other would be too long to include here, but I will say that we met in high school because we had the same homeroom and were in many of the same classes. Upon reflection, it was not easy for Darrell to get close to me. I had bought into the idea that I was not feminine, or certainly not feminine enough to be date-worthy. He spent a lot of time convincing me otherwise and took great pains to take me places that had been previously off limits (he carried me up a lot of stairs in those days). One event that particularly sticks out in my mind was when our high school's football team went to provincial championships in Regina. I wanted to attend the game but believed I would need my parents to drive me there since I could not get on to the chartered school bus that everyone else would be traveling on. Darrell insisted on the two of us getting on that bus (he carried me on and off and made a place for my wheelchair to be stored) and traveling the four hour ride with everyone else.

During the early part of our courtship, I was suspicious about what he found attractive about me. He had astonishingly blue eyes and a smile that was anchored by the deepest dimples I had ever seen. He had all the qualities of a great boyfriend: he was smart, funny, kind, friendly, and physically strong and fit. He was the kind of boy who could be with anyone he wanted. Therefore, I wondered why he wanted to be with me. I would try to "catch" him having negative attitudes about my paralysis and my wheelchair. When I once asked him what the first thing he ever noticed about me was, (expecting he would say my wheelchair and thus make me correct in my assumptions that my disability

was “in the way” of our relationship), he replied without hesitation, “I noticed your sunburn,” I finally allowed myself to fall head over heels. When I look back on that time, I marvel over how he defied social expectations and how much of a social risk he took by dating me. The reason I am convinced of his bravery is simple: although in our graduating class of nearly 300 people, I had a lot of friends who were boys who would have lunch with me, hang out with me during our “spares,” and party with me on the weekends; most of those same boys were reluctant to dance with me at a school dance and none of them, at least to my knowledge, would consider dating me.

### **Not the Girl Next Door**

My disability often rendered me sexless and genderless but I have to admit that this was not always a disadvantage. Garland-Thomas (2002) clearly states that “banishment from femininity can be both a liability and a benefit” (p. 18) and this was certainly my experience in high school. While it is true that my genderless identity did make me undateable in the eyes of many boys, however, at the same time, my non-threatening and almost chameleon-like identity allowed me to make connections with many of the strongly formed “cliques” in our school. I was friendly with leaders, geeks, jocks, drug heads and loners. The advantage of having so many friends allowed for enough votes to win me the class president election – a shared role between a girl and a boy named “Senior Pin” and “Senior Ring.” Despite my role as co-president and my unconventional popularity (the traditionally popular people were good-looking and fit, as I suspect they are in most high schools even now), I was not considered a social commodity and it was still highly unusual, gossip-worthy, and socially risky for Darrell to be seen dating me, kissing me in the

hallway, and holding my hand during library time. When I recently asked him about it to help me piece this part of the story together, he simply brushed it off, saying it was “no big thing,” but I remain convinced of how both his bravery and strong sense of self enabled us to come together. The act Darrell took in dating me was one of stepping outside firmly established social norms.

For our wedding, my mom (with help from my grandma) made me a spectacular ivory chiffon dress with a skirt so full it covered up half my wheelchair. During our first dance, Darrell surprised me (and most everyone in attendance) by taking off his tuxedo jacket, lifting me out of my chair and carrying me around the dance floor while the whoops and hollers of our friends and family nearly drowned out the music of “our song”: “Why Worry” by Dire Straits. Not a typical love song, it fit with our non-typical relationship. The melody was graceful and soothing and the words are meaningful and comforting, even now almost 20 years later:

Baby I see this world has made you sad  
Some people can be bad  
The things they do, the things they say  
But baby I'll wipe away those bitter tears  
I'll chase away those restless fears  
That turn your blue skies into grey  
Why worry, there should be laughter after pain  
There should be sunshine after rain  
(Knopfler, 1985)

### **Finding my Inner Girl**

At the time that I write this, Darrell and I have been married almost 20 years. I recently delivered a guest lecture on my perspectives on mothering with a disability and I

was asked by one of the students how my relationship with my husband influenced my sexual identity. This student explained that she assumed that simply, once I had a sexual relationship, surely I then saw myself as sexual. My response was, yes, that was true. My connection with Darrell was an intensely important part of my development and sexual identity, and yet, at the same time, I still did not feel *innately* sexual. My romantic and loving relationship with my husband definitely helped me with my views on how I defined myself as female, but his validation of my worth as a sexual person was still external to my inner core and my intrinsic feelings of femininity. Simply put, his love of me and my body were not enough. I needed to experience an embodied change as dramatic and altering as pregnancy and childbirth in order to finally see that I was a woman.

These feelings make sense when I consider the literature on how becoming pregnant can prompt a shift in the ways women identify themselves. Becoming a mother often means a re-evaluation of one's body (Grue & Laerum, 2002; Mullin, 2005). Because bodies with disabilities are often seen for what they can not do, taking on the role of mother can give the body a different value, status, and worth (Finger, 1990; Grue & Laerum, 2002). Grue and Laerum also found that for women who were injured in childhood, or who have lived with their disabilities all their lives, becoming a mother often gave women an opportunity to reclaim their lost or absent sexual identities. As I reflect on my relationship with Darrell, I suspect that the privacy of our sexual relationship did not adequately allow me to believe in and trust my sexuality. On the other hand, when I was obviously pregnant, my body was open for public presentation, and therefore no one could deny my sexuality and femininity, not even me.

August 17, 1996

Mother. Pregnancy. Parent. I never expected these roles for myself. These roles were never expected for me. How am I going to do this right when it was never in the imagination for what is possible?

These days, when I read the above passage, I am not sure what I mean by “right.” While I do not believe that there is a right way to be pregnant, give birth, and be a mother, there nevertheless exists a societal expectation that once pregnant, women’s bodies are open for public scrutiny more than they ever were prior to being pregnant. In particular, it is such an ingrained societal expectation that pregnant women are doing everything in their power to have a “healthy” pregnancy, there is no alternative perception available on this issue.

Robyn Longhurst (2000, p. 453) suggests that this is part of an array of “normative expectations” that prescribe how women will do pregnancy the “right” way. Alexandra Howson (2005) agrees and also argues that these surveillance practices, like pre-natal care, that are so much a part of our social consciousness, that we completely take them for granted. Other feminist writers such as Rosalyn Diprose (2002) have addressed how bodies (especially female bodies) are open for public scrutiny and how the pregnant body is constantly under surveillance. Carol Thomas (2007) argues that women with disabilities are particularly vulnerable to this scrutiny.

The public scrutiny that Thomas writes about makes me think about a particular memory of mine when I became pregnant with Patrick. I spent weeks and weeks in disbelief that I was actually growing a baby and I was overwhelmed daily with fears of how I would be scrutinized by others. I spoke to my general practitioner about how frightened I was, how I lacked confidence, and how difficult it was to accept that

something was happening to me that I never imagined would. While what I actually needed was an encouraging word and help making connections with other paraplegic mothers, my doctor instead mistook my symptoms to be depression and gently suggested that I should have a “therapeutic” abortion. Women with disabilities frequently miss out on supportive health care during their pregnancies and therefore some of them even receive strong suggestions to abort their fetuses (Lipson & Rogers, 2000).

As I end this section, I once again think about the story of the comments and questions from my judges at the Life and Health Sciences Research Day that I detailed at the beginning of this introduction. My conversation with them makes me think about how when we were first married, Darrell bought me a Barbie doll named Becky who used a red wheelchair. He gave me this doll when I was as a university student and Women and Gender Studies classes were widening my thoughts and reflections on my sexuality and my femininity. I immediately loved that doll and I still treasure her today, as do both my children who still play with her. When Darrell handed me the trademark bright pink box, I remember saying out loud how differently my life might have been if such a toy had existed when I was a young girl. I might have been able to see myself reflected in society, in my community, my school, and in my peer group. After all, my environment was devoid of other people with disabilities. Furthermore, I now see that my situation was more complex than that. While it is true that my community lacked other children or grown-ups who used wheelchairs, however, what is also true that the over-riding culture that was an invisible and pervasively able-bodied one (Garland-Thomas, 2002). It is only very recently that I see that these two things are not one and the same.

Of particular interest to me is the idea of the able-bodied environment, the pervasive able-bodied ideology and ubiquitous pro-ability culture that hates everything disabled (Garland-Thomson, 2002). Garland-Thomson draws comparisons between disability and race, using Pulitzer-prize winning author Toni Morrison's novel *The Bluest Eye* (1970) as an example. Since *The Bluest Eye* was a novel that I recently covered in my WGST 898 class on bodies, I have a heightened interest in the race-disability comparison. *The Bluest Eye* is a story about a little black girl named Pecola who loves blue-eyes – white images are everywhere from the films shown in the local movie theatres, to the nicknames “Ginger Rogers” and “Greta Garbo” that the adult men give to the little girls to the white blue-eyed dolls those black girls receive. So strong is the white ideology, Pecola prays for her own eyes to change from brown to blue, believing that if they did, all her problems would vanish and she would be left with a wonderful life. In the story there are no white people telling Pecola that she is ugly and that she needs to be blond-haired and blue-eyed in order to be acceptable and loveable, rather, Morrison reaches beyond this work of literature to speak to how a racist social system is so all-encompassing, that dominate images of whiteness show young black children that to be white means to be successful and happy. When those same black children then look around at their own lives of poverty and oppression, they learn to hate their black heritage for keeping them from the Shirley Temple world.

I include this brief analysis of the novel because I believe that Pecola's beliefs and desires to look white, blond, and blue-eyed are similar to my own feelings of wanting to be able to look and feel more like my able-bodied peers when I was a little girl. I think that

although no one was telling me that being paralyzed made me unlovable and unacceptable, the ideas of disability as a pervasive social ideology strongly informed my ideas of who I was (Garland-Thomson, 2002).

For me, receiving a doll that had a wheelchair would have meant that someone (particularly “someone” as large as the Mattel corporation) had seen disability as acceptable and worthy of inclusion. Sometimes, something as simple as a doll really can make a difference in how a child sees herself mirrored in the world. Similarly, I think I would have experienced my future maternal roles more confidently if I had been able to read another disabled woman’s story about her pregnancy and childbirth. I think both myself and the medical professionals who worked with me would have been better prepared if we had all had access to more information, research, and testimony about how disability, pregnancy, and childbirth can intersect. Just as I do not look like Becky, (the wheelchair and the red sneakers she wears are our only real commonalities), I do not expect that my story will ever be a direct comparison to someone else’s. However, I still believe that sharing my story can make a difference. Amy Mullin (2005) argues that the study of both able-bodied and disabled women’s experiences with pregnancy is both rare and new and not enough is known about how it affects a woman’s sense of herself as a female. Mullin also argues that because pregnancy is such a meaningful embodied experience, it is important to look at all kinds of contexts (e.g., social, cultural) because there will not be “such a thing as a typical experience of pregnancy” (p. 45). I know that when I was pregnant I would have liked to know I was not alone.



## **Big Girls Don't Cry**

I could have chosen to conduct another research project. I could have chosen to forgo the academic exercise all together and just write a book or memoir. I could have chosen to just protect the stories from public eye forever, leaving my journals for my children to find and read someday. I made a decision to write an autoethnography and I have made many decisions along the way about what stories are written down, which stories stay, and which ones leave. At the same time, however, it is almost as though some of the stories have lives of their own. They want out. They insist. Writing them down can be a mechanical process at times, but most other times it is a painful embodied process containing an aching chest, a nauseous stomach, and eruptive tears. It is difficult during emotional moments like these to even think straight, and yet, miraculously, my fingers nevertheless just keep putting down the words. During these times they insist on breaking the silence by typing despite my emotional response. So despite all my consciously-made choices, I also recognize that there is a story, or a collection of many stories here, that have been unheard for too long and that in the telling, they have the ability to bring about change. They can change attitudes about what it means to have a disability. They can educate medical professionals. But what I hope for most is that these stories can give strength and hope to other people with disabilities who want to experience all the depth, richness, complexity, and reward that can only come from the experience of loving a child.

## CHAPTER 2: RESEARCH METHODOLOGY

### Rationale for Qualitative Research

I make such a good statistic  
Someone should study me now  
Somebody's gotta be interested in how I feel  
Just cuz I'm here and I'm real  
(difranco, 1994b).

John Creswell (1998) asserts that qualitative research is a method well suited to a study or a topic that requires exploration. A qualitative study presents a detailed view of a topic by delving into the natural settings of individuals, and providing long, detailed and literary-styled data (Creswell, 1998). Furthermore, qualitative research, according to Norman Denzin and Yvonna Lincoln (2000), is “multi-method in focus, involving an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them” (p. 3). Qualitative research, and autoethnography in particular therefore, provides the means by which I can problematize the taken-for-granted notions of pregnancy and childbirth.

Increasingly, qualitative research is being conducted by researchers who belong to social minorities (Creswell, 1998). There is a growing belief that the stories of those from whom we have not traditionally heard, need to be listened to and understood in order to expand what we already know. “What qualitative researcher interested in social life would not feel enriched by membership in such a culturally diverse, inviting community?” (Richardson, 2000, p. 16).

## **Autoethnography**

Broken down, autoethnography is comprised of auto, or the self; ethno, the cultural; and graphy, the application of the research process (Ellis & Bochner, 2000). Literally, autoethnography is the formation of an ethnography that is concentrated on the self; the researcher is both informant and examiner (Cunningham & Jones, 2005). There has been a surge of autoethnographic writing in recent years (Anderson, 2006; Gannon, 2006). Patricia Clough (2001) claims autoethnography has quickly become “the most developed form of experimental ethnographic writing” (p. 280). Several authors remark that autoethnography is a provocative new way of writing and thinking in the social sciences (Bochner & Ellis, 2002; Denzin & Lincoln, 2000; Ellis, 2004, 1997; Reed-Danahay, 1997). However, it has also been argued that it is not a new method -- it just has the new name of “autoethnography.” For example, Foucault called autoethnography ancient writing (1997). An autoethnography is usually written in the first person and highlights emotions and self-consciousness as stories affected by history, society, and culture (Ellis & Bochner, 2000).

## **More than Just a Story**

One critical component of autoethnography is the stories that it tells, the important part of knowing that comes from an individual experience. Stories are an important way of bringing understanding to the lives of those from whom we otherwise do not hear. Autoethnography is about “lots more stories waiting to be told, stories that are sometimes difficult to tell, that need support and understanding in the telling” (Muncey, 2005, p. 7). However, autoethnography attempts to do more than just tell a story. Autoethnography connects the personal story to the cultural, situating the self within and yet apart from, a

social context – therefore flowing from a personal perspective to a cultural or societal one and back again is vital to this research method (Ettore, 2005; Reed-Danahay, 1997).

Denzin and Lincoln (1994) have stated that autoethnography is part of a methodological trend that they refer to as the fifth moment in the history of qualitative research, whereby participatory research and experimental writing are robust features. One of the qualities that distinguish ethnography from autoethnography is that the autoethnographic researcher is not trying to become an insider in the research setting -- he or she is already an insider (Duncan, 2004). Disability researchers such as Anne-Mette Bredahl (2007) and Titchkosky (2007) assert that more people with disabilities need to be active in their own academic research.

### **Bodies**

Autoethnography is a good fit for examining the experiences of bodies (Gannon, 2006; Holman-Jones, 2005). The method of autoethnography acknowledges the body's source of knowledge or what Elspeth Probyn (2003) calls "a site for the production of knowledge, feelings, emotions, and history, all of which are central to subjectivity" (p. 290). Furthermore, autoethnography is connected to the stories that only bodies can tell, especially pathologized bodies (Gannon, 2006) and bodies that have experienced disability and illness (Ettore, 2005). The experience of pregnancy and childbirth was particularly life-changing for me, and because I have always felt compelled to write down the stories of my life, I documented these experiences with my two children throughout several handwritten journals. I feel that these stories, my lived experiences as a woman with a disability experiencing pregnancy offers insights and understanding into what it is already known

about women's bodies. Kathryn Church (1995), in reflecting on her own autoethnographic work stated:

Critical autobiography is vital intellectual work....it is possible to learn about the general from the particular; second, the self is a social phenomenon....Writing about myself is a way of writing about these others and about the worlds which we create/inhabit...Because my subjective experience is part of the world, the story which emerges is not completely private and idiosyncratic (p. 5).

Autoethnography is a useful research method for uncovering lived experiences from those who live in "different" bodies and are living "different" experiences (Holman-Jones, 2005; Neville-Jan, 2004). At the same time, however, all bodies are stories with both sexual and social histories intertwined with multiple plots (Foster, 1994). As Wendell (1996) asserts, the experience of disability expands the variety of possible human physical experiences that the able-bodied human population may never experience. A more complete understanding of embodiment, therefore then requires a comprehensive understanding of the embodied experience of disability.

### **Looking Inward/Looking Outward**

Autoethnography requires internal reflection while being committed to a scholarly pursuit of the new discovery for the social sciences (Duncan, 2004). In other words, there is authenticity around autoethnography because it is committed to developing theoretical understandings of broader social phenomenon while also documenting the moment-to-moment details of an individual's life (Anderson, 2006; Reed-Danahay, 1997). This distinguishes it from autobiography. Autoethnography is a research method that is about narratives that "connect the autobiographical and personal to the cultural and social" (Ellis,

2004). This research method can encourage empathy and connection beyond the self and contribute to meaningful sociological understandings (Sparkes, 2002).

I also found that often a good way to understand this method of looking inward and gazing outward was to look at an example. In his work “The Fatal Flaw: A Narrative of the Fragile Body-Self,” Andrew Sparkes (1996) describes what it was like to define himself as an elite athlete and have both his athleticism and regular life activities interrupted when inflammatory back disease became a part of his daily life. He writes “I...attempt to take you as the reader into the intimacies of my world. I hope to do this in such a way that you are stimulated to reflect upon your own life in relation to mine” (p. 467).

Sparkes’ reflections on athleticism resonated with me. Having several years of experience in high performance target shooting, I like to think of the personal and cultural components of autoethnography in comparison to shooting an air pistol. When a shooter peers through the sights of an air pistol, he or she can clearly see either the front sight, which is directly in front of him or her (the personal), or the target which is down range ten metres away (the cultural). A skilled shooter creates a picture of both of these and depending on where he or she is at in the process of releasing the shot, either the sights or the target will be emphasized and sharply seen, but both must and will be part of the image. “Autoethnography is setting a scene, telling a story, weaving intricate connections among life and art, experience and theory, evocation and explanation...and then letting go, hoping for readers who will bring the same careful attention to your words in the context of their own lives” (Holman-Jones, 2005, p. 765).

## **Data Collection**

### ***Journals***

The process of writing my life is not new to me as I have been writing for over twenty years. As a child, writing was a way to keep myself “company” on those lonely days in the hospital. When I was a young girl, I called these books my diaries. As a teenager I started to call them journals which felt like a more sophisticated and mature label. For me now, the difference between a diary and a journal is one of focused content. A journal is a place where I can explore my thoughts, my feelings, and my questions about life. A diary, at least for me, is a place where events are recorded in a specific place and time. My journal holds some day-to-day events, such as documenting my children’s birthdays or the anniversary of my car accident. However, my journal also contains lists of things I want to do while I am still lucky enough to be alive, the songs that I consider to be the soundtrack of my life, and my anticipations and fears about growing old. My journal writing these days contains fewer day-to-day accounts and instead, more about the nuggets of meaningful interactions or thoughts I had during a day.

Whatever the label, diary or journal, writing in small, blank books when I was a little girl was a way to tell my secrets, since many of my childhood experiences, particularly those times spent in the hospital, were not always positive and happy. My journals were my friends because I trusted them with my secretive stories and therefore became one of my main means of coping. As a teenager and in my early adult years, the writing process gradually evolved to become one of self-reflection, even therapy. Max van

Manen (1990) captures my reason for journaling: “Intensive journal writing is used for the purpose of ‘self-discovery’ or for coming to terms with personal problems or issues in one’s private life” (p. 73). Later on, as I studied the genres of women’s life writing, including diaries, autobiography, memoirs, and biography in university (English 270, 281; WGST 398), I started to look at my journals in a fresh way. I wondered if they could contribute to our meanings of bodies, of what it means to be a woman, and of what it means to be a woman with a disability.

Journal writing is considered a valid method of data collection amongst qualitative researchers: “Journals are a method of creating field texts” (Clandinin & Connelly, 2000, p. 102). Journal writing, as a form of writing about one’s life, can be an effective means of documenting and understanding an individual’s life: “Journals are a powerful way for individuals to give accounts of their experience” (Clandinin & Connelly, 2000, p. 102). van Manen (1990) argues that “Another common interest in the human sciences are diaries, journals, [and] logs for purposes of educational, research...value” (p. 73). The journals entries from which I drew for the stories of pregnancy, childbirth, and disability were the ones I started on the day I learned I was pregnant with each of my children and ended on the days I gave birth to them. However, my graduate committee encouraged me to also reflect on journal entries that were outside of these timelines, so I did that as well. Some of those stories are included in this thesis. Although I eventually had to limit how much I went back through the years of journal entries, I found that a few pivotal experiences from other times in my life besides the times I was pregnant, were key to the analysis.



Through journaling I explored, documented, and reflected on the life changing experiences of pregnancy and childbirth with my two children. Like my diary keeping as a child, I also included day-to-day details of what was happening around me and how my body was changing. I wrote the journal entries in long hand, and I have re-read them several times before I transcribed them into an electronic format. Between my two experiences with pregnancy and childbirth, as well as the entries from other times in my life that seemed to fit in the analysis, I recorded and transcribed over fifty single spaced pages of rich, intensely personal and moment-to-moment stories.

When undertaking the process of analyzing my data, I looked to work of other autoethnographers. For example, Elizabeth Ettore (2005) wrote an autoethnography that drew on data and analysis from diaries that she kept for two years while living with a chronic illness. She also attached letters to her diary entries. Before writing, she thoroughly read her diaries several (four) times. She then wrote down the key events in a chronological order. Ettore found that engaging in this process is painful and emotional, and yet she writes that it is this painful introspection where she found healing and the chance to make sense of her illness experience. I used a similar process of analysis of reading and re-reading, writing down key events in a chronological order, and determined the themes. The process of categorization and theming changed again once I started writing. Many ideas from the chapters overlapped and I found it important to make fewer, longer chapters. Margot Duncan writes about “meaningful units” (2004, p. 7) and I interpret these units as one’s “best” stories. What was surprising was how they emerged in

a much messier way than I could have ever anticipated. Themes and sub-themes were revealed to me at my desk, but also at unexpected times during the course of a day.

**From:** Heather Kuttai [mailto:heather.kuttai@shaw.ca]  
**Sent:** Fri 5/25/2007 3:06 PM  
**To:** Donna Goodwin  
**Subject:** I'm having a hard time

Hi Donna,

I am currently going through my journals and cutting and pasting entries as they fit into particular themes. This process, coupled with my general tendency to have “flashback” memories, is getting tiresome. It’s not as though I haven’t emotionally dealt with things – I have, quite well I think, considering how much I have written and reflected during the tough times, during the good times. I don’t even know why I am telling you this, however, maybe I just want you to know that I am working hard, and that it is hard work.

I thought the hard work was over, but it is like I am reliving all that has happened, and that is also hard work. Sometimes I will just be working away at anything – laundry, cooking, diapering, grocery getting – not just the writing – and I will just want to shout “Stop! I need to talk, cry. Don’t you know what has happened to me?” Pretty crazy, huh?

Heavy sigh.

Have a great weekend, Donna. Thanks for listening.

Heather

I also used other sources of journal data besides the stories in my pregnancy and childbirth journals. During the process of analysis, especially when I wrote down a timeline of key events in my life, I remembered other stories I had written down in my other journals. During data analysis, I re-read my pregnancy journal entries at least six, if not more, times. The process of transcribing involved another reading. Through the process of reading my journals and transcribing them, I experienced some of the introspective pain that Ettore describes. I believe that I fully understand how this process of remembering and making one’s memories and stories public has become too much of a

barrier for others who have attempted autoethnographic writing. Interestingly, exploring my personal story against the landscape of disability theory and feminist theory connected it to the larger cultural and social context which made the sometimes painful introspection easier to take. Perhaps this was because I felt my experiences were given validity and legitimacy and that writing them in this way had the potential to contribute to a “higher purpose.”

### *Music Lyrics*

Like many people, I simply love music. Music nourishes me and gives me energy. This has been the case ever since I can remember whether the music came from my Mother’s many songs that she would spontaneously break out in whenever she was inspired (which was often), the many songs my Dad would whistle, or the countless popular songs from the 1970’s that my brother would introduce me to on his 8-track stereo. It was not unusual to watch my mom dance a little jig in the kitchen while she worked or to secretly witness my parents dancing to a waltz in the living room after dark. These days, I am always on the search for new, usually independent and “alternative” music to listen to. I tend to steer away from music that is considered popular and instead seek out to support music by musicians that are working hard to make a living with their art. My son plays a few instruments; I also dabble in playing the guitar and the piano. I sing, well or otherwise, every day.

I consider music and music lyrics an art form. Music lyrics are forms of art that give me feelings of connection in the social world. I have collected music lyrics that

“speak to me” for over 20 years and these lyrics help to tell my story. Some of the lyrics I used in this thesis are ones that I have captured in my journals, some are posted on the bulletin board in my office, and still others are kept on scrap pieces of paper in my wallet. During the writing of this thesis, I have started keeping electronic files of music that is important to me. The collection is eclectic. Many of the lyrics that I collect are written by women singer/songwriters or are songs by both men and women about social justice and fairness. A few are by popular music artists, most others are more obscure and lesser-known. It felt both natural and critical that some of them were included in this thesis, in the telling of my personal story because they are a part of who I am and who I consider myself to be to others.

In this time of government cuts to our country’s arts and culture programs, I have reflected on the need for and the relevance of arts in our lives. One conclusion I have come to is that we cannot thrive or survive without beauty. Music lyrics provided inspiration in my writing process. As is the experience of many graduate students, my friends, family members, and acquaintances frequently wanted to know “how much more I have to write” or who wondered when (on earth) I was going to be finished this thesis. I would consistently answer, “I want my thesis to be a beautiful thing.” And although many times they would roll their eyes at this comment, I truly believe that lyrics helped me find this beauty.

Additionally, the music lyrics, many of whom are written (and performed) by women added a piece to this puzzle which was my experience with pregnancy, childbirth, and disability. According to Charlotte Greig (1997), this makes sense. She writes that the

presence of women songwriters who disclose their experiences with femininity, identity, childbearing and motherhood has an impact in how women listeners see themselves and their own experiences. The connection I felt to music lyrics during my pregnancy and childbirth was significant to my experience. I needed to hear what other women thought about motherhood and reflect on whether their words described my own thoughts. I felt compelled to find music that made me feel connected to other women because while pregnant, I was feeling like a woman for the first time in many ways.

I also included music that reflected themes of social fairness and that spoke out against social injustice. These lyrics are written by both men and women. These themes resonated with me due to the difficulties I was experiencing with my doctor, the inaccessibility of the hospital, my own conflict about my identity and expectations, and the negative attitudes others had of my pregnancy and childbirths. I was also inspired by music lyrics often during the writing of this thesis. Sometimes I sought out the lyrics, but most of the time they found me; the ones I chose to include in this thesis spoke to my emotions and my experiences. Greig (1997) echoes my feelings of connection when she writes that music can make a listener feel like she is part of a community of those who share dilemmas, problems and decisions.

Adding music lyrics allowed me to reflect on how I make decisions on how songs resonate with me and the process by which I make decisions on what parts of a song to use and which parts I leave behind. The whole practice of contemplation, decision-making, and interpretation of music lyrics was one I found intriguing. Music theorist Anthony Pople (1994) asserts that there is no “real” meaning in theory, and that we all use different

ways to emphasize and combine meanings for our own purposes. In this light, there is not “true” meaning in a song. For example, “Change is Gonna Come” a famous song by Sam Cooke (1964) that was originally intended as a protest and commentary about racism in 1960’s America reverberates with meaning for me – a white Canadian woman with a disability. The meanings of the lyrics I chose are interpreted, constructed, and even re-written through the lens of how I interpret, construct and re-write my own life, my own self.

### *Letters to Sharon*

As a young girl, I was a letter-writer and had several pen-pals, especially in Western Canada, due to my involvement as a creative writer for one of our agricultural newspapers. Years later, when physiotherapist-turned-trusted and dear friend Sharon embarked on a trip that physically separated us for several months, we started writing letters to each other. Later, when she re-located to another city, we continued writing and have never really stopped. Sharon kept all my letters (as I kept hers) and knowing I would appreciate the gesture, she returned them to me when she was packing and moving to a new home.

**From:** Heather Kuttai [mailto:heather.kuttai@shaw.ca]  
**Sent:** April 13, 2007 10:07 PM  
**To:** Donna Goodwin  
**Subject:** the lottery

I feel like I just won it.

I read another 2 new journal articles (one by Duncan, one by Ward) on autoethnography today. One of them just briefly mentioned other artefacts and named letters in the long list. A huge light bulb went off.

My former physiotherapist and now very close friend, Sharon, and I exchanged letters for years. About 5 years ago she sent all of mine back to me with a note saying that she had the feeling I might need them someday. She was right. I wrote her at least once a month while I was pregnant with Patrick. The fact that she was my physio is relevant – we had a close relationship that centered around my body. Furthermore, she went through a life change by leaving her husband for another woman (with whom she has been in a long time relationship – over 10 years) and those themes are important because we were, in these letters, exploring our new identities as women together. These letters will definitely be part of my data.

Don't you love it when the stars just line right up for you?

Had to share. Talk to you soon.

hk

As I said in my email to Donna, I knew the letters would contribute to my story and provide another dimension to how I was thinking and feeling during my pregnancies.

Therefore, I transcribed eight letters I wrote to Sharon during my first pregnancy.

While my journal entries provided the main body of my data, the letters will take on another angle to my story because of who I wrote them to. Ever since I took English 270 as an undergraduate student, I have been interested in the concept of audience in forms of life writing. I read Anne Frank's famous diaries with the question of who she was writing to – a friend, her version of God, herself? When words are put down on paper, I think the writer is aware that someone, someday, may read those words, and thus, an audience is present. My letters to Sharon speak to this idea. I disclosed experiences and feelings differently to her than I would in my "private" journal, and therefore I believe the letters provide another dimension of analysis to my autoethnography.

### ***Treasured Items***

I am including two items that are meaningful to me. One is a print by Pablo Picasso that I purchased at the Picasso Museum in Barcelona, Spain at the 1992 Paralympics. The other is a poem that my coach, Finn, wrote to me during a training camp held prior to the 1988 Paralympics. The stories that accompany these artifacts are told later in this thesis.

Creswell (1998) states that in qualitative research, artefacts can assist in telling stories and understanding themes. Duncan (2004) claims that gathering documents and artefacts support the researcher's opinions by confirming or triangulating their data. In understanding artifact use, I looked to other autoethnographies that use artifact analysis to help piece together a complete story.

### ***Photographs***

The photographs I chose to bring to my data collection are from personal photo albums, scrapbooks, and shoeboxes that hold pictures of me and people I love from various points in my life. Many are from my childhood. Others are from my days in competitive sport and still others are of me when I was pregnant.

When I initially made the decision to add photographs in my thesis, I did not construct an organized and planned process for choosing them. Instead of thinking for example, that I wanted a photo from childhood, one from the Paralympics, one when I was pregnant, I instead simply randomly sorted through photos. I made quick decisions on which pictures were meaningful to me and which ones struck me as symbolic of a meaningful story. However, although the photos assisted my memory to be triggered



which enabled me to remember, reflect, then write, in the end I decided not to include them in my final thesis. Most of the photos I looked at did not hold enough meaning for me to be included here; still others were too private and intimate that I did not feel comfortable sharing them.

## **Data Analysis**

### ***Getting it Right***

Autoethnography cannot be just used to tell a personal story, and it is this possible inclination that has led to its criticism for being narcissistic and self-indulgent (Coffey, 1999). Furthermore, its use of self as the sole source of data has been questioned (Denzin & Lincoln, 1994; Sparkes 2000). To counter this potential problem, Laurel Richardson (2000) argues for holding autoethnographies to “high and difficult standards” (p. 15-16) and outlines five criteria that she uses when reviewing papers for social-science publications. These criteria are: (a) substantive contribution, which assesses whether the writing will contribute to a deeper understanding of social life and whether the author has a solid knowledge of social science; (b) aesthetic merit, which judges the artistic and creative qualities of the writing; (c) reflexivity, which requires the author to consider and understand the epistemology of postmodernism, the history of how he or she has come to write the text, deliberation on any ethical issues, adequate self-awareness and a strong capacity for personal responsibility for what is being written; (d) impactfulness, which requires the writing to be affectual, emotional and influential to the reader; and (e)

expresses a reality, which is the manifestation of a deeply considered and believable account of a lived experience. Richardson also suggests that autoethnography should be evaluated by questions about whether the work has an emotional or intellectual impact.

In my attempt to demonstrate authenticity to my research process, I feel I used these criteria on my own writing. My original intention was to contribute to the understanding of our complex social world and the multifaceted relationships we have with our bodies living in that world, and I believe I have stayed true to this goal. What is important for you, the reader to understand, is that I did not post up Richardson's criteria and review them every day. Rather, when I read them for the first time, I was struck by their intensity. The criteria she outlined made sense to me and I knew I wanted my thesis to reflect those qualities. In that moment, I made a commitment to those criteria and it was in this spirit of commitment to a beautiful, reflexive, self-aware, and emotional story that I wrote. While I certainly did numerous self-checks with myself and with others close to me, this initial vow was what actually set the tone for this text.

Nevertheless, the process was not terribly organized. I started by writing down a timeline of the key events of my life and I taped this timeline to the wall in my home office where I could always see it, but it was the decision making around those key events that were the most important work. Deciding which events mattered the most, or were the most critical to my identity and development led me to think about the symbolic meaning of those events and how they led to other events. I could also see how some situations happened over and over again (such as wearing dresses).

From there, I went through the journal entries and wrote down key themes in the columns of the paper. Then I decided what words and phrases stood out. From there I determined five themes. I found some coloured paper, marked the themes at the top in bold letters, then listed all the stories I considered to be meaningful in point form underneath those titles. The themes thereby became the chapter titles.

**Sent:** March 10, 2008 10:57 AM  
**To:** Donna Goodwin  
**Subject:** I forgot

Donna,

Sheesh. I forgot to tell you that I also did a re-read of my journal entries, made a chronological timeline of events and picked out my “best” stories. From there, I found 5 themes:

How Sport Prepared Me for Pregnancy and Childbirth  
Change in Identity  
Fear of Public Perception  
No one is Listening to me (I have yet to think of a better title for this theme – it is mostly about the problems I had with the medical system)  
Sacrifices/Gains (this one is short, I wrote it as a sort of poem and I attached it to this email)  
hk

However, once writing the chapters, I was continually frustrated. I was peppered with doubting questions: Did I just repeat myself? Did I miss an important story? Hadn't I just said that, even in a slightly different way, a few chapters ago? I would often become overwhelmed with the amount of stories and words and feel like I was not making progress. I then decided it was important to just tell the whole story as basically and matter-of-factly as I could in the first chapter, or Introduction of my thesis. This seemed to help the organization somewhat, and it was with this organization in mind that I handed in my first draft to Dr. Donna Goodwin.

**From:** Heather Kuttai [mailto:heather.kuttai@shaw.ca]

**Sent:** May 22, 2008 3:16 PM

**To:** Donna Goodwin

**Subject:** progress

Good afternoon, Donna,

I hope this finds you well. I want to give you an update on where I am at with my thesis. I have written 4 chapters based on themes. I have consolidated them into one big document with my introduction, literature review, and method chapters. I am now going through this "big" document to make small and bigger changes. I fear that I have repeated myself in places, having been absorbed in (more or less) a one chapter at a time approach. That being said, I never could have imagined how messy and untidy the process of theming and writing could be. Shocking.

Once this task is finished (within the next day or 2), I need to update my literature review, update my references, and include a section on the theories I turned to (I expect this will go in my methods chapter).

I don't know if this matters, but right now this document is 133 pages without a discussion chapter.

I often find myself wishing selfishly that you were right next door.

I will send you this first draft by the end of this month.

The queen of choppy emails,  
Heather

After reading the first draft of my thesis, Dr. Goodwin thought I was on the right track in many ways. Nevertheless, she confirmed my nagging thoughts. I was repeating myself and without a clear picture of how the sequence of events unfolded, it was easy for the reader to become confused. She suggested that I attempt to re-organize my thesis again, but with a chronological order in mind. While it initially felt like I was betraying the goals of theme-based qualitative research somehow by being linear and orderly, I quickly realized that an autoethnography is a story first, and that my story at least, needed to be told in a chronological way in order to be the most effectual and clear. Themes quickly became clear within the chapters, and I used my sub-headings to state what those themes are. Once the story was in this linear order, I then saw how inaccessibility was a theme all on its own

and because it permeated all the timelines and most of the stories, I made it into its own chapter. Similarly, I was slightly dismayed at the sadness that many of my stories evoked and I knew that while I had struggled every day during my pregnancies, that there was also a happy story to tell. I felt compelled to balance out my thesis with a chapter on the joyful experiences of being a mother and I found that music lyrics were present throughout those stories as well.

Leon Anderson (2006) contends that autoethnography occurs when the researcher is dedicated to analytic reflexivity, dialogue with informants beyond the self, and “an analytic research agenda focused on improving theoretical understandings of broader social phenomenon” (2006, p. 375). Anderson pushes the use of the term “analytical autoethnography” to push the ideas of analysis and deep personal reflection while always making the attempt to make links to the bigger social world. Carolyn Ellis and Arthur Bochner (2006) echo this statement when they wrote that the analytical autoethnographer is committed to developing theoretical understandings of broader social phenomenon that goes beyond the data. This is one way that autoethnography, particularly analytical autoethnography, distinguishes itself from story-telling or autobiography. In order to use the research method of autoethnography and thereby distinguish this work from an autobiography, I displayed multiple levels of personal and cultural consciousness while consistently connecting to the larger understandings of the culture of pregnancy, childbirth, and disability.

On the other hand, Anderson (2006) warns that because the researcher is a complete member of the researched group and given the textual visibility of the self in the writing

and research, “the potential for self-absorption can loom large” (p. 385) in autoethnography. I continually did self-checks and deeply reflected on my story’s connection to the larger network of cultural and social discourse as represented in the literature pertaining to disabled embodiment. Tami Spry (2001) is clear on the importance of keeping an authentic voice throughout the writing process while also looking to the broader social world: “Good autoethnography is not simply a confessional tale of self-renewal; it is a provocative weave of story and theory” (p. 713). Done well, autoethnography communicates world views that might not otherwise be seen, and presents insights that might otherwise have been too subtle to extract (Cunningham & Jones, 2005).

Autoethnography has been criticized for neglecting the use of theory (Anderson, 2006; Cunningham & Jones, 2005; Gannon, 2006). However, Susanne Gannon also states that “bodies are connected to other bodies. They exist and acquire meaning in social spaces” (p. 477), and therefore will always have a theoretical perspective. Bodies and the stories that they tell are always situated in particular social, historical and cultural spaces and times (Gannon, 2006), therefore as Jacqueline Zita (1998) writes, “The body is always in theory and...theory making is a labor of the body” (p. 204). As I illustrated many times throughout my thesis, writing my story as honestly and provocatively as possible was enormously challenging, as was interpreting and analyzing my experience in the light of feminist, social medical, Foucaudian and disablement theories.

## Self-Checks

The writing process for this thesis was complex and multi-dimensional for me. It was lonely, yet comforting, painful yet healing, depressing yet invigorating. With these conflicting emotions and experiences, it was important for me to frequently talk some of my thoughts out loud. Talking through some of my stories allowed me to “hear” the stories from a different perspective than just through typing them and seeing them on a computer screen. It was not so much that I needed to speak the stories out loud to verify or authenticate them or complete any missing details. Rather, often talking them through allowed me to toss the stories around, see them from different angles, and sometimes remember an important detail. I talked primarily to my husband, but I also had some conversations with my Mom and Dad, as well as a few email exchanges and long-distance telephone conversations with Sharon and Finn.

Lastly, I want to mention that it was important for me to give the stories some time and space once they were “saved” or printed on paper before I went back to edit or restructure them within the larger document. This is an important component to a creative process (Horner, 2006). It has also been suggested that there are many problems better served by slower, more intuitive thinking, rather than the linear, logical process (Claxton, 1999). Although I wrote something nearly every day since I presented my proposal a year and a half ago, giving the stories (and me) time to breathe was important to how well they were told.

## **Ethical Considerations**

Autoethnography sparks unique ethical concerns. For one, most research projects where an application for ethics approval is obtained at the beginning of the research process, however, I applied for ethics approval near the end of my writing. This is because I would not have known for certain the different individuals that would be included in my research. My main ethical concern was with the individuals in my life that I have written about. For example, my husband's identity cannot be altered to protect him. The same is true for my children, my parents, and my parents-in-law. When I discussed these ethical concerns with Finn and Sharon, they both understood, but voluntarily and enthusiastically chose to have their real names used in my thesis.

I attempted to create as transparent of a process as possible with these people. After all, they are among those who I love best in the world. To minimize harm to them, I have discussed my writing with them and when they wanted, I have allowed them to view sections of my thesis that includes information about them. I have been clear that they may ask that sections they perceive as harmful to them be removed from my thesis. For other individuals that I have written about (e.g., doctors, teachers) I have altered their identities by changing their names and sometimes their genders in order to protect their anonymity. In the end, however, the person who was most at risk for harm and emotional upset, was me. It was a often a difficult emotional process and I have written about that stress at various points in my thesis. I relied heavily on a small and trusted circle of individuals, including particularly, Darrell, to support me through these challenging periods.



Since examples of autoethnographic ethics applications and consent forms were not available to me during the writing of this thesis, I have added mine as appendices for future researchers to consider.

### **Postmodern Disability Discourse**

Traditional forms of science have required that researchers try to minimize their bias and subjective experience and deny their identities within the research (Wall, 2006); and historically, science has been defined as quantitative, experimental, and objective (Holt, 2003, Neuman, 1994). Postmodern thought challenges authoritative definitions and dismisses the idea that there is any one truth, or that any theories can claim truth. The postmodern research movement has raised misgivings about the privilege of any one method for obtaining authoritative knowledge about the social world (Holt, 2003). Therefore, in the wake of the postmodern, traditional writing practices for qualitative research have been critiqued (Richardson, 2000). Indeed, a postmodernism approach must affirm that there are many ways of knowing and inquiring and that there is no one way that should be held in higher esteem than others (Duncan, 2004; Wall, 2006). Postmodern discourse therefore offers us a rich research methodology in which we can draw upon several methods of inquiry. Questioning any research methods that claim to be the “right” way of knowing is at the core of postmodernism (Holt, 2003; Richardson, 2000). For Richardson, postmodernism claims that the self cannot be separated from our research and writing despite traditional efforts to repress our presence and the desire to act objectively. Furthermore, as a form of evocative writing, Richardson argues that autoethnography finds

roots in postmodernist thinking because it acknowledges and values the self that always exists in writing and research, while relating the personal to the cultural.

Teach myself to be new in an instant  
Like the truth is accessible at any time  
Teach myself it's never really one or the other  
There's a paradox in every paradigm  
(difranco, 2005).

Postmodernism, fundamentally, contributes to an understanding of disability and embodiment. Miriam Corker and Tom Shakespeare (2002) explore what “post-modernist and post-structuralist scholarship can contribute to our understandings of disability and the diverse experience of disabled people” (p. 1). Historically, they argue, the medical model defined disability as abnormal functioning of the body that needs fixing.

Moving forward in time, the social model attempted to understand disability as something that is socially constructed. This worked for many disability researchers and social construction theory has therefore had a strong history within disability studies (Davis, 2002; Wendell, 1996). Disabilities are social processes that do not have inherent meanings that reside in their physical differences, but rather that those differences are assigned, named, and labeled by societal processes and systems (Davis, 2002). Despite the focusing of attention on the disability experience, a preoccupation with dichotomies, such as sickness/wellness, nature/culture, and impairment/disability and other dualities based on hierarchical systems, the lens of social constructionism ignores more complex social realities: “Analyses of the subjectivity of those positioned by social structures and practices as having disabilities” (p. xiv) [and are] “an important complement to and deepening of these political [social model] arguments” (Davis, 2002, p. xiv). This, they

posit, is what a postmodernist contribution to disability studies offers. Put another way, the social constructionist perspective sees only a black and white forest while paying little heed to the obscured realities of the trees on the forest floor.

In writing this thesis, I used different theories and a diverse amount of literature to make sense of my personal narratives in the larger social and cultural world. I primarily used feminist disability theory, social medical theory, disablement theory, and Foucaudian analysis.

### **Feminist Disability Theory**

Feminist theory that centered on perspectives on disability was a significant influence on my thesis writing. In particular, I drew on work by Wendell (1996) and Garland-Thomson (2002). Wendell uses her experiences with disability to connect with feminist theory as well as literature on disability. Wendell sees disability as a social construction and her views on how the embodied knowledge and experiences of people with disabilities can provide a significant contribution to feminist theory were particularly influential to my own writing. Similarly, Garland-Thomson calls for a new feminist disability theory. She asserts that the meshing of disability issues into feminist claims refreshes, challenges, and augments feminist theory. She clearly acknowledges that although feminist theories have repeatedly ignored disability, she feels that disability theorists need not start from scratch constructing their theories of disability just because they have been neglected. “The pronouncements in disability studies of what we need to start addressing are precisely issues that feminist theory has been grappling with for years” (p. 1).

### **Social Medical Theory**

Arthur Frank's writings (1995, 2002, 2004) had a tremendous influence on my thesis writing. Offering testimonies on being both a survivor of heart disease and prostrate cancer, Frank offers illuminating insights into the need to hear, respect, and understand the voice of the patient in medical systems and settings. Although he does not specifically address disability in his work, his analysis of the experiences and needs of patients is frequently applicable to the stories of my own life. He calls his books both theory and a "survival kit, put together out of my need to make sense of my own survival, as I watch others seeking to make sense of theirs" (p. xiii).

### **Foucaudian Analysis**

Foucault has had enormous influence on body theories, feminist theory, and queer theory. His work is also starting to have considerable impact on disability theories. In particular, I found Foucault's accounts of the disciplinary practices that construct "docile bodies" (1979, p. 135) insightful for the content of my thesis. Additionally, feminist and disability writers who use Foucaudian analysis were helpful. Those modern social institutions and systems that produce docile bodies that are a "certain size and general configuration; those that bring forth from this body a specific repertoire of gestures, postures, and movements; and those directed toward the display of this body as an ornamented surface" (Bartky, 1990, p. 65). The power of these disciplinary systems is their invisibility – they are everywhere and nowhere all at once. The disciplinary practices are often self-imposed and appear to be natural, voluntary, and taken-for-granted, for

example, dieting, exercise, control of bodily movements, removal of body hair, and so on. I found that thinking about disciplinary practices in terms of my pregnancies helpful.

### **Disablement Theory**

Although disablement theory has implications for many of the experiences I had when pregnant when I wrote the chapter on the inaccessibility barriers I encountered during my pregnancies and childbirth experiences, I found the theory of disablement particularly helpful. Lois Verbrugge and Alan Jette (1994) claim that disablement is a result of a person's functional capacity interacting with the social and physical environment. For example, according to Verbrugge and Jette, a mobility disability like paraplegia is not a personal characteristic or flaw but is rather a gap between personal capability and the environmental. "Disablement" refers to impacts that chronic and acute conditions have on the functioning of specific body systems and on people's abilities to act in necessary, usual, expected, and personally desired ways in their society. Disablement theory brought insight to my continual difficulties and barriers with accessibility during my pregnancies and childbirths. Disablement theory states that in medical and public health settings, interventions that will improve or maintain physical functioning is a major focus. While this is important, this perspective neglects the importance and malleability of demand that disability necessitates. Efforts to reduce demand are a common feature of the disablement process. Disability can be diminished swiftly and markedly if the physical or mental demands of a given task are reduced. To reduce demand, the options are activity accommodations, environmental modifications, psychosocial coping, and external supports.

### **Concluding Thoughts**

I build each one of my songs out of glass  
So you can see me inside them I suppose  
Or you could just leave the image of me  
In the background I guess  
And watch your own reflection  
Superimposed...  
Because I know there is strength in the differences between us  
And I know there is comfort where we overlap  
(difranco, 1994a).

With reflective stories, connections to social contexts, guiding theories, journal entries, music lyrics, personal letters, and treasured items, my intent was to build this thesis out of glass. With an authentic and transparent voice, I want you, the reader, to be able to clearly see me and my experiences with pregnancy, childbirth, and disability. I also want you to be able to “leave the image of me in the background” so that you can see your own life in new ways.

### CHAPTER 3: IN THE FAMILY WAY

October 7, 1996

...we were soon then ushered to our ultrasound. And I discovered the most amazing thing: there really is a baby in there, in here, in me. We saw it. It's head, body, arms, legs, heart. It's spine, hip bones, stomach. And it raised it's hand to us, as though it was waving. The woman doing the ultrasound said, "Hi mom, I'm waving!"

In many ways, I found this the most difficult chapter to write. Living through the bodily and emotional difficulties I experienced while I was pregnant, writing those stories down, and then re-living them over and over again during the writing of this thesis has been more tremendously challenging than I could have imagined. I am reminded by the words of Audre Lorde, "It is every woman's responsibility to live a considered life" (1997, p. 59). I am sharply conscious of the fact that through this autoethnography I am not just considering my life, I am inviting others to also consider it. I am both looking at myself, and showing/displaying myself. It is one thing to tell the story with my tongue, to speak it to other people and yet another thing altogether to read the words I wrote during those difficult times. Speaking the story to another person is a public act where I have control over the delivery of the story and where I make constant decisions on how revealing to be. Reading the story in my journal is generally a private act where I am free to weep, to feel whatever it is that I need to feel. When I read my journal entries from my pregnancies, from the most difficult points in those lived experiences, sometimes a sentence will reach out and hit me so hard in the chest that I will physically buckle over and cry.

The deeper level of contemplation, so necessary for writing about lived experiences through the autoethnographic method, often invokes intense personal reactions. The writing is an emotional process. Tears become full out sobbing with my arms wrapped around myself in an effort to comfort, hold, and protect me, this body, and this spirit, from the startling reality of these words. At other times the mourning over what happened nauseates me and, in doubling over, my head comes so close to the keyboard that I cannot see the keys to the left or right of my nose, but it does not matter. Fingers, wet with splashing tears and shaky with excess emotion, keep putting down the memories, the thoughts, the feelings, the mourning, in words, one keystroke at a time. They have to come out. It has been through this experience of considering my life that I have learned that even a paraplegic can be “brought to her knees.”

Like Lorde, Frank (1995) also believes in the responsibility to consider one’s life. He argues that there is a powerful reciprocity that comes from the act of storytelling. Telling a story is important to the teller, but is also vital to the listener: “Telling stories in postmodern times, and perhaps in all times, attempts to change one’s own life by affecting the lives of others” (p. 18). In doing so, we acknowledge that the bodily experience continues where medicine leaves off. Frank believes that it is often hard to listen to stories of bodily suffering and that those voices are easy to ignore because they often remind others of our own vulnerabilities. Yet, despite how difficult it can be, he encourages us to listen, accept the faltering tone of the teller, and be open to the ways in which the story can resonate with our own lives: “...to realize the best potential in postmodern times requires an ethics of listening. I hope to show that in listening for the other, we listen for ourselves.



The moment of witness in the story crystallizes a mutuality of need, when each is for the other” (p. 25).

At the very same time, however, my pregnancy experiences were joyful and exciting. Those emotions appear in this text as well. To be reflective of the joy and of my personality, I have chosen to play with pregnancy euphemisms for the sub-titles in this chapter. Although I would normally opt for straightforwardness over colloquialisms, I chose to use these everyday and usually taken for granted terms to bring this chapter lightness and a sense of humour that I felt was lacking. I also hope that using these terms can challenge the reader to think about the words we use. After all, so many euphemisms are used to name bodily functions, body parts, and sexual matters, as well as disabilities. Light and dark, bound together through this text we will share my embodied experience with pregnancy.

### **Family Planning: How Shooting Gave Me Confidence**

When I think back to all the negative social expectations that surrounded me, it was a wonder that I ever made the decision to become pregnant. When I think even more deeply, however, I know that my history with sport had a lot to do with my choice. Very simply, sport experiences gave me a certain, although surely a limited, confidence in my body’s abilities. Some of this confidence was physical, a faith in my body to be able to be strong and perform as I trained it to. For example, after a training session in preparation for the 1992 Paralympics in Barcelona, I wrote:

July 26, 1992

I truly shine when I shoot well. My arm feels steady and strong, my heart rate is low and controlled, my breath is slow and in rhythm with my movements. Doing well gives me power and confidence. I know the competition will be tough in Barcelona, but sometimes I just feel that gold medal around my neck, the sun shining on my face and my flag raised for the world to see.

Some of this confidence was mental – I learned to choose my perspectives and how to reframe difficult situations. Some of my most meaningful experiences with confidence came from the adventures I had that came with just traveling to different places and leaving my comfort zone.

One of my most memorable examples of this occurred to me when I was compiling artefacts for my thesis that are meaningful to my experience of pregnancy and childbirth. I re-discovered a print that I have loved for a long time. Just laying my eyes on it made me feel strongly that it must be placed with my other artefacts, and not long after, I realized why. It was the Paralympics in Barcelona, Spain in September, 1992. I was 23 years old. My competitions were over; I had won a bronze medal in a challenging category. The categories had been re-classified just prior to the games, the targets and the 10-ring had become smaller, and for the first time internationally, there would be finals after the matches (a series of 10 timed shots each added to the qualification round). In a final, the top eight contestants qualify. The final consists of 10 shots and the score zones are divided into decimals, so that each final shot may give up to 10.9 points. The finals also add a great deal of excitement for spectators and pressure on athletes. Moreover, due to the new classifications, I knew I would be competing against athletes with disabilities that were

quite different (and some would say less disabling) than mine. As it turned out, I was the only wheelchair user on the podium; my other competitors could walk. I had shot well enough in the final to move from 4<sup>th</sup> place to third, thus earning my medal. I was feeling pretty good, strong, and satisfied with my outcome. I wanted to treat myself by going to the Picasso Museum.

Neither my teammates nor my roommates were interested in going with me or had schedules that allowed them to take an afternoon off, so I decided to go alone. I felt excited, brave. I knew I would have to negotiate not just my own body, but also my wheelchair through cab rides, crusty cab drivers, Spanish language, a huge city, and a part of the city that had a reputation for being rough, dirty, and a little dangerous.

I hailed a cab from just outside the village. The taxi was hot and sticky and so was I. I dismantled my chair for the driver, showing him how to do it, but I got the feeling that he was not interested in taking apart or putting together a wheelchair as long as I could do it myself. When I was dropped off at the Admission desk of the museum, I remember feeling so overwhelmingly hot, but as I entered the museum, I was struck by how deliciously cool it was in there, like I had just entered a very dignified and civilized place. My instincts told me I was in for a special time.

I remember feeling very independent, sophisticated, and grown-up. I wore my red Canadian team uniform and felt proud of being a Canadian in this place. I took my time, making mental notes of how the artist's style had changed from his time in Paris to when he lived and worked in Spain. Without anyone to talk to about what I was seeing, I developed my own inner dialogue, which from my sport psychology training, came easily

and suited me just fine. I became particularly mesmerized watching how many times the theme of mother and child popped up in Picasso's paintings. On my way out of the museum, I picked up these three prints: the *Three Musicians*, a cubist painting that reflected my love of music, *The Embrace*, that was lovely and romantic, and *Maternidad*, an image of a mother protectively holding a small child.

Clearly, my feelings of confidence went beyond performing well athletically and winning medals. This is reflected in my journal.

September 10<sup>th</sup>, 1992

Going to the museum alone was a rush. I felt like I was on a real adventure, that I was a strong and independent woman in charge. It wasn't just going to the museum, I am talking about the choice to make a bold decision, to carry that decision out, and to feel good while doing it. Being in Barcelona (and winning the medal and making the 3P final), I feel like I am able to take on whatever challenge that I choose.

Getting the print back to Canada in one piece was no easy task. On the way back to the village, I once again had to negotiate my body and wheelchair, as well as these precious rolled up prints into and out of a taxi in a huge, hot and humid city. I packed the prints in bubble wrap and tucked them in my equipment bag amongst my leather shooting jacket, aluminum shooting table, and other "less than soft" sports items. I gave the prints a kiss and hoped for the best. When it arrived home in almost perfect condition, I had them framed.

I was particularly attached to the *Maternidad* print. I remember when my roommate asked me why I chose this particular one when there were so many to choose from, I replied, "it was the one that haunted me." When I look at this framed print now, I

believe it was not a coincidence that led me to choose it. Although I was not admitting it out loud, I secretly yearned to experience the love of a child. As I read the above story, I am also struck by how I chose to navigate my body through that journey to the museum, and how in many (probably unconscious) ways I was preparing myself for the intense and demanding challenge of becoming a mother: I was okay with my physical life being difficult and I was becoming accustomed to having the confidence necessary to take risks. I am convinced that my involvement with sport is what gave me this confidence.

It is important to address here the influence Finn, my national coach, was having on me during my competitive years. Even though he has not coached me for over 15 years now, I still feel strongly attached to him. He had a gift for adjusting his coaching style to different personalities thereby making each of his athletes feel connected to him. He seemed to understand a potential that was within me and he was comfortable with regularly articulating that to me. He would say, “You exude confidence” and “You were born to succeed” when I least expected him to. Aware of how I was a young girl compared to many of my shooting peers, he would also talk about me in only the most positive of terms around our team as well as when we collaborated with other national teams, such as the year we worked with the US Team at the Colorado Springs Olympic Training Centre. While my teammates would jokingly disparage me for being a girl, I do not recall that Finn ever did that, not even once. I also remember one time in particular when he told some American shooters that “Heather has forgotten more about shooting than most shooters ever get to know.” Comments like this coupled with his strong Danish accent, made him an endearing and loveable character to shooters all over the world, and his confidence in

me eventually became my own. In other words, I began to believe him. I developed a confidence within myself and I became stronger, more self-assured, and eventually a leader in my athletic community.

Finn also respected my need to keep notes and journals. He always declared that writing was not his strong point and that he disliked paperwork, and yet, he took the time at a training camp on September 25, 1988, just prior to the Paralympics in Seoul, Korea, to write me a poem. Because it is meaningful to me beyond shooting, I have kept this poem in a safe place and I refer to it whenever I need to smile or remember reasons I can be bold and that I should have faith in myself.

Heather be bold  
In that rifle barrel lies gold  
It could happen in four years  
If not to my eyes it will bring tears  
Don't let it mold  
Nor get too old  
Heather be bold

Your Coach.

Another great gift I received from Finn was how he to treat situations positively – he would often tell me that “if worrying is going to help your situation, then worry like hell.” I do not remember him ever becoming angry with any of his athletes, and as I recall, there were many times when anger would have been understandable. Likewise, he did not complain when the conditions were less than perfect, he saw those circumstances as opportunities for all of us to “get comfortable with being uncomfortable.” It was perhaps

this “reframing” that I gained the most from – understanding the power of being able to choose my perspective, my viewpoint on any given situation.

Upon Finn’s retirement, I wrote in my journal:

September 27, 1994

My whole life drastically changed when I ended up on the national team and going to California for the World Championship. I learned independence, a different kind of strength that comes from being out of one’s “comfort zone”, and I developed a new sense of self – someone I did not even know existed. The competition was good for me, the mental training was too. But the best part was the people I became so close to and learned so much from. This team was my other family, my community. Finn described the feeling of family among this team as being like the first time you fall in love, and how that cannot be duplicated.

And Finn, I do not know who I would be without him. He taught me how to have confidence in myself and why I should have confidence in myself. He taught me how to see everything and anything in the way that I decide I want to see it. I could reframe any situation then...and I owe all that to him.

I do not think that either Finn or I could have predicted how this skill would help me through my pregnancies. However, during these times, I often used the tools of re-framing to manage difficult situations as well as my sometimes overwhelming emotions.

February 24, 1997

I am not complaining, just stating the facts. And the facts are also that this pregnancy has been hard, probably the hardest thing I have ever done, both physically and emotionally. I have to believe that hard isn’t necessarily bad, and easy isn’t necessarily good. I hope that someday I will be able to look at this time with wonder and appreciation and say “wow, look at all I have learned.”

## **Knocked Up and Knocked Out: Autonomic Dysreflexia**

The first such difficult circumstance was in the first trimester with my first pregnancy. It was emotionally challenging and physically difficult because I suffered an acute attack of autonomic dysreflexia due to a urinary tract infection that quickly spread to my kidneys and bloodstream, making me septic. Autonomic dysreflexia is a potentially life-threatening condition that occurs in spinal cord injured persons with lesions T6 and below (Krassioukov, Furlan, & Fehlings, 2003). It is triggered by painful or noxious stimuli such as a bladder infection, a bone fracture, or any kind of wound and can result in high blood pressure, pounding headaches, and sweating. Complications can result in seizures, pulmonary edema, myocardial infarction or cerebral haemorrhage, stroke, and death.

In my journal I wrote:

October 6, 1996

This baby must really want to be here. She/he has been through a nightmare in the last few days.

Last Tuesday I suspected a urinary tract infection. I took a sample to the Dr's office, but because the results were not in on Thursday, I did not get any antibiotics. Thursday night I became very ill. It started with severe chills for a few hours and then a raging fever. Darrell and I figured it must be dysreflexia which can happen to people with SCI's at T6 levels or higher. I knew my blood pressure was high because my head was pulsing so hard with each of my heartbeats. I really wondered if I would die. I don't know that I would have made the night if Darrell had not been there. Dr. S. had sent us some information on autonomic dysreflexia a while back so Darrell dug that out of my briefcase and read what to do. The first thing he saw was "This Emergency can be Fatal" in bold letters at the top. He wanted to take me to Emergency, due to the second bout of chills and fever I had, but of course I wouldn't go, I couldn't go. I couldn't get out of bed. And he



wanted to call an ambulance, but I didn't want that either. I wanted to just give it a little time. So we did. Darrell sat me up, as he read he should do, helped me to the bathroom so I could empty my bladder. All of it eventually worked well enough and I settled around 3 a.m. It was much harder for Darrell than for me, without a doubt. I was also quite disoriented and it really scared him. I am sorry for that. But I am grateful he was there, nevertheless.

In the morning we went in to Emergency. The resident on call wanted to admit me, but because I was feeling better, I talked him out of it. They did bloodwork though, a special test where they take blood from both arms. I went home and had a good sleep. At 7 am the resident called and said my blood culture was positive, meaning that the infection had traveled into my bloodstream. So here I am, in room 3031, and will be here for a while, apparently.

The Dr. says that the baby should be fine. We will have an ultrasound tomorrow: my birthday. I hope Darrell will be able to come.

So far this stay in the hospital has pretty well been awful. Although the IV went in well yesterday, I had a high fever and chills again and generally felt horrible. Today the IV had to come out and it took 5 tries to get another line. Dr. H. from Anesthesiology was the last resort and she found a vein and made it work right away. They had been collectively trying for over an hour so when Dr. H found it so quickly, I was so relieved and grateful. All the trying had been torture. My veins are fairly prominent, but they are thick with scar tissue and very hard to penetrate, and keep, a vein. I have blue and purple bruises up and down both my arms. The new IV is in my left hand.

The whole IV ordeal was very upsetting for me and I have been crying a lot. I pray the IV stays in this time. I am terrified of being dug into again. I can't do it alone anymore, I can't, I swear. Please, God, I am not kidding, just a small amount of mercy, please.

My episode with AD was frightening. However, I responded well to a course of intravenous antibiotics and a prophylactic antibiotic for the duration of my pregnancy. I could have possibly prevented this episode with AD from happening

if I had just had access to more information about how a body with a spinal cord injury sometimes experiences pregnancy.

### **With Child: Seeing is Believing With Ultrasounds**

It was after this episode with AD that my doctor insisted on having regularly scheduled ultrasounds so that we could closely watch the growth of the baby. Based on that history, it was decided we should do the same for my second pregnancy. Although I was happy to have the ultrasounds done, I still yearned to know more about how my spinal cord injury would affect the rest of my pregnancy and the birthing process. It made sense to me that if I could at least know more about the baby, I would have a bit more control over what was happening to my body. For example, although having ultrasounds done was physically difficult for me, I also loved seeing my babies.

January 30, 1997

I had a rough night again. I have to do my glucose tolerance test today. I also had another ultrasound which was also hard on me. Filling my bladder so full makes my legs even more spastic than usual and because they need to be straight out in front of me while I lay on my back, it is very uncomfortable and exhausting. Darrell holds them and straightens them the best that he can. However, what is important is that all looks good on the inside. Pat is now four pounds, six ounces and has a heart rate of 142 bpm which is good. He is laying in a good position, head down, feet up, spine to the right.

May 3, 2005

Well, I have my facts. Our first six week ultrasound is complete and we have seen a teeny heartbeat. I wish ultrasounds were not so hard. It is

necessary to fill my bladder so that the ultrasound can see my uterus but it is an extremely uncomfortable procedure. Filling, but not draining my bladder brings on autonomic dysreflexia and is something I wouldn't wish on anyone. It makes my legs spasm hard which makes it difficult for the technician to get the information that she needed. I feel bad about that but at the same time my head was pounding, I am sweating, and I am caught in the conflict of wanting to focus on the beauty of this moment of seeing my baby for the first time and wishing it could all be over as soon as possible.

Darrell held my legs down as best he could. To add further embarrassment to this already awkward situation, my bladder burst and leaked on to my pants and the examination table. I had to go home and change my pants and my shirt, which was soaked with sweat.

Feeling bad about the spasms and reaction of autonomic dysreflexia that made my ultrasound technician's job more difficult was part of my anxiety over public scrutiny of my pregnancy. According to Diprose (1994), my feelings were justified. She argues that the pregnant body is the target of surveillance and that a social network of surveillance practices are in place in order to continuously monitor mothers and parenting methods. The power of these practices is that we generally do not even realize they are occurring. The fact that I was pregnant and had a disability only served to accentuate this scrutiny. Furthermore, women may desire the monitoring of their reproductive bodies by attending to the message that these surveillance practices help them feel in control and knowledgeable about their pregnancies (Howson, 2005). I know I certainly valued the feelings of control and knowledge that ultrasounds seemed to give me and with knowing so little about how my body could handle pregnancy, I devoured any information I could get despite the pain and discomfort my body felt while having them done.

I had experienced a life-long history with often being seen as weak and helpless. Once I was pregnant, I strongly desired to be seen as strong and in control more than I

probably ever had before. Women and people with disabilities often represent dependency, vulnerability and weakness (Garland-Thomson, 2002) and Foucault argues that bodies such as these represent what he terms “docile bodies” (1979, p. 135). Docile bodies are ones that are regulated through a set of regimented disciplinary acts. In *Discipline and Punish*, Foucault looks at the practices of disciplinary power through settings such as prisons, hospitals, factories and schools, but according to Shelley Tremain (2005) who writes about Foucault through a disability lens, the ideas can also be used more extensively when understanding social regulation and control in areas concerned with disabilities such as asylums, workers’ compensation benefits, special education, sheltered workshops, telethons, and pre-natal diagnosis. When I reflect and question why I had the ultrasounds done, I think of two things: I wanted to “see” my baby and therefore know more about him or her. In the spirit of Judith Butler’s ideas on “performativity” (2006), I also wanted to “do” pregnancy like other women do. Ultrasounds are part of a “normal” pregnant woman’s experience. Ultimately, however, I had ultrasounds done because my doctor ordered them. In this light, essentially everyone perpetuates the idea of the docile body, and mine was simply a more highly watched docile body.

In many ways, mine was an atypical docile body existing outside the boundaries of the experience, expectation, or understanding of those that held sway over my physical presence at many points during my pregnancies.

February 12, 1997

Because this is an experience my body was never expected to have, I am having a lot of challenges integrating these new ideas into my sense of self. I have so little information about how this pregnancy is supposed to be for

my kind of body, if I could just have a little control, a little information about the baby, I think I would feel more secure. Knowing the sex would just be ONE thing I actually know about this pregnancy. I don't think anyone gets it.

During my first pregnancy in particular, many ultrasounds were scheduled for me and because it was so important for me to know as much as I could about my pregnancy, I had a strong desire to know the sex of my unborn child. I saw the many ultrasounds as many opportunities to see the sex, but I was terribly disappointed when my ultrasound technician refused to pass this knowledge on to our doctor, and therefore on to us. Our conversation about this quickly went from a discussion about knowing a baby's sex to an argument about disability. Our conflict went like this:

Me: If you are able to tell, I want to know the sex of this baby.

C: That is not important to know, Heather.

Me: Why?

C: Parents only want to know for entertainment purposes. They just want to know how to decorate the nursery or what colour clothes to buy.

Me: That has nothing to do with it for us. If the baby is a boy he can wear pink! Seriously, I need information to help me adjust mentally. This pregnancy has been a lot for me to take in and there is not much information about what I can expect.

C: All that matters is whether or not the baby is healthy.

Me: What if the baby is not this so-called healthy?

C: Then mom and dad have choices.

Me: (Hotly) Not in my house they don't. Whether or not the baby has a disability is irrelevant to me. I will still want this baby! (C. went about her business, ignoring my argument).

I turned to Darrell and whispered to him I did not want to call the baby an "it" anymore.

He sighed heavily as these on-going ethical conversations with C. were beginning to wear on him. He knew she had no intention of letting us know the sex of our baby so he smiled

and said in a voice only I could hear: “We are probably not going to know. It is okay. Let’s just call the baby Pat.” He was referring to the androgynous character, “Pat” played by Julia Sweeny on Saturday Night Live who always had viewers guessing whether she/he was male/female. Despite my frustration with C., I laughed out loud and agreed. The baby was “Pat” to us until he was born and we named him Patrick.

What is not a laughing matter, however, were the messages I received about the lack of value and appreciation we have for disabilities and diversity. Garland-Thomson (2002) asserts, “The popular utopian belief that all forms of disability can be eliminated through prophylactic manipulation of genetics will only serve to intensify the prejudice against those who inevitably will acquire disabilities through aging and encounters with the environment” (p. 16). Wendell (1996) agrees, “To people who value disabilities as differences, attempts to prevent disability by preventing the birth of people with disabilities can seem analogous to attempts to guarantee the birth of male babies because they are more highly valued, or to wipe out colour differences by genetic technologies” (p. 81-82). I believe my ultrasound experiences were larger social, political, and bioethical issues concerning the lack of worth we have for disabilities and how we want to avoid them at all costs. Wendell bluntly asks, “Is saying ‘Everyone wants a healthy baby,’ morally and politically similar to saying, ‘Everyone wants a white baby?’ If not, how is it different?” (p. 81). Furthermore, I question what the definition of “healthy” is.

Feminists have historically justified a woman’s power to choose by giving the example of the disabled fetus as a reason why a woman should be able to have an abortion (Garland-Thomson, 2002; Wendell, 1996). While I would not argue with a woman’s right

to choose what happens with her body, I do object to the argument that it is justifiable to abort a fetus just because a disability may be involved. I know that it was this personal belief that fueled my frustration with not knowing the sex of my own baby during my first pregnancy and why my husband and I opted to not test for different disabilities while I was pregnant the second time. Wendell sums it up best for me: “People who take it for granted that it would be a good thing to wipe out all biological causes of disability (as opposed to social causes) are far more confident that they know how to perfect nature and humanity than I am” (p. 84).

### **There is No Recipe for this Bun in the Oven: Lack of Information**

Although research on women’s embodied experiences and pregnancy has been embraced by feminist scholars (Mullin, 2005), feminist research has largely ignored the bodily issues, including pregnancy, of women with disabilities (Chouinard, 2005, 1999; Fine & Asch, 1988; Gill, 1997a; Mullin, 2005; Thomas, 2007; Wendell, 1996). For women with disabilities, the expectations tend toward not taking on adult social roles such as wife, partner, lover, or mother (Asch, 2001; Fine & Asch, 1988; Grue & Laerum, 2002; Mullin, 2005; Neville-Jan, 2004; Prilleltensky, 2004, 2003). As a result, discourse on motherhood and that of disability rarely occur in combination (Grue & Laerum, 2002; Prilleltensky, 2003, 2004).

March 9, 1997

Dear Sharon,

Our public health nurse was here to discuss labour, delivery, etc. with us. It is not likely that I will need to get any instruction on breathing, labour pain management, etc. since I don’t have functioning abdominal muscles and therefore I won’t be able to push. The nurse also came over last week to go over breastfeeding. Sometimes I know more about what I need than she

does, in respect to my paralysis that is. So we end up learning a lot from each other. She's very nice, but she asked if I will have a c-section. I think I might scream if someone else asks me if I will have to have a c-section. I mean, maybe I will, it is a possibility for any woman, but why is it always assumed for my body? My vagina worked well enough to get pregnant in the first place, didn't it?

Love,

Heather

A mother is traditionally seen as an adult who is physically able and therefore sexually capable. For most people, this typification does not apply to women with disabilities (Kuttai, 2005). Some argue that a woman with a disability even seems to pose a danger to society: "Society generally invalidates disabled women's sexuality. If anything, our reproductive potential is feared. We are presumed either incapable of producing the kind of babies society wants - healthy babies - or incapable of adequately nurturing children" (Gill, 1997a, p. 101). Disability theorists, Michelle Fine and Adrienne Asch (1988) argue that "Motherhood, the institution and experience that perhaps dominated all cultural conceptions of women - eclipsing even expectations of beauty, softness, or ever-present sexuality - often has been proscribed for a woman with a disability" (p. 21). There was so little information on how women with spinal cord injuries can experience pregnancy that I simply had to deal with one challenge after the other with the limited resources I had.

January 12, 1997

I don't want to go back to work tomorrow. Last week was hard on me due to a lot of back pain and increased spasticity in my legs. I have also been dizzy and light headed, which is scary. I really do not know what is going on, but I know I had better take a leave of absence soon, for Pat's sake as well as my own.



January 13, 1997

While at work today, I fainted in the bathroom. With some help, I called Dr. T's office, spoke to the nurse, who told me to come in as soon as possible so that she could check my blood pressure. By the time I got there, I was feeling a bit better, but Dr. T suspects what happened was due to Pat's pressure on my spine, so I feel faint because I am not getting enough blood to my brain in those moments. He feels my restricted blood flow would not be as much of an issue if I could stand up, walk, and stretch. If these episodes increase, I will need to be on bed rest.

February 17, 1997

I am coughing up stuff which makes me worry that I have an infection. I am scared that I am going to end up in the hospital again. I saw Dr. C. today though and she reassured me that Pat is okay and well protected.

Thank God I am not at work or it would be much harder to manage this. It is not like I am on vacation though. It is hard just getting through each day. My pain and fatigue are difficult enough, but transfers in and out of my chair have gotten harder too. I try to minimize how many times I get in and out and I am not having regular showers or baths anymore. I should be drinking more to help get rid of this cold, but that means I will have to do more transfers in the bathroom.

During this time of great physical change with so little information about what I could expect, it only took one small positive comment from my doctor's resident to give me some feelings of confidence and support.

February 27, 1997

This has been a long, full day. We began with our Dr.'s appointment this morning. Dr. B found Pat lying sideways again. She thinks this is partly due to a lack of gravity to pull Pat in the right direction since I don't stand or walk. I told her that I think when I am sitting, Pat has more room and probably more comfort when he lies sideways. I sure feel more comfortable, less crowded and like I can breathe easier. Pat's heart rate is 130 bpm. Next time will be our last ultrasound and all the measurements will be taken. We may have a cervix exam done then too. After that, we will go in every week to see the Dr. until Pat is born. Dr. B said she was

just remarking to Dr. T about how well I am doing and that made me feel great. I don't hear that kind of thing very often. Everyone else tends to focus on my problems and my disability.

When I now think about Dr. B's positive comment, I agree with her. I was doing really well with my pregnancy. I was active, eating well, and adjusting to an identity I had not imagined for myself. I was managing a job, the negative reactions of others, and the necessary adaptations to our home. I also see that I should have been giving myself more credit, and that I deserved more credit for how well I was doing from others. When I reflect on why her comment was so memorable, it was because the sentiment was out of step with the traditionally held beliefs about women with disabilities as dependent, weak, and vulnerable (Garland-Thomson, 2002) and not as autonomous and robust. Dr. B's words reflected that I was strong and capable; these were opinions I was not accustomed to hearing, and I was grateful to her.

### **Eating but not Medicating for Two**

Part of feeling strong and in control of my mind and body has also been my diligent decision making about taking medications. Even as a child, I have been critical of the number and amount of medications that have been prescribed to me. However, to control the spasms in my lower extremities, I find Baclophen, the commonly-prescribed for people with spinal cord injuries, truly helpful. When I found out I was pregnant with my second baby, I was advised by my doctor to stop ingesting it, at least for the first trimester. I readily agreed because I did not want to

do anything that might harm my baby. Omitting it, however, had more of an affect than just increased spasms. I also had a lot of difficulty falling asleep and getting recuperative sleep. The lack of sleep and living with a body that was never still was hard on me psychologically and only contributed to my already overly-emotional state of mind.

May 24, 2005

I am now nine weeks pregnant. The hardest physical part has been the absence of most of my medications, especially Baclophen which helps settle my legs and allows me to sleep. However, when I don't sleep, opportunities remain to learn about my body. I used to sleep through some of my pain, discomfort and spasms. Now I can not sleep through them, but I seem to understand where the spasms are coming from. The problem seems to be in my right leg and in my back. Lying on my right side is impossible and since this is the only position where I have been able to sleep in for years, obviously I am not sleeping. I wish I could sleep sitting up. Lying down seems to aggravate the pain and spasms.

The lack of sleep and the hormonal changes have made me emotional. The pulling and spasms in my abdomen that stem from my back pain is so uncomfortable. It is hard to breathe. My digestion is also out of whack. I am either constipated or I have diarrhea. I was rarely at ease with my body before, but now I am feeling like it is unrecognizable – a complete stranger. I am trying to honour it by feeding it well and keeping it active. I see Patrick at lunch and I pick him up from school. I walk our dog Bailey every day.

### **What Not to Expect When You are Expecting**

April 20, 2005

Everywhere I look, I see babies. There were babies in the restaurant too. However, I do not see any families where the mom is using a wheelchair.

There are many ways in which my experience with pregnancy appeared to be similar to the way other women would experience pregnancy. I believed that at least part

of my pregnancy would be “normal”, and in an effort to find my experience reflected in the world outside of me I read *What to Expect When you are Expecting* and *The Girlfriend’s Guide to Pregnancy*, (books that are considered pregnancy “Bibles”) as well as countless pregnancy magazines. I also subscribed to a group on the Internet that sent me week by week details of how my baby was developing and what to expect from the “average” pregnant body. I followed the latest nutritional advice, and watched for and celebrated the signs of what the texts consistently called a “normal and healthy” pregnancy.

September 12, 1996

So much has happened to my body that has not happened to most people. Now I am pregnant which is something that happens to many women. This is the most bizarre, yet normal phenomenon I have ever experienced.

December 6, 1996

I think Pat kicked me for the first time! It took my body by surprise. My legs went out straight in front of me in spasm and my torso was thrown back in my chair. I didn’t really feel anything on the inside, but I saw what happened my body from the outside. I hope it happens again soon. I want to be sure.

December 19, 1996

I felt Pat kick me today, from the outside of my belly. It happened this morning while I was lying in bed talking to Darrell. I have had feeling of movement before but I was never 100% sure that it was Pat. I thought it might be a spasm and I was afraid to admit the kick, in case it wasn’t real. But today, I know that kick was real, my hands absolutely felt kicking. In fact, Pat booted me about 12 times, and Darrell felt it too so I have a witness. He says that in many ways, I am the first woman to have a baby.

However, I sometimes found myself wishing that I knew someone else who had experienced pregnancy while living with a spinal cord injury. I missed my peers with

disabilities that I had become connected to through sport because of the disability related issues I was facing during pregnancy. Gill (1997b) calls this part of disability identity development as “coming home”. Coming home illustrates the level of connection, ease, and comfort that people with disabilities have with other people with disabilities and who share their disability issues. At the same time, however, I knew that even if I could connect with my teammates their ability to empathize would be limited because they were all men.

February 9, 1997

My digestion and elimination processes have always been a tremendous source of shame because I have so little control over the process, and now I have less control than ever before. The only people who understand are my buddies in wheelchairs but they are all men and they don't know anything about being pregnant. And besides, they all live so far away.

February 20, 1997

M., the nurse from Public Health came to talk to us about breastfeeding this morning. I just want to do it. I want to do it for Pat's sake. My only 2 concerns are that my injury is right at nipple level, so I don't know if that will affect my milk supply. I am also concerned about not having support if things go poorly. My mom and Darrell's mom did not breastfeed.

Not only did I not have other moms with disabilities to accompany me in my pregnancy and childbirth journey, I must repeat here that I did not have enough information about what I could expect from my own body. With a lack of resources at my disposal, I did not know how my body would adapt to pregnancy, childbirth, or breastfeeding.

Although I was taking care of myself and my developing baby the best I could with the information I did have, I still had underlying fears that my body was not truly capable of pregnancy and giving birth.

March 15, 1997

Tonight I hope I can sleep without having any bad dreams. I have had a few nights of scary dreams about Pat, Darrell, and I. Last night I dreamt about the Children's Rehab Centre in vivid detail. The night before I dreamt that I gave birth, but only to a lot of fluid and a cord - no baby. I asked Darrell if he thought a person can know something is real intellectually, but not know it in her heart. He says he thinks I am normal, that these fears and feelings and denial are normal. Little Pat, I know that I need you. I need to see your face and touch you – and soon. I feel more ready for you now than ever before. Please come soon.

Additionally, my doctors had a limited understanding of how my body would be affected by pregnancy and childbirth. The many unknowns and uncertainties during my pregnancy often left me feeling vulnerable and frightened. Women with disabilities may experience different intensities with their health issues and medical services need to adapt to those complexities (Gill, 1997a). Gill also asserts that in addition to other women's health issues such as osteoporosis and disability, more research is needed about reproduction health, hormone functioning, fertility, contraception, and parenting in women with disabilities. Furthermore, others have stated how some women with spinal cord injuries have suffered because of the way contractions caused dysreflexia which brought on high blood pressure, strokes and even death (Verduyn, 1994).

January 30, 1997

I have been up since 5 am. My back hurts so much and I can only sleep in one position, which is my right side which is aching. I have too much of a belly to lay on my back – restricted blood flow to my head I've been told. And I can't lie on my left side because of my dislocated hip. All the books say to lay on your left, it is best for the baby. I guess most pregnant women don't have dislocated hips. I also have a headache and I am congested. I have tried all kinds of things to relax – writing in here is my last resort. Writing in here is what keeps me focused and strong and relatively positive.

February 3, 1997

I fluctuate between good and bad days and on the good, I just try to keep busy. When they are bad, they are just bad and it is all I can do to not just sit around feeling sorry for myself! When I sit too long or in the wrong position, I get violent abdominal spasms and I am unable to sit up. It is quite uncomfortable and a little scary because I don't know what is going on. The transfers in and out of my chair are hard now, mostly because my legs don't want to cooperate. Pat seems to be fine though. He has a strong heart rate, he also kicks, moves, and wiggles a lot.

March 22, 1997

Our last Dr. appointment scared me. Pat is in the right direction but hasn't yet dropped. If Pat does not drop by our appointment next week, we may have to seriously consider a c-section delivery. And if my water breaks, Pat's head won't act as a "cork" and that could be dangerous because the cord might come down. This is also a risk of my membranes rupturing. These things may not be detected by me because I can't feel much. This is not good if they happen and then I would need to get to the hospital right away.

The thought of something happening to Pat is very upsetting. It is as though a great wave of protective feelings have overwhelmed me. I am trying to think positively and have faith that everything is going to be okay.

Whereas maternal mortality is now a phenomenon that rarely occurs, pregnancy and childbirth can certainly increase complicating factors for women with permanent disabilities or chronic illnesses (Gill, 1997a). Health care providers simply do not know enough about the intersection of pregnancy, childbirth, and disability (Gill, 1997b; Lipson & Rogers, 2000; Mullin, 2005). Even obstetricians who specialize in high risk pregnancies lack this kind of information and their priority tends to be on the health of the fetus (Mullin, 2005). This certainly resonates with my second experience with pregnancy. My doctor was open about his lack of interest in how my paraplegic body was being affected

during pregnancy. He did not want to understand or deal with my spinal cord injury. Any issues related to my paralysis were always passed off to my rehabilitation medicine doctor.

### **Riding the Baby Train Alone: Without Community**

My feelings about a lack of community continued into my second pregnancy. As a result, I would get frustrated and even angry with messages, whether through media or from people, about how “all” women experience pregnancy. I think I wanted someone to acknowledge that what I was experiencing was different, a feeling that was escalated probably because my experience was also physically and emotionally difficult. Without a community to see my experiences reflected in, I often felt lonely and scared. It was not just the absence of pregnant women in wheelchairs, it was the ubiquitous presence of able-bodied pregnancy images – women that were walking and “healthy” and wearing their pregnancies like fashion statements. There were images of the fit, active, sexy pregnant woman on the covers of fashion magazines, on magazines entirely devoted to pregnancy and childbirth, and on daily television shows (on networks such as TLC and Slice). “Healthy” pregnancy and childbirth books warrant an entire section of our large local bookstore. Since I could not fit that image in many, if not most ways, I had several moments of bitterness laced with humour and sarcasm. It was a way of coping. Sometimes with all the difficulties we were experiencing, Darrell and I just needed to laugh. It has been my experience that “crip humour” or “in-group humour” is often used by people with disabilities to identify, challenge, and simply deal with the barriers – both architectural and attitudinal – that exist in our everyday lives



(Shakespeare, 1999). Humour can give people with disabilities the permission to be angry and frustrated.

February 26, 1997

I am growing weary of all the people who ask if I will automatically have to have a cesarean section. Darrell is a little tired of this assumption too, so he has taken the approach of telling people that while we are not so worried about how a vaginal birth will go for me, we are concerned about how the baby's little wheelchair will come out. This shocks people, most of the time they laugh, and hopefully they get the message that my body was capable of making this baby, therefore, it is capable of delivering it too. He says he wants them to see that while my disability is certainly important in this pregnancy, my body is also more than my disability.

However, although I certainly had light and humorous moments like this during my second pregnancy, my journal's angry moments stood out even more.

April 22, 2005

I am waiting to have my blood work done after having just finished a complicated procedure of giving a urine sample. Fill to the line of the first container then fill the second to the top. I have heard many women complain about this, claiming the task is hard to do. I want to say to them, "Do this with one hand and a catheter! Then do this when your bladder is totally full, you are having dysreflexia, and your legs are spasming. Talk to me about how hard it is then." I may be sensitive right now but the women in the clinic seemed annoyed at the length of time I spent in the bathroom. Argh!

November 15, 2005

I hate "The Mom Show." These women are rich, white, spoiled, superficial, boring, and without any real problems. I want to like it, some of the information is good, but I simply can't relate to these pretty, perfect, coifed women.

If I see one more poster, or segment in a book, or column in a magazine telling me how great Kegel exercises are and how and why I need to do

them, I will scream, cry, and rip up the very paper I see it on. Watch out, Doctor's office, I am ready to do some vandalism.

November 26, 2005

Why did I have to get this cold on top of everything else? With a cough that keeps me awake at night and is sometimes so harsh I will gag and vomit? And a pressure sore? And severe sweats that no one understands how uncomfortable they make me, and how constipation in addition to zero bladder control? The nurse says lots of women develop a lack of bladder control and I am no different. But that is bullshit. I am different. These women can get up, get easily cleaned up, do not have to do loads and loads of laundry including cushion covers, sheets, bed protectors, towels, underwear, pants, socks, even shirts. These things make my situation with bladder control very different indeed. I still haven't gotten the smell out of my cushion's foam part completely, or out of my chair's upholstery. Do other women have this problem? Do other women have rods in their backs that are broken and out of place and in need of major surgery? Not fucking likely.

A woman at Pat's school commented to me yesterday about how I will be giving up sleeping through the night. I told her that I haven't had a full nights sleep for months. "Just can't get comfortable?" she asked, and proceeded to go on about how she couldn't get comfortable in her last few weeks. I just didn't need to hear it. People have no idea. It's not their fault, how could they know? But I still want them to shut the fuck up. I want someone to inhabit my body, for a day, even a few hours, to experience this, to feel what I feel, in order to make myself heard, to validate my experience. No matter how much Darrell and Patrick love and support me, I still feel so very much alone.

If I seem edgy I want you to know  
I never meant to take it out on you  
Life has its problems  
And I get more than my share  
But that's one thing I never mean to do  
I'm just a soul whose intentions are good  
Oh Lord, please don't let me be misunderstood  
(Simone, 1989)

### **On Stork Watch: My Body Matters Now**

At the same time that I was feeling displaced, lonely, and sometimes angry, I also had many other times when I felt more validated as a woman while I was pregnant than I ever did before. My pregnancies enabled me to feel truly “female” because I was experiencing something that many women also experience and because of how my body was changing into ways that felt feminine to me. I also felt like my body “mattered” in ways it never did before. In other words, I felt as though my body was “showing” more societal worth than it did when I was not pregnant. I also often felt a strong sense of positive femininity and a brand new sense of sexuality.

December 8, 1996

Dear Sharon,

Buying groceries last night, we saw your dad. He says Deb, your sister-in-law, looks enormous and is due in February. I smiled at that. I feel enormous too. I am round and ripe. My belly is so pronounced, my breasts are bigger, and a lot of people say I have “the glow” of pregnancy. My body image has never been worse. Or better. I belong to a group now, a special club called “woman” in ways I never dreamed I ever would.

Love,  
Heather

Once my pregnancies were over and my children were born, I found myself remarking to friends and family how I still wished I was pregnant. I remember telling my thesis supervisor, Dr. Donna Goodwin, that I loved being pregnant, that the experience made me feel “special.” When I reflect on that now, however, I realize that pregnancy did

not make me feel special, rather the experience made me feel normal. When pregnant, I was not the “Other” for probably the first time in my life.

**There is Nothing Delicate About this Condition: Strength and Power from  
Belonging**

Although the theory of Otherness was derived from feminist work, it is also a useful concept in understanding people with disabilities. Simone de Beauvoir (1952) coined the terms “Self” and “Other” to illuminate how men are considered essential and women are created inessential; man is the subject, woman is the other. Wendell has further insights:

...when we make people ‘Other’, we group them together as the objects of our experience instead of seeing them primarily as symbolic of something else – usually, but not always, something we reject and fear and project onto them. To the non-disabled, people with disabilities and people with dangerous or incurable illnesses symbolize, among other things, imperfection, failure to control the body, and everyone’s vulnerability to weakness, pain, and death (p. 60).

One day while I waited to see my doctor at the rehabilitation unit, I noticed some of the other wheelchair users in the waiting area. I scrawled many words in tiny script in the margins alongside this passage in Wendell’s book:

Even more than winning Paralympic medals and demonstrating physical competence through athleticism, pregnancy and breastfeeding flies in the face of the notion of being the Other. For the first time in my life I had feelings of femaleness and belonging. These feelings, whether they are right or wrong, made me feel more normal. It was like, “See? I am not so different. I can do what other women do – my body is sexual, strong, and healthy – this baby proves it!

Later on, as my wait for the doctor’s appointment dragged on, I further vandalized the back blank pages of Wendell’s book with these thoughts:

It is a terrible, wrong thing to say and awful to admit, but when I was in the rehabilitation department waiting for the doctor, I watched the other patients and I thought, 'I can not bear to turn out like them. One man was in a power wheelchair, tilted back, with a water bottle in the cup holder, a fleece blanket decorated with puppies draped over his legs. A woman was next to him in her wheelchair. She looked un-bathed with long, grey, unkempt hair and with half a dozen windshield ornaments dangling from the handlebars and what looked like a bunch of garbage stuffed into the basket in the front. I am not these people, I thought to myself. I am reminded of Wendell's word on hierarchy of disability, and I am aware that when it comes to the continuum, I would like to be near one end more than the other. I am educated! I worked at the University, I am completing a graduate degree. I am married, I have a lightweight manual wheelchair, I have been pregnant, I have children, I have 3 Paralympic medals, I won the President's Service Award, I have even coached able-bodied people. I cannot be that caricature of disability, I cannot embody that stereotype. I am not that. I am not them. I can't be.

March 21, 2006

I am horrified with myself. I have realized that the attitude I had about the people I saw in the rehabilitation department the other day is despicable. It is no better than the people who say and believe that they would "rather die than not be able to walk/see/hear." It is not up to me to decide whose bodies are acceptable or unacceptable. I am glad, however, that I learned about this tendency to judge within myself. I am sure I would have denied it if I had ever been accused. I am happy to be aware, so that now I can work on changing this attitude.

I was deeply ashamed of my thoughts that came from a belief that I had more power, status, and worth than other people with disabilities. I was embarrassed that I had seen myself as better and more in control than my peers who have disabilities and yet, I can not deny how at times during my pregnancy, and later on with my experiences of breastfeeding, the benefits I received from defining myself more as Woman than Disabled.

Wendell (1997) argues that this sort of projection happens all the time but that most of us do not realize it.

The disciplines of normality, like those of femininity are not only enforced by others but internalized. For many of us, our proximity to the standards of normality is an important aspect of our identity and our sense of social acceptability, an aspect of self-respect... These reactions are completely understandable, given the disciplines of normality, and they all contribute to the Otherness of people with disabilities (p. 88-89).

Writing and reflecting and reading and writing some more about the above thoughts and feelings that I had on being the Other, made me consider the other ways in which I have experienced this situation before.

### **She's Starting to Show: Experiences of Being Seen but Not Heard**

Reflecting on the ways I felt once my body was "showing" its pregnancy made me think about the strong memories I have with my body being on display as a young girl. As I have previously written about, I was just a few weeks shy of completing grade one when my spinal cord was injured. My teacher was a thoughtful woman who rallied my classmates to send homemade cards made from colourful construction paper to the hospital where I was a patient. I remember receiving a card from one of the boys in my class that I ended up keeping for years although I do not have it anymore. On the front of the card he had drawn an empty wheelchair and he had printed underneath the question, "Are You Invisible Now?"

I do not pretend that I have any clues as to why he would ask me such a thing (or why my teacher would allow him to send this to me). I do not know if he thought I now possessed magical powers or whether he actually wondered if my inability to walk somehow made me less important. Whatever the reason, I have often thought about that

card and the ways in which having a spinal cord injury renders me both invisible and (ultra)visible at the same time.

When I returned to my elementary school in the fall after the accident, I am sure that my teachers would assert that our school was now accessible to wheelchairs. After all, ramps had been built and a washroom had been renovated in anticipation of my arrival. While the barriers to physical accessibility were easily made, there were many invisible social and attitudinal barriers that created situations of “ultravisibility”. General assemblies, for example, brought on some of my greatest discomforts and created some of the biggest inequalities and most noticeable differences between my peers and me. Entering the gym, I would inevitably feel anxious about where to sit. Everyone else would be able to sit on their bums on the gym floor and I would still be sitting in my wheelchair. That act of sitting on the floor would instantly change the height differential – when I was surrounded by standing and walking people, I was the short one; when I was surrounded by people sitting on the floor, I would be the tall one. Instead of feeling tall though, I would just feel awkward, “in the way” and unable to hide. Full of anxiety, I would wish for a way to minimize my wheelchair so that I could somehow blend in. These days, as a mother attending the general assemblies of my school-age son, I can comfortably sit along the sidelines with the teachers and other parents. Yet, with the experience of childhood anxiety brought on by general assemblies burned into my body’s memories, the experience of attending an assembly now, no matter what the subject or theme, inevitably stirs butterflies in my stomach, and brings tears to my eyes.

Feminist theory offers some illuminations about invisibility and visibility. While de Beauvoir (1952) first suggested that women are not born, but rather made or taught to be female, more recent feminist theorists have taken this point further, suggesting that the female body can also be seen as a “thing” or as an object that is subject to the “male gaze” (Holland et al, 1994). Furthermore, Marion Young (1990) asserts that the notion of the “male gaze” is one of what Foucault termed “disciplinary techniques” that strongly influences the way women perceive their body’s appearance. Because I was more acutely aware of my body’s femininity and sexuality during pregnancy, I became more sensitive to the way other people perceived my changing body. I was also accustomed to concealing my body and minimizing the space which it took up (as I had tried to do during those dreaded general assemblies). Becoming so much obviously bigger and epitomizing the image of femininity (at least in my mind), forced me to confront how visible and how open to the gaze of others I had become.

### **Living with the Baby Bump**

While I was pregnant but before I started to “show,” I felt more uncomfortable with my body than I did at any previous point in my life. I was worried that people would just think I was fat, further perpetrating the stereotypical image of a person with a disability as being inactive and physically incompetent, images I had worked hard to change for myself for years, particularly through my involvement with sport.

November 13, 1996

Darrell tries to assure me that I am not getting fat in other areas besides my belly, but I remain very self conscious. I keep thinking that people will



assume I am fat, not pregnant because they will not expect me to be pregnant in the first place. I don't think I am imagining things – I see the looks I get. Some people look surprised, some look confused. I have even seen people do double takes. I wish I could put a sign on my chair that says “You are not imagining things, yes, I am pregnant”. Or I could get a t-shirt that says “No longer a virgin”. I know that I am awkward at best with this new identity, this role that I also did not expect for myself. I feel that I don't know how to do this pregnancy with grace.

July 3, 2005

For a couple of weeks now, my pants have not fit very well and when I tried to shop at the maternity store, I felt so strange and out of place that I just left without trying anything on or buying anything. In fact, now that I think about it, I felt like an imposter!

This weekend though, after seeing me expand my pants with elastic bands in order to make them fit around my expanding belly, Darrell insisted that we shop at the maternity store together. He blazed a trail right into the store and kept taking things off the racks and piling them into a dressing room. He came into the dressing room with me and helped me try on a bunch of different things. He was quick with his appraisals- he either liked or disliked and then made piles depending on his assessment. He looked like he was having a great time. He even put the pregnancy pillow around his own stomach to see what he would look like if he had a belly like mine. He looked hilarious! With all of our laughing and carrying on, we made a lot of noise. I think the staff who work there were surprised he came into the change room with me in the first place. In the end, we bought 3 pair of pants and 2 blouses. I even wore the new jeans out of the store.

The experience makes me feel more legitimately pregnant somehow, like it validates this very female experience.

During pregnancy, particularly the latter months when a woman starts to show, women are confronted with constant and intense physical transformations, emotional upheavals, and social changes. Amy Mullin (2005) argues that the study of both able-bodied and disabled women's experiences with pregnancy is both rare and new and not enough is known about how it affects a woman's sense of herself as a female. Mullin also

states that because pregnancy is such a meaningful embodied experience, it is important to look at all kinds of contexts (e.g., social, cultural) because there will not be “such a thing as a typical experience of pregnancy” (p. 45).

One social change that some feminist theorists argue is that a tension exists for pregnant women between being seen as a mother and being seen as sexual and desirable because there is a sharp distinction between the two images (Mullins, 2005; Young, 1984). This might explain the shift in recent years in media images from pregnant women wearing over-sized, flowing garments to tight, skin and belly-baring clothes. However, this does not speak to my experience. I suspect that because non-disabled women are assumed to be sexual prior to being pregnant, and because we do not usually expect mothers to be sexual, is at least one of the reasons why they experience this tension. However, because I was not previously seen as a sexual person, my pregnancy, especially once I started to show, revealed something about me that was not expected: that I was actually a sexual person. In short, where some pregnant non-disabled women experience a loss of sexual and feminine identity, I experienced a gain.

### **When You Are Not Expected to Be Expecting: Fear of Public Reaction**

At the same time that my sexuality and femininity were being confirmed in many ways, I was also deeply concerned that others might negatively perceive my pregnancy. I was anxious that strangers would just think I was fat, a fear that is based in a societal view of people with disabilities, especially women, as passive, weak, and inactive (Fine & Asch, 1988; Gill, 1997a; Wendell, 1996). My anxiety was sometimes confirmed by how others interacted with me.

January 2, 1997

I need a new bra. My rib cage is expanding to make room for Pat. So I went to the maternity store. Isn't that what pregnant women do? There were three salespeople and no one would help me, so I approached one of them, saying I did not know what size I should buy. She said, with surprise, "Oh! Are you expecting?" I was stunned. I am in a fucking maternity store. I am seven months pregnant. Look at me! How did she think I was going to respond? "Oh, sorry, I thought I was in Zellers"? She just thought I was fat, I guess. A different woman ended up helping me and I did buy a bra in the end.

I was also worried that others would perceive my pregnancy as something I did not deserve and that I was causing an unnecessary burden on society, due to medical and healthcare intervention. In short, I feared a public perception that I would not be able to take care of my child independently. Thomas (2007) argues that while all women who become mothers are subject to surveillance by the public, women with disabilities are particularly vulnerable to scrutiny.

I was also concerned with how others would react to the news that I was pregnant. Whereas most women who have planned pregnancies expect to experience a positive response from others, I was on guard for the potential negative response each time I told someone. I was fortunate that the nurse who did the pregnancy test for me was also a good friend. While her news affirming my pregnancy was shocking to me, having her emotion-filled and sincerely positive response to the news definitely made the moment easier and even memorable. Similarly, telling my family, co-workers, and friends was a positive experience. They were congratulatory and, although many of them were surprised by our news, they seemed genuinely pleased for both Darrell and I.

June 22, 2005

When I went to J's thesis defense this afternoon, Kent stopped me and commented on my need to delay my proposal. I told him that I am pregnant. His response was so positive; his smile spoke volumes. I was so worried about what his reaction was going to be. His reaction was simple in a way, after all, people smile all the time when they hear a woman is pregnant. But because I have a lot of respect for his opinions, because I am in the middle of my graduate studies, a SSHRC scholar, and yes, yes, yes, because I am a paraplegic, his reaction to this news really mattered to me. I do not think I will ever be able to fully thank him for doing the right thing at the right time.

However, not all responses were happy ones. "Oh dear" were the first words out of the mouth of the doctor I saw after I learned I was pregnant the first time. Similarly, "You have certainly complicated your life" were the first words out my doctor said when he learned of my second pregnancy.

May 29, 2005

I am officially 10 weeks pregnant; the baby is an inch long and about the size of a walnut. More people know and I am okay with that. I need to tell the kids I help coach and I need to tell my own team and Finn, of course. I told Neil, my current coach, over the phone. He was civil, but he didn't even wish us congratulations. Instead, he just commented a few times about how shooting is no longer a priority for me.

Honestly, for all the warm and enthusiastic responses we have had, there have also been many cool, negative and judgmental comments. One doctor's first comments was that I have "complicated my life" with no words of congratulations at all. Other people have frowned, or given me a look that I can't quite explain, but it certainly isn't a happy look.

On one hand, my disability and my wheelchair represent my constant visibility especially as I encounter barriers in space and architecture. Paradoxically, the ways in which I am ignored, silenced, disrespected, and not understood as a disabled person, and as

a disabled woman, are symbols of my invisibility. “Women’s bodies may be highly noticed, yet their capacities, lives and desires unseen” (Zitselsberger, 2007, p. 394).

### **Spare the Child/Spoil the Rods**

As I said in the beginning of this chapter, this was probably the hardest section to write and reflect on. My journals are often written in during the “heat of the moment” and in the middle of crisis. I faced a particular crisis during my second pregnancy.

Early on I sensed that something was not “right” with my body. I was suddenly experiencing autonomic dysreflexia on a regular basis; an indication that there was something wrong below the level of my injury that I could not detect, but was being alerted to nonetheless.

May 25, 2005

I have hit the wall. Last night I could not find a restful or comfortable position. Impossible! My body can not be still. It spasms and jerks constantly. The lack of sleep caught up with me and I cried for hours. I feel so betrayed and alone when this happens. I feel like I have no where to turn and it is terrifying. I finally fell asleep around 4 a.m. and I was shaken awake with spasms again shortly after 7. Something doesn’t feel quite right about this. Once I took Patrick to school, I came home to try to sleep awhile, but the same thing happened, not surprising, but since I was already upset, I continued crying. It has been months since I have had a good night’s sleep.

August 6, 2005

Tonight Pat and I are at the farm. I have had a hard time when I have to be somewhere that is not particularly accessible. The bathroom here is big enough but the transfers are different than at home and that makes everything awkward right now. Plus, just when I thought my rib pain was as bad as it could get, it got worse. I am having sharp, stabbing pains in my

chest. I need to go to physiotherapy next week and I will go home to Saskatoon early if I need to.

August 7, 2005

I had another tough day. This time it is my bladder. I am having a lot of profuse sweats and I feel what is a bit like a slight bladder spasm off and on all day. I don't know if it is a spasm or some other kind of discomfort.

October 2, 2005

This is my second night in the hospital. My body is completely unpredictable, bizarre and incredibly difficult to figure out. I have an on-going high fever, my back is having a lot of pain, especially on the right side, my heart rate is very high, ranging between 110-140 bpm, I am short of breath, and my posture has become very crooked. We are exploring infection and blood clots. Further, since the indwelling catheter came out on Wednesday, I have not had one single bladder spasm, not one single sweat. My feet are even dry. I have been incontinent twice, I didn't feel a thing. I also had a pelvic exam and I didn't feel a thing. Nothing. My sensation is completely gone.

I hated those spasms and those sweats. Now that they're gone, I am scared. I am scared that I have lost the sensation forever. One resident doctor thinks it is all a coincidence. This is shocking to me. I absolutely do not think it is a coincidence and that the AD is connected to my bladder, something I have maintained all along. Why doesn't anybody listen to me?? I know my body better than anyone. Why don't they even ask for my opinion? I am starting to feel really scared.

October 12, 2005

I have been back in the hospital for a few days now.

We were waiting on this final test to let us know if the pain and the fevers were due to an infection in my back from the fracture of my rods, or from injuries I sustained here from this inaccessible room last week. One of Dr. O's residents was here to tell me. Then she asked whether I had 4 rods or 2. I felt an overwhelming sense of dread and I answered, "2." She looked a bit confused, then said as if it were the simplest thing in the world, I distinctly saw 4", then showed me in the air with her fingers where they were placed. That little air drawing upset me beyond words. This is how I learned that

the rods had moved apart. I can't believe she told me in this way. Doesn't she have an idea of how horrible this is?

I don't know what it all means, but I know it isn't good. No, this is very, very bad news for me. I don't know what it means for the baby. I need a good cry and I can't do that with Darrell because Patrick is always here when Darrell is here. Pat sees me in enough pain, this is not a "normal" home life situation, I have enough vulnerability with him around. I can't break down sobbing too.

However, he is sensitive to my emotions (he wanted to know why I am sad even though I wasn't crying) and I felt that he needed to know the truth. Tonight I told him about my broken rods. I told him as honestly and simply as I could. I said, "Honey, the rods in my back have broken. We do not know why. It may have happened even if I was not pregnant. We can not do surgery to fix the rods while the baby is still inside me, but once she is born, I will need a big operation."

He just held his head in his hands. He said he wasn't sad about being afraid of how I may not be able to look after him, nor was he sad about being afraid that I wouldn't be there for him. Instead, he said in a sure, strong, and steady voice that he knew I was always with him and will always be there for him. He is sad, he told me, because he is afraid of all the pain I will have. Then he crawled into bed with me and I held him in my arms. We stayed like that for a long time and I stroked his hair and kissed his cheek.

I intended to sing him a song to make him feel better, but what actually happened was one of those precious mother-child bonding moments that I am sure I will always remember. I sang/prayed to my boy-child, my unborn child and me:.

ooh, child, things are gonna get easier  
ooh child things will get lighter  
ooh child things are gonna get easier  
ooh child the world is gonna get brighter  
someday we'll walk in the rays of the beautiful sun  
someday when the world is much brighter  
someday we'll get it together and we'll get it undone  
someday when our heads are much lighter  
(Vincent, 1970).

I cannot read the above journal passages without tears brimming in my eyes. Those are raw words that sear the paper in my journal, and they appear on the pages without the consolation of time to soften or heal them. I have frequently written in my journals right in the moment, not later in the day when I have had time to think, reflect, or contain my emotion. In re-reading these and other stories about my pregnancy with Chelsea, for example, I see how relatively quickly my back's steel hardware broke, how quickly my spine became unstable, and how it felt like I became morbidly crooked overnight and it terrifies me, even now, almost two years later, that it might happen again. Every sharp pain, every excessive sweat, and every creak and groan my bones make threaten to shatter my inner sovereignty. Survival takes strength, faith, and the ability to be comfortable with the uncomfortable, which are many of the qualities I learned as an athlete. Survival means I am in control, if not of the situation and the things that happen to me, then at least of how I manage those situations, how I see them and live with them. Lorde (1997) said that "I am not only a casualty, I am also a warrior" (p. 19).

In many ways, I certainly was a casualty. At the beginning of this chapter I recalled my challenging medical experiences and outlined how women with disabilities are subjugated to what Michel Foucault calls the "discipline" of medical systems. This discipline exerts significant social pressure to "shape, regulate, and normalize subjugated bodies" (Garland-Thomson, 2002). I definitely feel that this was a large part of my pregnancy experience. However, at the same time, I believe I was also a warrior, because just as significant to my experience was my drive for personal choice and free will. It has been argued that one of the limitations of a



Foucaudian perspective is its disregard for human agency (Garland-Thomson, 2002) and individual resistance to the disciplines and their power. After all, there are numerous (and many famous) testimonies that detail how human beings are complex, multi-faceted people who can be controlled, regulated, and oppressed while at the same time as we can be strong, resistant, and in control of our choices. Despite its apparent or assumed docility, it is equally important to note that mine was also an active body capable of exercising free will and making conscious choices about my situations. My practical embodied experience of disability and pregnancy, however, was often lived in the juxtaposition of these two theoretical positions – individual autonomy versus the overarching predisposition against disability. Many of the above personal stories are about things that were done to me, how I was victimized and oppressed, and yet, there is also much evidence to my individual agency, like how I dealt with my ultrasound technician’s biases and the way in which I told my son about my broken steel hardware. So although it makes me sad to read about it, and it makes me angry to write about how I was sometimes treated, I am also comforted to see in my journals my many acts of what I consider to be strength, and how I knew that I should not be dismissed and underestimated.

don't sell me short!  
you've been wrong too long  
don't brush me off  
just because I don't belong  
pass me on by, ignore my cry,  
forget me when I die  
just don't sell me short,

not while I'm still alive  
everybody's talking about  
heaven on earth,  
I'm still trying to figure out  
just what I'm worth  
I'm full of emotion  
and stuff you can't contain  
and you just want to  
flush me down the drain  
but you can't make me go away  
(Graffin, 2000)

## **CHAPTER 4: IT’S TIME! MY BIRTHING STORIES**

As a unit director working at the University of Saskatchewan, I once had the opportunity to hire several people at once and during that search I conducted over 45 interviews. One of the more unconventional questions I always asked was “What is the bravest thing you have ever done?” During one of my de-briefing meetings about the candidates, one of my colleagues on the hiring committee who was intrigued by my odd questions, turned to me and asked, “Heather, I am curious – what is the bravest thing YOU have ever done?” Without having consciously thought about my own answer prior to this, I nonetheless responded without hesitation, “Two things. Getting involved in wheelchair sports and making the decision to have a baby.” These two ideas that seem to have nothing in common with one another are linked in my mind because both becoming involved with sport and making the decision to have a baby required me to extend the ideas of what I expected for my life and beyond what others expected of me. “Female, disabled, and dark bodies are supposed to be dependent, incomplete, vulnerable, and incompetent bodies” (Garland-Thomson, 2002, p. 7). Both sport and my decision to become a mother required me to re-define who I thought I was.

After having read, reflected, and written about my childbirth experiences, I also see how often I both unconsciously and consciously used sport terminology and “shooting talk” throughout. It is with these reflections in mind that I constructed this chapter.

### **Going with the Flow**

The sport psychology training I received as an athlete provided me with invaluable skills to deal with the physical difficulties I encountered while I was pregnant. How I

learned to lower my heart rate and relax for shooting was key to managing the difficulties my body was having during pregnancy and in childbirth. The skills of being able to reframe and re-focus during a competition were also useful during pregnancy and childbirth. I was able to mentally deconstruct moments of crisis which was critical to my ability to cope with pain and emotionally trying times. Self-talk in particular was an important tool that I used while I was an athlete. Simon Jenkins (2005) describes self-talk as a tool that athletes can use to focus attention, provide motivation, strengthen self-confidence.

When Finn first introduced me to the concepts of self-talk, I was immediately intrigued. Self-talk came naturally to me since I had been using music as a form of self-talk for years. I was accustomed to planting a song in my head while I was training and competing, so incorporating words was a relatively easy transition. Canadian sport psychologist Terry Orlick (1986, 2000) describes self-talk as a tactic that encourages confidence in an athlete by concentrating on positive beliefs the athlete has about his or her abilities. Those beliefs should be grounded, Orlick says, on real past histories of successful outcomes. Furthermore, many athletes use the practice of self-talk to enter into “flow,” what Jenkins (2005) considers to be an “altered state of consciousness” or “total unity, inner strength and wholeness of being, as well as a loss of fears, inhibitions, and insecurities” (p. 171). My ability to use self-talk to enter the “flow” experience was a significant contribution to what I consider to be the best competitive performance of my shooting career.

September 13, 1992

I made the final again – this time in the co-ed 3 position! I was so surprised and I did not expect that I would make the final so I even had my gear already packed up and was ready to sit in the stands and watch all the excitement, not be part of the excitement! But Finn came running towards me with my equipment bag and told me to get suited up – I don't know who was more caught off guard, him or me. I was known as a pistol shooter, not really a rifle shooter, so a lot of people who came to watch the final did not even know or realize who I was.

I was last in the final, 8<sup>th</sup>, and the only girl, and the only North American. All the other finalists were men from Europe. My sighters were absolutely awful, all over the place, and I knew that if I wanted any self respect at the end of all of this, I had better get my shit together. So I tried to settle down, relax, and remember my one shot match. My one shot match allowed me to see my shot, feel my shot, and even hear my shot. Several deep breaths later, my first shot on target was gone...and it was a good one (10.5). In fact, it was the best one of all 8 of us.

About shot #4, the crowd turned my way, cheering the loudest for the lone Canadian girl on the end, shooting her heart out. And my heart was out – it was beating so hard, there was not time or point in getting it to quiet down, I just went with it instead. As a result, I would raise my rifle into position, get on target, feel that crazy heartbeat, and have to lower the gun again. I took all my 75 seconds that are allowed, and expended twice the energy that should have been needed. My face was so hot and flushed that the cheek piece would slip around my face and I had to wipe it down with my glove. I was sweating so hard that some of the perspiration would slip around the head band that held my eye patch and drip into my eye, stinging me. Despite all this though, my shots were strong, I could call all of them, and they were all solid 10's. Between shots, I would close my eyes and see, feel and hear the 10's. Using self-talk, I just kept repeating "I am calm, cool and confident" and for some reason it was important to me to not just say it in my head but to mumble it to myself. I swear I could also feel Finn having a heart attack behind me in the stands. My shots were fantastic, and the crowd was roaring every time I took one, chanting "Can-a-da"!

In the end, I moved up two spots to place 6<sup>th</sup>, but the best part was that I had the highest final score, even better than the gold medalist. I am so impressed with myself for getting focused and staying calm and confident. Why do personal bests have to require so much work? I really did not know

I had it in me, to tell the truth. I had no idea my body could make such an amazing thing happen. I had to do it to believe it.

Finn is just beside himself with pride. He was holding the video camera but the footage shows a lot of shaking and jumping up and down by the cameraman.

According to Jerry Lynch and Chungliang Huang (1998), the words we say to ourselves can be used as a powerful tool to enhance performance, and often acts as an energizer, problem solver and controller of physiological responses. Through the words and images I chose to use, I was able to both take responsibility and credit for the successful outcome. What I could not have anticipated was how critical self-talk and entering into flow would be to me when I gave birth to Patrick.

### **Patrick's Birth**

March 29, 1997

It is 9:05 p.m. and I am breastfeeding my son. He is about 17 hours old.

At 12 midnight Darrell and I decided to go to the hospital as I was having what I thought were violent bladder spasms. Not knowing what labour pains would feel like, I thought I was having another bladder infection. We called Dr. T. first as I was reluctant to go to the hospital in the middle of the night for what I thought would result in a course of antibiotics. We arrived around 1:00 a.m. and Dr. T. announced to us that I was having "8 cm dilated bladder spasms". I went into the delivery room and Dr. T. asked me if I wanted to try and push. I told him I did not know how because everyone thought my body was incapable of that. We had not attended pre-natal classes because we were told that the pushing would not apply to me so there would be no point in learning about it. Nevertheless, Dr. T told me to try. Why not?

After a brief tutorial, a contraction came but my first attempt at pushing did not work. Dr. T, knowing my sports background, said, "Okay, we are going to try this again but with a little visualization. We are going to put your sport mental training into practice". He painted me a picture of what needed to happen and we waited for the next contraction. This time I was ready.

Darrell held my legs and braced my back. I held on to the sides of the bed and pushed. I had the one shot match that Dr. T helped me build and that became my focus. It was hard work. Using all the strength I had in my arms, shoulders, hands, even my face and neck, I bared down and pushed until sweat plastered my hair against my head. In between contractions I was in Barcelona on the shooting line, relaxed, focused and set on my task. I kept saying out loud, “Yes”, “I can do this”, “I am strong”, and “My body can do this.” I was so pleased and surprised that I could progress the birth by pushing.

Darrell and I were amazed. We actively pushed this way for about 45 minutes, and then Dr. T. told me to reach down with my hand and touch Pat’s head. He said he had never seen a mom’s reaction quite like mine before – total shock. It is true; I was still dumbfounded that my body was actually making this event happen! At the very end, Dr. T. thought he should assist the baby with a little bit of vacuuming. And the next thing we knew, our baby boy was born. Dr. T. clamped the umbilical cord and Darrell did the cutting. We called our parents to give them the news. My mom cried with relief.

Because we decided at the last minute to not have an epidural, my blood pressure was monitored throughout the delivery to be sure it would not go too high due to the pain. It went high, but not so much that any intervention was needed. Everyone had believed that I would need an epidural to control for pain, an IV and a foley catheter. I did not need any of these things. All I really needed was a doctor who believed in the abilities of my body, a pair of strong arms, a lot of husband support and a good mental plan.

I had exerted so much physical energy that my blood pressure dropped drastically low, so low it did not even register at first. Yet, I felt fantastic, like I had just had completed the final of the most intense match of my life. What a miracle. My body did not fail me. My body worked. My body worked well. I pushed! Me!

Until I started the process of selecting journal entries into themes for this thesis, I had not fully considered the parallels between these above two experiences. Part of the autoethnographic process is a “rewriting of the self and the social” (Reed-Danahay, 1997, p. 4), and an ability to go beyond the every day stories of one’s life, especially those stories that have been told many times, and deeply reflect on the reasons why those stories hold

meaning. Both of the above stories I had told many times. Both of these stories illustrate moments of high drama where I pushed my body's abilities to its limits. Both gave me the opportunity to test my mental toughness. Both experiences culminated in great "wins". This, I think, is obvious.

What is probably less conspicuous, however, is the magic that happens in telling the stories *to* someone. My listener is almost always captivated, entertained, and surprised. I love this inevitable reaction of the listener because both the stories and the reaction to them reinforce who I sketch myself to be – strong, unexpected, and interesting, characteristics that are usually the opposite of who we expect people with disabilities to be (Garland-Thomson, 2002). Frank (1995) would also argue that through such stories bonds of empathy are created through the teller and the listener and "the circle of shared experience widens" (xii). This is a way, he says, that my body that is oftentimes silenced, can speak and be heard. I believe that the telling of these stories allows my body to be seen, or perceived, in a different, more positive, and definitely unexpected ways. It is these unexpected ways of strength and remarkable physical ability that I want to be seen as having after so many years of having received the message that mine was a body not made for such extraordinary experiences. "People do not make up their stories by themselves. The shape of telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy" (Frank, 1995, p. 3).



### **Oh, Come On, There is More To it Than That**

What is also less obvious (at least initially to me) is the other factor that contributed to the successful or happy ending to these stories. When I deeply think and reflect, I am honest both to myself and to the words I write down. When I first did this, it suddenly occurred to me that “it was more than self-talk that culminated in those successful outcomes.” I then thought the other factor must have been pure grit, a toughness, or an ability to “dig deep” or “suck it up” and get it done. While I think it is true that I have that ability to draw on inner resources in critical times, as many of us do, the truth is that when I kept that idea for a while another honest factor was revealed to me. And that was simply my zealous desire and deep-seated drive to **win**. When I was in the final with all those older, seasoned European men and when I was pushing my body to independently deliver Patrick into this world, I wanted to win. I wanted to succeed, to accomplish something extraordinary that would allow me a great story that I would never tire telling.

### **Chelsea’s Birth**

I prepared for Chelsea’s birth with this high drama, test of mental toughness and physical exertion that Patrick’s delivery necessitated in mind. Although I knew my body was now different and therefore the delivery would also be different, my only other experience with childbirth was the only information I had that I could draw on to help me prepare. I once again drew on my history with sport to work on this preparation.

November 27, 2005

To tell the truth, I feel like I am preparing for a competition tomorrow. My mind frame is changing. I am getting mentally tough, strong, ready. I have rehearsed my one shot match. I am anticipatory, but I am also relaxed – my ideal performance state. Focused. Clear. Ready. A gold medal performance, a personal best, awaits. That’s my mind, my mental preparation. As for my body? No problem: It has been training for months.

Using terminology and processes that I would employ for competition felt comfortable during my second pregnancy and childbirth experience. Simply, if it had worked before, I thought it could work again. I also used terminology from the “one shot match” – the process a shooter determines is the necessary one to achieve a successful shot. This was another mental training strategy that I learned from Finn, my first coach. Understanding the components that achieve a perfect shot in a one-shot match is really about breaking down an experience into a series of moments. In most ways, a one-shot match is about focusing on the present moment. The magic of the one-shot match and living in the moment for me was that I was also able to take the skills of living a one-shot match and apply them to having ownership over my birthing experiences. The lessons I learned in sport are with me all the time and it is a powerful feeling to be able to draw on them for dealing with life events that seem to have nothing to do with sport.

These lessons were intensely tested during my last trimester of my pregnancy with Chelsea. The broken steel hardware in my back was causing autonomic dysreflexia everyday, all day long. There was no relief. I was dealing with excessive sweats that would leave my pillow case soaked after only a few hours of sleep. I would have to change it in the middle of the night; oftentimes I also slept with a towel on top of the pillow case. I

had to change my shirt several times a day because it would be so wet that you could actually ring out perspiration like a wet towel. As a result, I was often shivering from cold. Accompanying this was a fever that for some reason would start in the late afternoon every day. I had a high resting heart rate all day and night long (around 140 beats per minute). Due to the broken hardware that had damaged my spinal cord, I had lost all my bladder sensation. It was especially because of this fact that I was convinced I would not be able to detect when I was in labour. Over and over again I was assured by the nursing staff, my doctor, as well as family and friends that I would most definitely know when labour was happening. “You know your body so well,” they would tell me, “so try not to worry.” “You will feel the contractions. Your belly will get hard as a rock, and you will know.” I remained unconvinced. Unbeknownst to me so did my husband.

I got up in the morning one day to find the *What to Expect When You Are Expecting* book open to the chapter on emergencies and what would happen if a woman has no choice but to have her baby at home. Darrell confessed that he had been reading the book in the middle of the night because he was too worried to sleep. This was a sign to me that I needed to try to convince my obstetrician that I should be induced. However, my obstetrician completely disagreed, telling me that induction was not the best route for the baby and if this was a spinal cord related issue, I had to take it up with my rehabilitation doctor. Having my thoughts completely dismissed by my doctor is one example of how patients are expected to be compliant to their doctor’s orders.

Talcott Parsons was arguably the first social scientist to theorize this kind of doctor-patient relationship and his ideas have had a profound impact on medical theory and

practice for decades. According to Parsons (1951), a central part of being sick is submitting to the care of a doctor. Frank argues that the “postmodern experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell” (1995, p. 6). Frank (1995) also argues that physicians as described by Parson’s sociology, are more accountable to professional policies than to individual patients. This is certainly how I felt when I left my Obstetrician’s office and I wondered if he had heard a word I had said. However, I did quickly take the matter up with Dr. L, my rehabilitation doctor. I remember feeling relieved and respected as he listened without interruption about my fears about not being able to detect labour. He said he would write my obstetrician a letter stating that it was his belief that I should be induced at 37 weeks so that the conditions were under control. My appointment with Dr. L was on a Friday afternoon. To my pleasant surprise, he asked me if it would be okay if my obstetrician would get the letter on Monday. I smiled, with deep relief, and said that I thought that would be just fine.

So at 37 weeks, I was scheduled for induction. My obstetrician was out of the city so I was assigned someone new with whom I felt quite comfortable even though I had only met her once before. In the morning, I received oxytocin, a drug typically used for induction, and although my water broke fairly early, no contractions accompanied it. In my room was Darrell, our son Patrick, and Jody, a close family friend who Patrick chose to accompany him should he need any support that his dad would not be able to provide due to primarily being with me. By dinner time that evening, no contractions were happening, so my new obstetrician said we would try a more aggressive route the next day. She left to go home.

Soon after, a nurse came in to check on the baby's heart rate with an ultrasound. When she was unable to find the heart rate, Darrell started to look worried. I was feeling suddenly nauseated and I wondered if it had anything to do with my position in the bed. Keeping the bed sheet draped over myself, I turned from side to side, all the while feeling that I might vomit. Darrell asked the nurse to call the resident doctor and she quickly obliged. We both got the sense that she was also nervous about not being able to find the baby's heart rate. When the resident came in to see me, she took charge and used the ultrasound wand herself. There was no detection of a heart rate. With Darrell right next to me on one side, and the nurse on the other, the resident doctor asserted that she was going to do an exam of my cervix. When she swiftly drew back my bed sheet, she shouted, "The baby's head is out. This baby needs to be delivered now. Call NICU (Neo-natal intensive care unit) stat!"

I watched Darrell's face drain its blood; he became as white as the sheet that had just been removed from my lower body. Strangely, my own face seemed to contain all its blood plus his – all of a sudden I felt very red and flushed. Tears sprung to my eyes, but I would not allow myself to cry. "There is no time for tears," I told myself. On my doctor's orders, I pushed like I had learned to do on the delivery table some nine years before, relying on the visualization techniques that I had firmly burned into my subconscious mind, and my baby slid out. She was checked over with the assertive speed reserved for emergencies and was declared absolutely perfect.

Almost immediately I expressed my gratitude towards Dr. L for listening to me when I told him I would not detect labour. Without the controlled conditions of the

induction, I most assuredly would have given birth to this baby at home, on the toilet, or in the middle of the night. My husband and I remain grateful to him to this very day.

November 28, 2005

All in all, a 10.9 delivery, just a bit different from my one shot match...

these are days you'll remember

never before and never since, I promise  
will the whole world be warm as this  
and as you feel it, you'll know it's true  
that you are blessed and lucky  
it's true, that you are touched by something  
that will grow and bloom in you

these are days you'll remember

when May is rushing over you with desire  
to be part of the miracles you see in every hour  
you'll know it's true, that you are blessed and lucky  
it's true, that you are touched by something  
that will grow and bloom in you

these are the days  
that you might fill with laughter  
until you break

these days you might feel a shaft of light  
make its way across your face  
and when you do  
you'll know how it was meant to be  
see the signs and know their meaning

you'll know how it was meant to be  
hear the signs and  
know they're speaking to you  
to you

(Merchant, 2005)

## CHAPTER 5: INACCESSIBILITY

Shut up!  
You're talking too loud  
Get back in your corner  
That's an order  
We've got you summed up  
We've got you defined  
And you're stepping out of line  
(The Au Pairs, 2006).

I deal with inaccessibility issues with on a daily basis. Because they are so prevalent, many times I am not bothered by them in a significant way. However, sometimes I get angry and frustrated. Other times I end up feeling quite hurt and small. In preparing to write this chapter, I made a long list of inaccessibility frustrations and I included a few of them here:

- I am told that I should have a physical examination once a year, but I cannot get on to my doctor's examination table because it is too high. I asked him what it would take to acquire a bed that raises and lowers in his clinic, and he scoffed at the idea, telling me that a \$5000 bed was just too expensive to justify.
- I have never found a gravel or sand-free playground where I can push my kids on the swings.
- I cannot guarantee that I will be able to park in the designated spot for wheelchairs at my son's school despite the fact that I am the only parent there who uses a wheelchair. There are no children who use wheelchairs in the school either. Non-disabled parents are always

vying for the spot, and a few months ago, I was given the finger by one mom when I told her (gently, mind you) that she did not have the legal right to park there.

- There are stairs getting into nearly every dance studio and gymnastic club in the city. What will I do when Chelsea wants to do these activities?
- Last weekend's paper's headline indicated that the major multi-million dollar development taking place in our city's downtown will only have stairs because a ramp would take away from the aesthetics of the design.

During my pregnancies and childbirths, inaccessibility was even more of an issue because my body had changed with my ability to feel balanced and because I had a new centre of gravity with my baby belly. I experienced so many difficulties with inaccessible spaces and what I term inaccessible attitudes during this time, and because I wrote about it often in my journals, it was clear that its theme was important enough to be a stand-alone chapter in my thesis.

Inaccessibility issues began before I even went home from the hospital. When I was first injured, there were many physical and attitudinal barriers to integrating me back into the community and as a consequence, my parents quickly found themselves in the roles of advocates. For example, after watching me 'attend' my science and art classes alone in a tiny dark room by way of a closed circuit television, while the rest of my classmates participated in the upstairs classroom, my parents pushed our public school



board to install a wheelchair lift in my junior high school. When they believed it was no longer acceptable to have my brother or cousins carry me on and off the school bus, they insisted on having a bus with an integrated wheelchair lift transport me to and from school. Both times my parents were met with great resistance from the powers that held the money that was needed to make these changes. Eventually they were successful and since then, many people have benefited from the accessibility.

Sometimes the advocacy was even messier than just dealing with the bureaucracy of a school board. My Dad once passionately expressed his contempt for a man who had illegally parked in a wheelchair parking stall and the ensuing altercation came to blows. My parents became advocates whether they were comfortable with the roles or not, and whether they intended to or not. They deserve credit for making tremendous changes both in my life and in our community.

I've got a good father  
And his strength is what makes me cry  
I've got a good mother  
And her voice is what keeps me here  
Feet on ground  
Heart in hand  
Facing forward  
Be yourself  
I never wanted anything so bad  
(Arden, 1995)

### **Inaccessibility of Public Spaces**

As an adult the role of advocate rests now primarily with me. Access is so central to my daily life that I have learned to expect inaccessibility rather than the opposite in public places like restaurants, stores, and even hospitals. While access issues are pervasive

and emerge in a variety of everyday situations, my pregnancies brought forward a new set of accessibility issues. Public places, especially Doctor's offices and hospitals, the spaces that are supposed to cater to the health and safety of all persons, were particularly frustrating.

September 27<sup>th</sup>, 1996

My new Doctor's office does not have an accessible bed – one that is low enough to get on and off of. Normally I would have been able to do the transfer, but once I have the extra belly weight it will be too difficult, I'm sure. He says this is no problem because there is a regular bed – the type you might have in a bedroom – just down the hall and although it might be a bit awkward for him to examine me there, and he will gladly do it.

My pregnant belly changed my physicality in ways that altered my sense of balance and my centre of gravity. I could not perform the kind of athletic/risky transfers I was used to doing before I was pregnant. If I fell I would not only endanger my well-being but also that of my unborn child. My doctor's offices did not have accessible examination tables; this was also true for some of the ultrasound tables I needed to use. While the delivery tables would raise and lower to a safe and correct height, the beds in the ante-partum and post-partum hospital units did not. Furthermore, most of the bathrooms located in the delivery rooms and hospital rooms contained grab bars in incorrect places and toilets that were low and therefore, dangerous to use, particularly when one has a large pregnant belly to negotiate or when one has just given birth and is weak and sore.

January 2, 1997

We also did a tour of the birthing rooms. The bathrooms appear accessible, even some with wheel-in showers. The nurses we spoke to felt we should skip assessment and go straight to delivery since assessment is not accessible at all. We learned a lot.

Wendell (1996) argues that while feminists contend that the world has been planned and created for the male body, disability theorists feel that the social world has been and often continues to be constructed “as though everyone were physically strong, as though all bodies were shaped the same, as though everyone could walk, hear, and see well, as though everyone could work and play at a pace that is not compatible with any kind of illness or pain, as though no one were ever dizzy or incontinent or simply needed to lie down” (p. 39). It is often incorrectly assumed that if there is a grab bar in a bathroom, even if that grab bar is ill placed or unsafely attached to the wall, then that bathroom is accessible. This situation is not just limited to spaces and architecture. “The entire physical and social organization of life tends to assume that we are either strong and healthy and able to do what the average young, non-disabled man can do or that we are completely unable to participate in public life” (Wendell, 1996, p. 39).

March 30, 1997

I have just given birth but my baby Patrick and I are going home. My hospital room is just not accessible to me. The bed is not the right height, the bathroom does not have grab bars in the right place, and the toilet is too low. I learned that after the baby is born, a woman’s ligaments are stretched; plus she is tired, physically drained. I needed things to be as accessible as possible to avoid injury. I really could have used more time in hospital, but because I need access, we decided to go home where I know I can transfer safely.

Some of the most difficult parts of my second pregnancy was seeing that in terms of accessibility of the maternity ward at our hospital, nothing had changed in eight years since I had my first baby. This seemed impossible to believe. Surely I was not the only paraplegic who had been pregnant and had given birth during this

time. Did not any one else experience these problems with the too small bathroom, the low toilets, the incorrectly positioned grab bars, and the beds that did not lower enough?

The public world is the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain, or a devalued body, people encounter resistance to mixing the two worlds; the split is vividly revealed. Much of the experience of disability and illness goes underground, because there is no socially acceptable way of expressing it and having the physical and psychological experience acknowledged. Yet, acknowledgement is exactly what is required for creating accessibility in the public world (Wendell, 1996, 40).

### **Inaccessible Attitudes**

Eight years later, and despite a push towards ‘universal design’ (and perhaps predictably), the accessibility of the hospital had not changed to accommodate pregnant women with disabilities. Similarly, positive attitudes towards disabled mothers to be were not universally embraced. While I was fortunate to have an obstetrician during my first pregnancy who was open to having a patient with a spinal cord injury, and who was willing to learn what he needed to in order to provide care to me and my unborn baby, I was not so lucky during my second pregnancy. My new doctor was unwilling to discuss my spinal cord related issues as they affected my pregnancy. He quickly separated his responsibility to the reproductive parts of my body from the non-productive parts of my body. Although he claimed that this was because my rehabilitation doctor was the expert in spinal cord related issues whereas he was not, I could not help but wonder if it was more a reluctance to acknowledge my disability. Gill (1997a) writes that some doctors are honest about their

discomfort when working with women who have disabilities and their complaints, especially when those health issues include reproduction. Gill also asserts that some health professionals appear to be uneasy by the idea that reproductive health or sexuality could possibly be important to their patients with disabilities.

May 4, 2005

Darrell and I saw our obstetrician specialist today. He works out of RUH in the department where we went when pregnant with Patrick. He questioned us as to why Dr. V had made the referral. I was honest and told him that we questioned her on the decision too. His response was that I was “too complicated, too special” and that he wasn’t “smart enough” to handle my pregnancy. It hurt that he didn’t even want to discuss the matter with us, but like I told our new doctor, I respect his decision if she is not confident. I talked to him about the dysreflexia I keep having and he quickly dismissed the idea that he could help me figure any of that out at all. This is a job for my rehab doctor, he says. I don’t think he is necessarily wrong, I just didn’t like his tone or how he made me feel, like I was asking for more than I deserved and like I should not be taking up his time with spinal cord related questions. He also did not know, or have any ideas about where we would do any of my physical examinations since there were no beds that raised or lowered. I feel like he didn’t even try to help us come up with a solution. I could probably get up on the table now, however, I won’t once the baby starts to grow.

My doctor’s discomfort likely comes from a prevailing social expectation that assumes that pregnant women, infant and children’s caregivers should and will be women without disabilities (Morris, 2001). “When disability and impairment are discussed, they are typically presented as features of fetuses that should be avoided or that justify abortion, rather than as characteristics of children [or] caregivers” (Morris, 2001, p. 4). I was also rattled by an experience that happened while I was hospitalized during my second pregnancy. Many different departments at the hospital were involved in trying to solve the

puzzle of my severe symptoms that turned out to be a result of the broken hardware in my spine. While I was awaiting an answer, I had an alarming interaction with the Infectious Disease department.

October 5, 2005

A team from Infectious Disease gathered around my hospital bed this afternoon, shortly after Patrick came to see me once school was over for the day. Something about being surrounded by lab coats while I was in my flimsy hospital gown, something about them wanting to be the team that discovered what was wrong with me and how my own opinions about my body did not matter all accumulated in a sense of powerlessness for me and put me on the defensive. None of this was helped by the conversation that then occurred.

Infectious Disease: “Your son was born at 36 weeks. Has he had any health problems? Is this your son? (She pointed to him sitting in the chair beside my bed). He seems healthy enough.”

Assumption made: How can an incompetent and disabled body like yours produce a healthy child like him?

My face burned with anger and I retorted: “What you see is what you get. He was a perfectly healthy baby and a perfectly healthy child.”

Then, as soon as the words left my tongue, I was angry with myself. What, after all, is wrong or shameful if he had been “un” healthy or born with disabilities? I had, at least to a certain extent, internalized the pride and accomplishment that comes from having a healthy baby and that, very simply, pissed me off.

Although the questions were, on the surface, about the welfare of my unborn child, I strongly feel there were an underlying assumptions about the health and competency of my already grown child as well as commentary about my body’s abilities to create and care for these children. There exists an ideology of mother that is supposed to be someone who is able to meet all the physical, safety, and emotional requirements of their babies and

children (Mullins, 2005). Because they are not seen as being physically or sexually capable, in addition to being seen as weak, vulnerable, and passive, women with disabilities are not expected to take on this social role.

### **Guilt**

Oh, the guilt  
(Nirvana, 1993)

Gill (1997a) argues that women with disabilities often feel that their medical complaints are not taken seriously by physicians. Furthermore, when women with disabilities do stand up (pun intended) for their physical and medical health needs, they often feel guilty for doing so but they may also not feel as though they are not being heard (Wendell, 1996). When advocating for a safe and accessible room or when I spoke up for my bodily needs that were related to my disability, I often felt guilty, as though I were asking for too much, or for something I did not deserve.

October 25, 2005

There is so much stress. The inaccessibility of the hospital really worries me. We have checked every single hospital room on the maternity ward and every single one won't work. The beds are too high for me to do a safe transfer; this is especially true because of my extra back problems. The toilets are all standard, and therefore too low. Although I have been offered a raised toilet seat that sits on top, I can't safely use this either because it shifts or moves. My centre of gravity is off because of my baby belly, so transfers have to be done carefully, if I can do them at all. I am already experiencing so much pain, and I am afraid of re-injuring myself like I did last week in the ante partum ward.

We have spoken to the Patient Advocate about all of this. She was nice, but said that she doubts there can be anything done to make a room accessible when (at that time) there was a month to 6 weeks before the baby comes. Legally, they have to do something! I can't risk falling, especially now with

my spine issues. I can't believe I have to fight this accessibility issue when I have so much else going on.

The stress continues. The inaccessibility of this room, namely the inaccessible bathroom has been the main reason that I have gone from an independent and private person to a dependent and public person. For example, my once private matters are public now – my showers, catheterizations, bowel care, even when pads need to go underneath my behind. I feel shame and embarrassment and guilt – I need help and it isn't easy to ask for it all the time.

I still feel some of this guilt, even now. When I reflect on the source of it, I think it comes from a need to apologize for taking up too much space, needing too much extra stuff, for taking up more time, effort, and money for many of the things that are effortless for non-disabled people. I think it comes from both a perception that I am somehow “getting more” than non-disabled people (like wheelchair parking) or designated seating at a concert, even though the later is always a limited choice and number). I think it also comes from a need in me to apologize for wanting and yet not feeling like I deserve, what other people have in their lives: love, children, gainful employment, a comfortable home, an education, some fun, and the ability to get from place to place. But all of these things require adaptation, extra time, extra planning, and compromise. Most significantly, at least these days while my “job” is graduate student, they all cost more money.

Since my second back surgery, for example, I need to drive a van with a lift instead of the small, sporty 2 door car I was used to. A van is more expensive to purchase, maintain, and fill with gas. It needs more space when parking to accommodate the lift. It causes more gas emissions. Another example is that one weekend this summer my niece and I took my children and my great nieces and nephew to a swimming pool with a



waterslide. The story of how a paraplegic gets in and out of a pool with kids and a toddler is enough to write a thesis on, and it takes all of my grit, adaptability, and courage to make it happen. However, this complexity is lost on my 2 year old who turned to me and asked me to take her up the stairs so she could go down the waterslide. I had to tell her that I can not do this and that she needs to go with her brother or an older cousin. “Okay,” she sadly replied, “I need a walking person.” Although I smiled at her odd use of terminology, I still felt like I was letting her down somehow. Because of these examples and countless others, I feel compelled to say, “I’m sorry” a lot – to my husband, for costing us more money, to my children, when I can not go to the places other moms go, to the earth, for making more pollution. Disability theorist Lennard Davis (2002) validates this: “When ‘special needs’ (and let us notice the valence of that term) are required, too often the person making the request is seen as overly self-concerned, overly demanding” (p. 125). Wendell also has illuminating comments about what I call “disability guilt” when she confesses that her “greatest psycho-ethical struggle is with guilt” (p. 4) for not being able to do more, give more, and put up with more. While I was pregnant the second time, I struggled with a lot of guilt, especially when I was hospitalized after the rods in my back broke. A large belly and broken rods made transferring extremely difficult and I grappled with the limitations of my hospital room.

October 4, 2005

I did not sleep well at all last night. My back is so sore and there are sharp pains in my ribs. Now there is a twitch in my left leg, so even though my head bobs and my eyes keep closing, I cannot fall asleep.

I tried to do my bowel routine earlier. With pads all around me I try to it in bed, which is the only safe place for me. I tried for an hour, but it just would not work. I was so frustrated. Something came over me and I felt compelled to take charge of this absurd situation. I covered myself up with a sheet, got into my wheelchair, asked the nurses to gather together the supplies I needed and I proceeded down the elevator and down the many hallways of the hospital to the bathroom on the main floor where I knew the grab bars were correctly positioned and the toilet was high and level with my chair. I realize it is bizarre and appalling to have to use a public bathroom when you are a hospitalized patient. But I felt I had few choices. I could not afford to slip, let alone fall, especially because of my back and the baby.

And I was right – the public bathroom worked. In some ways it was a metaphor for the last 2 weeks – my private, independent body forced to be public and dependent. I am so ashamed. And I am ashamed of being ashamed. I should be stronger than this.

When I read this now, I know that I had nothing to feel ashamed about and that it was, in fact, the hospital staff that should be ashamed that I needed to use a public bathroom while I was a patient. However, in the moment my shame and guilt were very real. It all makes sense to me now when I consider the social stigmas that are attached to being not just disabled, but dependent, weak and vulnerable and how much, in turn, strength and independence are valued (Garland-Thomson, 2002). There is also shame in asking for more than what seems deserved when one has a disability (Wendell, 1996). People with disabilities generally function at a lower social status level and therefore asking or demanding for accommodations that bring us to the same level as everyone else can seem rather like we are asking for too much. I also know that by insisting on going to a public bathroom where I knew would be safer, I was taking control of my life and acting as my own advocate. Even though he was singing about black pride and self-determination, James Brown's lyrics speak to my anger about being forced to make this decision and

claiming control over my situation: “I don’t want nobody to give me nothing. Open the door, I’ll get it myself” (1969).

### **Dignity**

Someone showed me a picture  
I just had to laugh  
Dignity never been photographed  
I went into the red,  
Went into the black  
Went into the valley  
Of dry broken dreams  
So many roads  
So much at stake  
So many dead ends  
And I’m at the edge of the lake  
Sometimes I wonder  
What it’s gonna take  
To find dignity  
(Dylan, 1994)

Although some disability theories have given immense value to the ideas that people with disabilities should be able to live barrier-free, with access to public places and activities, as well as education and employment, the result has sometimes been a displaced emphasis on independence and a decreased emphasis on dignity (Wendell, 1996). It has been argued that this perspective placed too much of an emphasis on living independently and in turn created an image of people with disabilities as “the able-disabled” who are reluctant to acknowledge their weaknesses and limitations, which further perpetrates the stigma of shame with which many people with disabilities endure (Wade, 1994).

Cheryl Marie Wade (1994) illuminates this discrepancy between needing help and maintaining one’s dignity:

The difference between those of us who need attendants and those who don't is the difference between those who know privacy and those who don't. We rarely talk about these things, and when we do the realities are usually disguised in generic language or gimp humour. Because let's face it: we have great shame about this need. This need that only babies and the "broken" have. And because this shame is so deep, and because it is perpetrated even by our own movement when we emphasize only the ableness of our beings, we buy into that language that lies about us and becomes part of our movement, and our movement dances over the surface of our real lives by spending all its precious energy on bus access while millions of us don't get out of bed or get by without adequate personal care. Because we don't want to say this need that shames us out loud in front of people who have no understanding of the unprivate universe we live in, even if that person is a disabled sister or brother. We don't want to say out loud a basic truth: that we have no place in our bodies (other than our imagination) that is private (p. 89).

October 12, 2005

I just want to go home. I don't know how I can and I know Darrell doesn't really want me there because he is so afraid of me being alone during the day and something going wrong. I don't know how I would manage anyway – having to catheterize in bed isn't hard, but it is easier psychologically without a nurse to hold the basin – it can wear at my dignity that's for sure. But bowel care – that's a tough one, I don't know what I will do about that. And although I hate this hospital bed, the way it adjusts to sitting then back to lying down is certainly advantageous when managing pain.

Frank asserts that medicine's ideals of "modernist universalism" (1995, p. 15) that strives to commit equal responsibility to all persons by placing an emphasis on professional codes rather than on the specific needs of the individual patient, results in the patient's actual requirements being overlooked and undervalued. This can be especially true of women with disabilities who often feel dehumanized or objectified within the medical system and who are seen solely in terms of their disabilities rather than as whole persons or complete women (Gill, 1997a).

October 13, 2005

Two days ago I was sent for an ultrasound of my legs to see whether or not I had any blood clots in them. When I arrived at the room, I saw the stretcher was a bit high and I was told it could not be lowered. I probably could have managed if I wasn't pregnant, however, I am just not that confident right now. My center of gravity is off and I don't want to fall. The female technician said she would get a lift. It had harnesses for each of my legs and a hammock/sling to go around my back and that was strapped to a bar. She said that she needed a second person in the room, so she brought in a male technician. Neither of them told me their names and they worked through the process of attaching me to this lift in virtual silence. As the male technician operated the lift to start raising me up out of my wheelchair, my legs began to spread apart. Because I had been there for a leg scan, I was wearing only underwear. Even if I had been wearing pants, I would have had to take them off at that point anyway. So, with my legs spread apart, he – this guy, this total stranger - stood there, right in front of me with a complete view of my crotch. I hung there like that for at least a few minutes while the female technician tried to figure out how to operate the lift to lower me down on the table. He stared right through me. My face burned hot with shame. I could do nothing but squirm and look around for help. But no one offered to cover me, no one said a word. I was completely vulnerable, there was nothing I could do to help myself or cover or hide.

The situation reminded me of something that happened to me when I was 12, sitting on that backless stool without a shirt or a bra on so that my back and chest could be photographed for my surgeon. Humiliating and degrading, reduced to nothing, insignificant, embarrassing, asexual – just a thing, not a female, not even a real person, nothing. I did not have a voice then, but I feel that I have one now.

All your expectations bury me  
Don't worry  
You will find the answer if you just let it go  
Give yourself some time to falter  
But don't forgo  
Knowing that you're loved no matter what  
And everything will come around in time  
I own my insecurities I try to own my destiny  
That I can make or break it if I choose  
(McLachlan, 2004)

This experience with the ultrasound professionals deeply affected me so much that I avoid re-reading the words, choosing rather to scroll down the page quickly whenever I am working on this chapter. When my cursor settles on Sarah McLachlan's lyrics at the end of the testimony, I feel my heart rate slow down and I can relax, knowing that I have come to a new page.

Searchin' high  
Searchin' low  
Askin' the cops  
Wherever I go  
Have you seen my dignity?  
(Dylan, 1994)

### **Invisibility**

You don't see me but I feel so exposed  
(Kreviazuk, 1999)

Frank's *The Wounded Storyteller* (1995) provides some insight into why this and other incidents may have occurred while I was hospitalized. He argues that when medical professionals adhere more to the pursuit of "truth" than to their responsibility to individual people, patients' narratives end up not being understood or even heard. Certainly, as the testimonies below attest, I did not feel listened to during my pregnancies and at times, I did not even feel as though I was seen.

November 10, 2005

In order to be induced at 37 weeks, Dr. Q says Dr. L has to formally recommend it. Dr. Q says that because the baby is developing well, there are no obstetrical reasons to induce, and in doing so, we pose a risk to the baby. I asked what kind of risk and he said respiratory. I said I thought that was taken care of with the steroid shots we gave the baby a few weeks ago.

This is what he led me to understand, but he responded by saying that there are no guarantees. 37 weeks is only 3 weeks early – it is considered full term. What about me? What about my body's health? Why can't we consider my health and how that needs to be the best it can so that I can look after the baby once she/he is born? I told him that my bladder is unmanageable, I have tremendous pain, I can not sit for any length of time, I am compromising my back, which is already in danger. I need to be strong after the baby is here. But he won't even listen. He wants a letter. I don't think he even cares about me and my body at all. When I told him about my cough, he just smiled patronizingly and said it was an issue for my GP. He wouldn't even listen to my chest. I told him the cough was keeping me up at night and he said I could take Advan. Advan? I am not having panic attacks! I need to sleep.

This doctor will only be happy when I finally go away and he does not have to deal with me anymore. I only wish I had listened to myself and changed doctors a long time ago, inaccessible offices and examination tables or not.

November 16, 2005

Dr. appointment today. We saw Kristen, the resident, instead of Dr. Q, which is fine with me. I feel deep resentment towards him, I don't want to see him and I don't want him to deliver my baby. He is away next week and so he has put Dr. M in charge of my care – I will meet her on Monday. And because Dr. L is fantastic to me and has recommended it, we have a date set to induce if the baby does not come on her/his own prior to that – November 28. 12 days. I was so sure the baby would come prior to 37 weeks and now I doubt it.

### **Gratitude**

This is not my obligation  
What does my body have to do  
With my gratitude?  
(difranco,1994b)

A few weeks later, and just days before the date set for being induced, we received a call from a hospital staff member who was excited about the “wonderful” changes that were made to one of the hospital rooms on the post-partum ward. We were asked to come to the hospital and see the changes.

November 25, 2007

We have just toured the room that they have made accessible. They have taken a room that normally holds 2 people and made it for one (me). I feel uncomfortable with this vast amount of space that I do not need and will not really use. I told them it was not necessary to make a double room into a single, but of course, no one listened to that. Now I realize it probably has more to do with where the room is situated on the post-partum floor. It is in a far off corner, away from the main area. It would be absurd to put the “wheelchair room” next to the high class, expensive “Victorian room”, wouldn’t it?!

They have changed the toilet to a higher rise one and added a grab bar. Although a standard hospital bed is currently in the room, they assure me that a bed that raises and lowers to my chair height has been secured for use on the day that I come in to be induced. These were not huge structural changes. Why did everything have to be so stressful, negative and complicated? Why was this situation not seen as an opportunity to make this ward friendlier? Why was I instead only seen as a complainer and a problem? It is so strange. The way they showed off the room to me sent a strong message that I am supposed to profuse my undying gratitude. Yet I know I won’t have much self-respect left if I do that.

November 28, 2005

I have just given birth to Chelsea a few hours ago and although I am in my “wheelchair room,” I am now I am lying once again on the delivery table. The reason is simple: the bed that was supposed to be saved for me was taken by another nurse for another ward even though there was a sign on it saying not to move it. I cannot get on the bed that was in here because it is too high. Darrell was pretty upset; he asked a lot of questions and made demands that something needed to be done. This further stressed me. I just wanted to lie down. It would be okay for Darrell to help me get on the other bed but once I have to get up and say, use the bathroom, I would be stuck with the high bed again. So, because it raises and lowers to the height of my wheelchair, I opted to sleep on the delivery table. They brought it from the delivery room to my postpartum room for the night. It is quite uncomfortable – very hard on the back, but at least it lowers enough so I can transfer. I cannot believe this is happening, but honestly, I do not have the internal resources to get emotional about this. I just gave birth – I am tired.



November 29, 2005

I cannot believe what just happened. I went for a little walk with Chelsea around the post-partum ward and as I approached a group of three nurses in the hallway, I heard them talking about the room I am in. The conversation went like this:

“I can not believe they changed the normal toilet to one of those high ones just for one patient.”

“They even let her stay in a room that should hold two patients.”

“Is she planning on having any more children?”

“It is amazing what some people demand.”

“I hope she is grateful.”

Overhearing this, I felt so shocked, so ashamed. My heart leaped up into my throat and I felt my face start to burn. Yet, I made a decision in that moment to not let them see my emotion. I wanted them to know that I had heard every word. I kept wheeling toward them. I even made eye contact. I gave them my strongest face. I would not let them get to me. And then I just kept going right on by with my new little baby girl. Screw them.

Some disability theorists such as Wendell would argue that the above architectural inaccessibility examples are illustrations of how disability is clearly a social construction:

“Disability is also socially constructed by the failure to give people the amount and kind of help they need to participate fully in all major aspects of life in the society” (1996, p. 40).

Certainly, the absence of a room, bathroom, and bed were disabling factors and authentic barriers to a safe and accommodating pregnancy, birthing, and post partum experience, but there was more to it than that. While giving due credit to social constructionism for making social change for people with disabilities, other disability theorists also think that the theory needs to be strengthened with the lived experiences of the body and that the vast experiences of people with disabilities is too complex to be reduced to one theory or unitary model (Corker & Shakespeare, 2002; Shakespeare & Watson, 2002). Howson

(2005) agrees, and argues that concrete examples of how the body is lived often get written out of text and theory.

Prejudice and discrimination come in all kinds of forms. Often, it is subtle comments like the one above that have the most impact. It is not as though anyone overtly declared that they believed I did not deserve to have children or that I did not deserve a room within which to be cared for, but nevertheless, the absence of care made strong although unspoken statements. Davis agrees that the worst discrimination often appears to be “trivial”: We are not speaking of people with tattoos that say, “I hate cripples” or “Death to Deaf!” What we are speaking of is well-meaning people who simply do not have progressive information and education, in part because we do not teach disability in the public schools and colleges as we now teach race and gender” (p. 137).

I am sometimes irritated with myself for not speaking up in the moment that the ultrasound technicians suspended my exposed and vulnerable body in the air. I am sometimes frustrated with myself for listening silently as the resident doctor flippantly described how the steel hardware in my back had broken. However, I take some comfort in that I am now speaking through the written word. I also take a great deal of comfort and receive much validation from Frank who wrote about his own anger when he was ill with cancer. “When I was ill, I expressed little of this anger...because I was doing what I had to do to get by. I write now for the times I had to remain silent and for those who are still silent” (2002, p. 114). Similarly, I am grateful for the voice I now have.

## CHAPTER 6: MUSIC AND JOYFUL EMBODIED EXPERIENCES

A post-modern perspective argues that we should steer clear of grand narratives and instead welcome stories that have often not been heard or included (Lochhead & Auner, 2002). It has also been argued that in an age of post-modernity, lived-experiences and perception of those experiences is an act of creativity (Lochhead & Auner, 2002). Writing about my experiences is not a matter of just recording daily activities, but is rather a process of creative testimony, whereby I choose which moments get written about and how those moments will be sculpted and framed. As the poem below illustrates, although many of my lived experiences as a pregnant woman with a disability required me to make great bodily sacrifices that were difficult and challenging, many other experiences were joyful, transformative, and rewarding. Furthermore, what I am left with, namely Patrick and Chelsea, were entirely worth any sacrifices that I made.

For they told you life is hard  
Misery from the start  
It's dull  
It's slow  
It's painful  
But, I'll tell you life is sweet  
In spite of the misery  
There's so much more to be grateful  
So, who will you believe?  
Who will you listen to?  
Who will it be?  
Because it's high time that you decide  
It's time to make up your own  
your own state of mind...

Life is sweet  
(Merchant, 1998)

Sacrifices:

Pain  
Edema  
Broken rods  
Dysreflexia  
Pneumonia  
Broken ribs  
Bone infection  
Pressure sores  
Weight gain  
Unstable spine  
Shortness of breath  
Pressure sores due to edema  
Racing heartbeat, even at rest  
Life threatening blood infection  
Profuse sweating in reaction to pain  
Lack of restorative or recuperative sleep  
Permanent loss of bladder/bowel sensation  
Loss of spastic activity in legs that aid in transfers and in blood circulation

Gains:

Unexpected body confidence during childbirth  
Positive body experiences while breastfeeding  
Two robust children who provide my life  
with love, fulfillment, joy  
and meaning

### **Music and the Embodied Experience**

I have written a great deal about the difficulties I experienced during pregnancy, but this thesis would be incomplete without an expression of what gifts I have received at the same time. I have tried to live my entire life with this perspective. Indeed, when I learned that the Chinese character for crisis communicated both danger and opportunity, I had the character tattooed on my chest. Similarly, this chapter is devoted to those sweet and happy

moments I have experienced and have been changed forever by; moments that I treasure above all others.

Interestingly, these positive moments are also almost always accompanied by music. You could say I consider my life to have its own soundtrack. Sometimes music, lyrics and a pivotal life experience simultaneously correlated with my lived experience. Sometimes, the music just happened to be playing. Other times, there was a serendipitous relationship between the music ‘in the air’ and my lived experience. Most significant to this thesis is how music often gives me an avenue with which to examine, re-experience, design, and reframe experiences. Named by some as the poetry of our times (CBC, “Q”, April 11, 2008), music lyrics can reverberate with people in many different ways over different contexts.

Music is often credited with creating a feeling of belonging (Whiteley, 1997) by bringing social issues into mainstream culture. Like the advent of the Blues movement that was built by African-American slaves, music has a history of expressing hope and joy as well as sadness and frustration among oppressed or marginalized groups. Similarly, some theorists assert that while early feminism was theoretical and basically inaccessible for women who lived outside of academia, music lyrics are a way that feminist messages can become a part of social consciousness (Paglia, 1990). Some female music artists have stated that music is a way to illuminate women’s issues by giving them voice and presence in a culture that would rather keep such issues silent (Kaplan, 2002). To my knowledge there is no music that speaks to being pregnant or giving birth while living with a disability. Nevertheless, I was drawn to music during this time in my life and in my years as a mother

probably more than I had ever been before. In a way, that order made sense of and gave meaning to my lived experience.

The first story that follows is an example of how I struggled with my new identity of being a mother when it was never expected that I would ever be a parent. Because I had internalized many societal attitudes about how people with disabilities are without sexual identities and incapable of adult social roles (Fine & Asch, 1988), I struggled with integrating the role of mother into my new life. Music helped me with this integration.

### **Dancing to the Drum**

October 7, 1996

I have spent a lot of time during this pregnancy denying that I could possibly be pregnant. Now, here I am in the hospital on my birthday and I just witnessed an ultrasound of my unborn baby. When I got back to my room from the ultrasound, the Universe continued to fit together and make sense – through music. Darrell put the CD player on, placed the headphones on my ears and played the most touching song that brought everything together and made my crazy, chaotic thinking make sense.

He had been driving home from North Battleford to Saskatoon, listening to CBC and was about to change the channel when this song came on. He knew it was just what I needed. He tried to memorize the artist's name, but the title of the song was not announced. Although he ordered that CD when he got home, when it came in, the song wasn't on it. The CD with the song was out of distribution. He didn't give up though. He went to a second hand music store, dug around, and there it was, like it was waiting for us. My reaction was more of a puzzle piece – I started crying upon hearing the first line. I wept because finally, finally, everything had come together, everything fit, it all made sense and had purpose and reason and revealed a blessed truth.

Fast asleep in the dream of darkness  
The soul of every child  
Has waited to be born a stranger  
Underneath the drum of his mother's heart

Lying deep in a dream of darkness  
Where fear has never gone  
Each spark of a life is started  
Blind and pure to the world we come  
Each of us a dancer to the drum  
(Chapman, 1993)

### **Dancing with Patrick**

When Patrick was an infant, I, like most young mothers, was overwhelmed and not at all confident in my abilities. Since there was no ready-made script for me to follow as a wheelchair using first-time mother, I felt I was ill equipped to deal with this new part of my identity. I remember one time in particular. I was thinking, at 3 o'clock in the morning as I sat alone in the dark breast-feeding my infant son, about all the activities I would never do with him. I mourned not being able to teach him how to ride a bike or go tobogganing with him. I especially grieved not being able to have a slow dance with him, which I believed to be a special mother-son bonding, or rite-of passage experience. In my mind, he should be tall and handsome and graduating from school or perhaps getting married, and I should be a proud mom wearing a dress with a made-for-dancing skirt with a big carnation corsage pinned just below my left shoulder. He would glide me around the floor and everyone watching would acknowledge that we were mother and son by their nods, smiles, and approving looks. The more I thought about this image, the sadder I became because it felt as though that this image was not possible.

That night I descended into a depression I had not known before. Struggling with my despair, I did the only thing that seemed natural, something that I had done frequently to comfort my young self in my bedroom or hospital bed whether by a soft playing stereo

or through a pair of earphones or picking up my guitar. I simply sang to him. While I did not know many children's songs, I quickly figured out that I could "lullaby" pretty much any song. As a result, the singing calmed us both and helped him to sleep. Since then, I sing to him nearly every night that we are together even though he is now eleven years old. Singing, in my "mother's voice" not only works but has transformed a coping skill into a bonding experience.

Between his second and third years, my son's appreciation for music grew beyond the need to hear the soothing and sleep-instilling sound of his mother's voice. Like me at his age, he loved to play music on the stereo. One evening, we were listening to "Elmopalooza", a recording of Sesame Street songs covered by popular music artists. We were dancing all over the living room and having a wonderful, laugh-filled time.

All of a sudden, a lullaby that I regularly sang to him, and one of the few children's songs I knew, and regularly sang to him, called "Visit the Moon" began to play. Patrick froze. He stopped his dancing and listened. He walked over to me, stepped up on the footrest of my wheelchair, looked me in the eye and said, "Mommy, this is our song. Will you dance with me?" Time, as I knew it, was paused. With tears in my eyes, I told him I'd love to. He put his arms around my waist and lay his head against my chest and we slowly danced to the entire song.

I'd like to visit the moon  
On a rocket ship high in the air  
I'd like to visit the moon  
But I don't think I'd like to live there  
Though I would like to look down on the earth up above  
I would miss all the places and people I love  
And although I would like it for one afternoon



I don't want to live on the moon...  
I'd like to visit the jungle, hear the lions roar  
Go back in time and meet a dinosaur  
There's so many strange places I'd rather be  
But none of them permanently.  
(Moss, 1978).

For me, the song illustrates how I thought I needed to have certain experiences in order to embody what it meant to be a “real” mother. I thought I wanted and needed to “live on the moon”. However, while the moon might be a nice place to visit, there are many ways to experience wonder. There are many ways to know what being a mother is like.

It wasn't a special event that had brought us here. It was an ordinary day. While short in stature and in desperate need of a haircut, Patrick was undeniably handsome. We were not dressed in formal attire; we wore jeans and t-shirts. And there was no one watching. There was just the two of us, the music, and the golden light of a prairie sunset pouring in through the windows, warming the room as we danced. I hope that if I am granted one memory to carry over in the moment before I someday die, it is that one.

The moment made me realize that I do not need a special occasion to mark the significance of my relationship with my son, nor do I require the approval of others in order to fully realize my role as his mother. I saw that remarkable moments are not reserved for grand events, but are available to us at any time if we choose to see them. While I learned through sport that reframing and thereby choosing perspectives provides immense personal power, I have also learned that there is great benefit in employing these strategies in the

rest of my life as well. The following story is about how reframing a particular childhood memory led to an amazing series of events.

### **Chelsea Morning**

I was once asked by a good friend, “If you could name your happiest childhood memory, what would it be?”

After my spinal cord was injured when I was six, I was required to spend months in hospital, an hour and a half away from my family’s home on a farm. The days in the hospital were lonely; I missed my family, my school friends, and my pets. With nurses looking after me instead of my mother; with hospital food served up on a tray rather than the homemade meals and farm fresh produce that I was used to; with frightening code blue calls that I would hear signaling dire emergencies in the middle of the night instead of the soothing, sleepy songs my mother would sing; and the steady invasion of needles, catheters, and intravenous tubes into my little body instead of hugs, kisses, and cuddles, I craved feelings of safety, familiarity, and comfort.

Finally, several weeks later, I was allowed a weekend pass to go home. My Dad and brother drove to the hospital to pick me up as early as was permitted for me to leave. I had not been in a car since the accident and instead of it being a strange or scary sensation; I remember enjoying the ride, the warm breeze through the window, and the sight of other people in the outside world.

When we arrived at the farm, Dad lifted me into the wheelchair, then lifted both the wheelchair and me up the steps into our house. As he raised me up the last step into our kitchen, the most beautiful sight greeted me. The sun was beaming through the window

and its yellow gingham curtains made the whole room look like it was washed with gold. Mom had stayed behind to bake bread and the warm smell overwhelmed my nose and seemed to fill up my whole body. I felt welcomed home, and as though it was as important to them to have me home as it was for me to feel I like I belonged there.

Mom had dressed the table with the bread, farm fresh milk, jams, honey, and fresh fruit. Everything was warm, sunny, joyful, and as comfortable as though I had never left.

Perhaps the best part of the experience, though, was how we sat down at the table, with Dad to my left, my brother Jim to my right, and my Mom sitting directly across from me in the same configuration as we always did, how we did not talk about the accident, how we spoke only of the day and how nice it was to be together. That is what I remember best. With so many childhood memories I could have chosen, I felt compelled to pick one from a time when it seemed that I should have been the saddest. I consciously chose the memory where although the life as I had once knew it would never be the same, I could still find times where I felt warm, safe, and strong.

I often visit that memory in my mind, whenever I need a happy thought. A handful of years after I recounted this memory to my friend, I was driving home to Saskatoon from the 1998 Rifle National Championships in Calgary. I knew the drive would be long with only myself for company, so I purchased new music for the drive. One of the CD's was Joni Mitchell's *Blue*. When "Chelsea Morning" played, I was struck by a feeling that I must have heard the song many times, but that this was my first real opportunity to listen to it. I listened to it again. Overwhelmed with memory and emotion, I began to cry. I pulled over and repeated the song over and over again.

Woke up, it was a Chelsea morning and the first thing that I heard  
Was a song outside my window  
And the traffic wrote the words  
It came reeling in like Christmas bells  
And rapping up like pipes and drums

Woke up, it's a Chelsea morning and the first thing that I saw  
Was the sun through yellow curtains  
And a rainbow on the wall  
Blue, red, green, and gold to welcome you  
Crimson crystal beads to beckon

Won't you stay we'll put on the day  
There's a sun show every second

Now the curtain opens  
On a portrait of today...

Woke up, it's a Chelsea morning  
And the first thing that I knew  
There was milk and toast and honey  
And a bowl of oranges too  
And the sun poured in like butterscotch  
And stuck to all my senses  
Won't you stay; we'll put on the day  
And we'll talk in present tenses

Now the curtain closes  
And the rainbow runs away  
I will bring you incense owls by night  
By candle light by jewel light  
If only you will stay  
Pretty baby won't you stay

Woke up, it's a Chelsea morning  
(Mitchell, 1970).

It felt like I had received a gift. I had already taken ownership over my perspective on my childhood by choosing my first trip home after the accident as my happiest memory.

Having a song to attach to the memory gave me possession of my own history and a sense of legitimacy for my feelings and my choices.

When I arrived home I wrote down the memory and the song. I continued to reflect on and treasure the narrative that had come to feel a little like a fairy-tale. A few years later, I was marking the 28<sup>th</sup> anniversary of my car accident and because of this event plus many difficult issues that were occurring in my life at the time, I saw a counselor a few times. When I told my counselor my “Chelsea Morning story” she was obviously moved and thanked me many times for telling her.

The next time I saw her, she told me that she had a surprise for me. She told me about how she had been at a friend’s house for dinner after she and I had our session together. She and her son had been outside playing in her friend’s front yard when, shockingly, Joni Mitchell pulled up to the curb only a few houses away. My counselor did not think twice: she walked right over to Joni and asked, “Do you have a moment?” and then leaving out my name for confidentiality’s sake, told her my story.

As I listened to my counselor tell me this, I could hardly breathe. All at once my Chelsea Morning story became more special, more treasured, and my memory became more validated. Joni Mitchell knew my story!

Several months after that, I was reading a catalogue from our neighbourhood bookstore and while skimming the children’s section, I could hardly believe my eyes when I saw a children’s picture book by Joni Mitchell called, *Chelsea Morning*. My hands shaking as I held the page of the catalogue out for him to see, Darrell immediately left the house, bought the book, and returned home. Holding it in my hands, I read the inside flap

of the book cover that said the book was for children who see ordinary things in extraordinary ways.

A few years later, I became pregnant with my second child, a baby I was quite certain was a girl. As has been detailed in previous chapters, my pregnancy became more complicated. My belly was growing and making my physical life more difficult, and whether it is a coincidence or not, the 25 year old stainless steel hardware that was keeping my spine stable succumbed to years of stress and broke, leaving me with pain, steady bouts of dysreflexia, and increased difficulties with breathing, transferring, and even just sitting.

Nevertheless, it was important to me that I create a safe and comforting environment for Patrick. I learned this well from how my mother had made my childhood home the same way, especially on that first visit back home. I felt sure that continuing to keep our little family's life strong, optimistic, hopeful, and fun was key to surviving this difficult time – after all, we would be welcoming a new baby soon. At the same time, the centennial celebration of our province was going on and a fireworks display was scheduled to occur along our city's river bank on the Labour Day long weekend. Patrick was desperate to go, so despite how difficult we knew it might be, my husband and I promised him we would.

The park was full of thousands of people. We were not sure where best to watch the fireworks display, but after assessing the space, we decided to move closer to the water. Despite the amount of people, it was surprisingly dark and difficult to see where exactly we were going, but this made it all the more fun and adventurous. With Darrell pushing me and Patrick at my side, we ventured down a rough and gravelly path when the small wheels

on my wheelchair suddenly hit a rut and I fell straight out of my chair, landing on my hands and knees. With the swiftness one can only really muster in a crisis like this one, Darrell ordered Patrick to hold my chair while he picked me up as though I weighed little more than a small child and tenderly placed me back into my wheelchair. He checked me over several times; our hearts were racing.

Just when we came to the conclusion that I seemed to be fine, we noticed that music had started playing over loud speakers set up in the park. Patrick tugged at my sleeve, then threw his arms around me, “Mom, listen, listen!” “Chelsea Morning” was playing, Joni’s voice floated over the dark sky like a protective blanket, letting us know that all was well in the world.

A few months later, my baby girl was born. Darrell, Patrick, and I took a good long look at her face and saw that it embodied “the sun through yellow curtains and a rainbow on the wall”, so we named her Chelsea. I whispered in her tiny pink ear, “Pretty baby, won’t you stay, we’ll put on the day, and we’ll talk in present tenses.”

### **A Natural Woman**

I have several journals filled with extraordinary moments that I have had with my children. One of the most significant experiences was breastfeeding. Breastfeeding both my babies were enormously satisfying and fulfilling embodied experiences which enabled me to feel great confidence in the amazing things my body could accomplish. Nursing was one of the experiences that made me feel productive, valuable, and truly maternal. It was not long into my new role as Patrick’s mother that I became very attached to breastfeeding, but it was not until I had given birth to Chelsea and experienced the physical trauma of the

broken hardware in my back that I began to realize the reasons why nursing my baby was vital to my feelings of competency as a mother.

February 19, 2006

In thinking about it, I realize breastfeeding makes me feel healthy and strong. When I say to myself (and I do this a lot lately), “My body is strong and healthy”, I visualize breastfeeding Chelsea. This body function gives me an overall feeling of wellness, strength, productivity, and vitality. Nursing is keeping me focused in the midst of a desperate situation.

February 25, 2006

I am lying down to write this. Once again, I am having a lot of discomfort. It occurred to me that most of my body is, has become, completely unfamiliar to me: the way I look, how my clothes (don't) fit, the way the skin now hangs off my newly atrophied legs, how my bladder and bowels no longer signal any fullness, how my feet don't settle on the footrest of my chair, and of course, how obscenely crooked I am, how my left hip bone grinds against my ribs on the right side, how laborious it is to take a deep breath, how pushed up and over my intestines are, how they push food back up my esophagus causing vomit to come in my throat. And the pain. And the sweating and the unrelenting effort it takes to hold myself up all the time when I am in my chair, making it so hard to dress and change Chelsea because I have to hold myself up with my elbows, yet somehow I do this and more.

The one familiar thing is breastfeeding. My breasts still work. No wonder I am so attached to it. So many people (well-meaning) continue to encourage me to give it up because they want me to have less stress. But they do not understand that I need to breastfeed so despite everything else, I can still feel a little bit healthy, useful, female, whole, human. My cells can not be so sick if I am nourishing Chelsea's healthy and strong cells. And sometimes I look at Patrick, doing his karate kata or practicing his guitar and I think about how strong and amazing all his cells are and how I nourished them once too. It is this idea that is keeping me alive.

Therefore, although it was undoubtedly intended as a love song, it was during this time that Carole King's “Natural Woman” became somewhat of an anthem for my



embodied experience of breastfeeding and mothering. The song became part of my “self talk.”

Looking out on the morning rain  
I used to feel uninspired  
And when I knew I had to face another day  
Lord, it made me feel so tired  
Before the day I met you, life was so unkind  
but your love was the key to my peace of mind  
cause you make me feel  
like a natural woman

And when my soul was in the lost-and-found  
You came along to claim it  
I didn't know just what was wrong with me  
till your kiss helped me name it  
now I'm no longer doubtful  
of what I'm living for  
cause if I make you happy I don't need to do more  
you make me feel  
like a natural woman

oh baby what you've done to me (what you've done to me)  
you make me feel so good inside (good inside)  
and I just wanna be (wanna be)  
close to you you make me feel so alive  
you make me feel  
like a natural, natural woman  
(King, 1971)

## **CHAPTER 7: BECOMING A LIVING TEXT**

Prior to starting the writing process, I read several journal articles and textbook chapters on autoethnography. Although the writings were different in style and approach, they all agreed that a distinguishing quality of autoethnography was the way the method tells a personal story while connecting to broader social issues. What became even truer for me, however, was how I, my body and my life became an autoethnography. I feel that in many ways I became a living text where there was no line between my private world and the public world for which I was writing. There were no lines drawn between my personal life and my academic writing. This was particularly revealed to me through my practices of being a mother to two children and through the process of recovering from my surgeries and by, as I hope to illustrate below.

### **Writing While Parenting**

Writing while full time parenting to two young children is rewarding and challenging. I wrote parts of this thesis between episodes of Sesame Street, Play-Doh sessions, and diaper changes. I put writing on hold to be with my son while he recovered from a tonsillectomy, ear infections, made decisions to change schools. Many times sewing Halloween costumes and listening to endless details about Lego projects were a greater priority than my thesis work. My office and writing space was never my own as hard as I tried. Today, as a matter of fact, the floor is littered with crayons, puzzle pieces, and Lego Bionicle parts. There is also a battery-operated toy train that mysteriously

“speaks” to my wireless mouse so that every time I scroll or click, I hear “Choo Coo.” It is funny that I have not gotten used to that yet.

Parenting and writing at the same time has proved to be more of a balancing act than I anticipated. Oftentimes I would just hit a moment of writing inspiration then look down to the clock in the corner of my computer monitor and realize I had twelve minutes to get the thoughts down because I had to dash out of the house to pick Patrick up from school (kind of like what is happening in this very moment!). Let us just say I was late a lot. I would carry a “Moleskin” notebook (and later, a pocket-book sized computer that was a Valentine’s gift from Darrell) with me everywhere, so that if I had even a few minutes I could make thesis notes. I had many inspired moments sitting in my van waiting for Patrick to finish karate class or while baking the two dozen muffins that get my family through the week or while talking to my mom on the telephone. My body became a literal site for text because I frequently wrote on my hand. Sometimes I would write on my hand in the dark in the middle of the night and when I woke the next morning the damp ink would have tattooed on to my cheek if my hand rested against it while I slept.

I wrote this thesis on the often considered cluttered artefacts of daily living: inspired words and questions appeared on the back of grocery lists, old receipts, used envelopes, and business cards; thoughts and sentences were dashed out on napkins, countless post-it notes, in my son’s school planner, and in the margins and even on the covers of books. I wrote some of my thesis at a table in the lobby of Saskatoon’s downtown movie theatre while waiting for my son and his friends take in a matinee. During the writing process, it often felt like the needs of my children came before mine. In

the end, I think that is what being a parent is supposed to be like. Perhaps my dedication to writing a little (or as it often turned out, a lot) everyday and making the most out of every spare moment that I had made this thesis better than it would have been if I had nothing but it to think about. Perhaps all those interruptions assisted the creative process that is often hard to describe. One thing I know for sure is that I do not regret a thing.

### **Writing While Recovering**

Some are born with more and some born with less  
So don't take for granted the life we've been blessed  
It's hard to understand that we're only a guest  
And each one of us shall be put to the test  
And we must all have the will to live...  
(Harper, 1997).

Frank (1991) states that “Narratives are essential not only to the coherence of our bodies and lives. They are no less essential to the mutual recognition on which relations with others are grounded” (p. 89). With this statement in mind, I feel it is important to connect with you, the reader, on another aspect of my life that made writing my autoethnography challenging and that is how my thesis writing intersected with my physical and mental recovery from two major spinal surgeries. For this explanation I feel the need to make a list of how I was affected. A list, as opposed to a paragraph, feels more matter-of-fact and less emotional. I have been a list-maker for years. Sometimes when there are just too many words to get out of me, making a list seems easier, simpler, and like less emotional work.

Recovery from:  
Two spinal surgeries  
10 litres of lost blood, 10 litres of new, donated blood

removal of 6 (in total – 4 broken, 2 whole) stainless steel rods and 20 stainless steel screws  
the installation of 20 titanium screws and 2 titanium rods and active bone cells from a  
donor's hip joint

8 weeks on my back, unable to angle my bed no more than 30 degrees

8 weeks away from my home and family

Never getting to be able to get ready for bed because I was always in bed

Not having a bath or shower for over 2 years

I made a list of "losses" in my journal about 2 weeks after my second surgery in October, 2006.

During this time I lost:

My stable spine

Height

Mobility

Comfort

Pleasure

Blood

Dignity

Driving

My car

Freedom

Bathing

Showering

Power

Muscle tone

Muscle mass

Spasms (who knew I would miss them?)

Sensation

Control of my bladder

Control of my bowels

Control of my home

Control over my kitchen

Control over the food I ate

Control over the food my family ate

Desire

Independence

Strength

Motivation

Hope

Friendships

Intimacy

Privacy

Breath  
Ease  
Fun  
Spontaneity  
Simplicity  
Productivity  
Efficiency  
TIME  
Quality  
Imagination  
Goals  
Visions  
Expectations  
Money

Starting the writing process after so much physical trauma is a story, and perhaps a thesis, in itself. It was incredibly difficult to separate what happened to my spine and the rest of my body from the experiences of my second pregnancy and childbirth. Yet I knew a thesis has to have focus and can only be so long. To give you, the reader, of an idea of where my mental state was at shortly after the second surgery, and the kind of trauma I had to work through in order to start living and being productive and active again, I include the following deeply personal journal entry.

October 15, 2006

A List of Things I Am Not Supposed to Talk About:

I cry everyday

I am hungry

I am lonely

It hurts

I am worried about getting an infection in this IV line that goes straight into my heart

I am terrified this surgery did not work

I have nightmares

I am afraid of not getting another chance

I am afraid I won't get to grow old with Darrell

I am disappointed that I have let Darrell down

I am desperately sad about all the stress I have caused Darrell, Patrick, baby Chelsea, my parents, Darrell's parents  
I am super stressed about money  
I am stressed about healing, or not healing  
Patrick gets tired of coming to see me  
Darrell is tired, irritable, impatient and is tired of coming here too  
I feel irrelevant  
We cannot be confident that I am going to get rid of the infection  
I do not sleep well  
I don't think I have ever been so sad  
Someone always has to watch me pee  
Someone has to help me with a bowel movement  
I have no dignity left  
I am nothing  
I cannot take a deep breath  
I still have lots of pain  
I am congested; there is no fresh air here  
I have no one to talk to  
I am alone  
If I can't be valuable, I want to die  
I have no strength left  
I have no motivation  
I cannot lift my baby.  
There is nothing left for me.  
I give up  
I give up  
I give up

My thesis writing and my recovery were just as blended as my writing and parenting. Just as I wrote parts of my thesis on whatever I could find, I also wrote down my dates, times, and fasting requirements for CT scans, MRI's, and bone scans on the back of journal articles that I was reading. I wrote down notes from telephone conversations with my doctor on post-it notes that ended up as bookmarks in library books. I jotted down questions I wanted to remember to ask my doctor on the blank pages of my text books while I made a career out of waiting - in hospital waiting rooms, while waiting for an x-ray, or while waiting to have my blood work done. On the back of Reed-Danahay's article on

autoethnography, I scrawled these thoughts to discuss with my surgeon in anticipation of his phone call to talk about my need for yet another MRI:

Is this type of test necessary? Or could I have something else? What are the alternatives? I understand MRI needs the use of a contrast dye to show inflammation. Will the results be skewed due to my dislocated hip? Concerns: amount of radiation I am receiving and how this test will affect breastfeeding.

### **Writing is an Embodied Experience**

It is through these life events of parenting and recovering that I have learned that writing is an embodied experience. Writing is something I think many of us consider being cerebral, something that happens in our brains that somehow finds itself on paper or on a computer screen. In my experience, this is only part of the picture. There were many times when I would read a journal passage and when I began to transcribe it by typing on my keyboard, I would shut my eyes tight, tears would be springing from the corners of them. I would sob, howl, ache in my chest, even double over with my head resting on the desk, and still my fingers would know the words and they would type out the story. Carolyn Ellis (2004) illustrates simply but succinctly that autoethnography is research and writing that connects the personal to the social, but that it is also, “concrete action, emotion, embodiment, self-consciousness, and introspection” (2004, xix). Echoing this statement is Stacy Holman-Jones who says that “body and voice are inseparable from mind and thought” (2005, p. 767). Sharing my embodied writing process with you, the reader, hopefully evokes your own emotion, interest, and curiosity. Bringing forth these qualities in readers is one of autoethnography’s goals of author-reader connection (Holman-Jones,



2005). Perhaps, though, poet Robert Frost (1939) says it best: “No tears in the writer, no tears in the reader.”

I have learned that writing my personal story was not a matter of copying and pasting from my journals. Writing a story such as mine is a complex process of intense emotion, vulnerability, painful memory evocation, self awareness, self analysis, and self actualization. It involves reading, re-reading, writing, re-writing, analysis, rumination, more reading, more writing, more analysis, and lastly, and probably most importantly, the need to be honest. It was this need to be deeply honest with myself, and therefore, with you, the reader, that I have found to be one of the most challenging parts of this writing process. By “digging deep” and revealing the “truths” I learned things about myself that I did not necessarily like, and that sometimes those “truths” made me uncomfortable and even ashamed. I needed to keep an open mind to the self-analysis, allowing for possibilities that I may not have otherwise considered. Through this autoethnography, I did what Reed-Danahay (1997) terms a “rewriting of the self” (p. 4).

I have written several times already about the emotional challenges I faced when writing this thesis. Also difficult for me were the comments from many of my close friends and family who had no idea what the writing process was like. Many of my family members, in particular, were clueless about what writing a thesis entailed. When they heard “autoethnography”, they tuned out to even my simplest of explanations. I heard comments even from my University educated friends like, “If you are writing a personal story based on your journals then half your work is already done.” “Writing your story must not be so hard. I mean, you have already lived it.” “What is scientific about the story

of one person?” The only ones who I felt truly understood and cared about me during the process were firstly, Darrell, who saw the tear stains, the stress, frustration, confusion, and fatigue printed on my very body. He also had to contend with many, many (too many) conversations about “what it all means.” Secondly, I relied on Dr. Donna Goodwin, my supervisor, who I would confide in from time to time and usually right at the moment I thought I might never write another word. She inevitably had just the right words for me at those moments, and I always returned to my work.

Another significant lesson I learned while writing this thesis is that an understanding of bodies with disabilities is essential to an understanding of all bodies. The more I wrote, the more I saw that although many of the experiences I had while I was pregnant and giving birth were different than most non-disabled women experience, those different experiences need to be spoken and understood in order to provide a more complete picture of what it means to live embodied in the world.

Titchkosky’s (2007) asserts that it is essential to understand bodies with disabilities in order to understand all bodies. Furthermore, Wendell (1996) argues that the experience of disability expands the variety of possible human physical experiences that the able-bodied human population may never experience. Like Titchkosky, Wendell calls for a more complete understanding of embodiment that requires a comprehensive understanding of the embodied experience of disability.

I was immediately struck by the radicalism of these statements. After all, disability has historically been an “added on” subject in most research and curriculum areas, not an essential core or central feature. Similarly, people with disabilities have traditionally been

considered as an “added-on” part of society in terms of architecture, accessibility, programs and policies and not as an integral, included part of our social fabric. Titchkosky (2007) reminds us that by the words we use to describe people with disabilities informs our laws, practices, policies and so on and that it is these words that construe people with disabilities as outsiders and problem-causers.

Sometimes people with disabilities do cause problems, but then again, so do people without disabilities. Sometimes the problem exists in the social structure, sometimes it is in the person. I am not being flippant, rather I wish to draw attention to the idea that identity, including that of disability, is dynamic and fluid, not static. Sometimes I am just a woman, sometimes a woman with a disability, sometimes a mom, sometimes a disabled mom, sometimes an athlete, sometimes a former athlete. Identity is not straightforward (Shakespeare, 2002). Foucault would add that our personalities and our identities are always changing, “Do not ask me who I am, and do not ask me to remain the same” (Foucault, 1969, p. 17). Identity is not just layered or multi-faceted or complex. It is also an action.

### **Universal Structures**

I have learned that this is not just the story of one person. The themes of disability, pregnancy, and childbirth have the potential to resonate with others. Foucault (1984) poignantly articulates: “Singular forms of experience may perfectly well harbour universal structures” (p. 335). It is a hope that by writing my story and connecting it to the larger social world, that readers will find strands of “truth” that apply to their own lives. Autoethnography should encourage empathy and connection beyond the self and contribute

to meaningful sociological understandings (Sparkes, 2002). Hopefully readers will read my words carefully and will bring the same careful attention to how those words resonate in the context of their own lives” (Holman-Jones, 2005).

I have aspirations to publish my thesis, in whole or part. It could serve as a teaching tool on its own or in combination with presentations for students who are studying in the health sciences. At the very least and in whatever form, I would like this autoethnography to be used as a spark of imagination to other women with disabilities who want to become mothers.

December 7, 2006

Today as I sat breastfeeding Chelsea in the waiting area before my appointment with Dr. L, my rehabilitation doctor, a young woman in her mid twenties using a wheelchair shyly approached us.

“Is she yours?” she asked me, brushing her long brown hair from her face. I laughed a little and assured her, that yes, this hungry little shrimp was my daughter. Her eyes widened, and I could swear that I saw some tears spring forward. She shifted awkwardly in her wheelchair in a way that made me suspect she was still adjusting to a new cushion or a new chair. She then smiled and confessed that she had been injured for only a few months and that she was still hospitalized here at this rehabilitation unit. “But when I leave here and go back home, I want to have a baby!” she gushed. “My husband and I have been married under a year, and although we first thought we should wait a while, we have changed our minds since the accident. Now we want to start a family soon.”

Our conversation took a pause as I moved Chelsea from my right breast to my left. Although I was trying to concentrate on latching this newborn, I was aware of this woman’s keen attention on what I was doing. So I offered, “If you have any questions, I would be happy to answer them. I didn’t have anyone to talk with about disability stuff when I was pregnant. That would have been nice. Chelsea is just over a week old and I have a son at home who is eight.”

She nodded enthusiastically and we spent the next several minutes talking about her fears that she wouldn’t be able to have children, and if she were able to conceive, how she had no idea what pregnancy would be like, or if she would be able to deliver the baby without a

cesarean section. She even admitted that she had wondered if breastfeeding would be possible. “Why is there so little information about women in wheelchairs who want to have kids?” she wondered out loud.

Before I was called in for my appointment, I gave her my phone number. The wide smile on her face told me she was excited about the prospect of having a child of her own. It felt good to have given her some hope.

## EPILOGUE

October 7, 2008

The re-writing is done. I have just printed my thesis. When I rest it in my hands it is still warm. It looks so big. There is something about the act of holding it in my hands that makes the words seem more real. An embodied act, I suppose. Holding it and feeling its warm weight in my hands I suddenly realize that I was never supposed to write it. You were never supposed to read it. I was not supposed to go home to live with my family. I was not expected to do any sports, finish high school, find a partner, go to University, get a job or become a mother.

While holding my thesis, I suddenly remember this past June, June 4<sup>th</sup> to be precise. It was the 32<sup>nd</sup> anniversary of my car accident. I always mark the day in some special way. This year Patrick, Darrell and I marked the day by going to see k.d. lang in concert. As I wrote earlier, there were no lines between my academic or public life and my private life during the writing of this autoethnography, not even, as it turns out, when attending a spectacular concert on the most personal of days. But when I heard k.d. sing "Coming Home", I reached into my purse to find a piece of paper, any piece of paper, and a pen, any writing utensil would do. And in the dark I scrawled that inspired and meaningful line, "I am happily indifferent to the ones who have consistently been wrong."

I do not know if I am always happily indifferent to the ones who have consistently been wrong about me, but I do know that I strive to be. Some days I get it right. Other days I struggle. The autoethnographic process has made me realize that I am living an extraordinary life and that I have a body worth celebrating. My body has done, and continues to do, incredible things. The lack of expectations that surrounded me as a woman with a disability were not ones I had to necessarily live with. I am an agent. It is hard work. But it is good work.

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**APPENDIX A**

**Behavioural Research Ethics Board  
Certificate of Approval**

## APPENDIX B

### Behavioural Research Ethics Board Application for Ethics Approval

1. **Name of researcher:** Heather Kuttai, College of Kinesiology, Adapted Physical Activity  
**Name of Supervisor:** Dr. Donna Goodwin

**Anticipated start date of the research study:**

The data for this study, personal journals authored over the last two decades, is the primary focus of the present research. I have been using this data to write an autoethnography since January 2007. I am applying for ethics approval at this point because I would not have known at the beginning of my writing the different individuals that would be included in my research.

**Expected completion date of the study:** November, 2008

2. **Title of the Study:** Maternity rolls/roles: An autoethnography on an embodied experience of pregnancy, childbirth, and disability

3. **Abstract:** As a woman with a spinal cord injury who uses a wheelchair, my thesis is an autoethnography that is based largely on the journals I have written in over the last twenty years, and in particular the journals I kept while I was pregnant and giving birth to my two children. Disability is a pervasive ideology that informs many of our cultural ideas of self and other, what constitutes acceptable and celebratory bodies, political stances, public policy, and language. Much of the literature that examines the female bodily experience excludes the stories and experiences of women with disabilities. Because the body with disabilities is often seen for what it can not do, taking on the role of mother can give the body a different value, status, and worth. I feel that my lived experiences as a woman with a disability experiencing pregnancy and childbirth offers insights and understanding into what it is already known about women's bodies. I display multiple levels of personal and cultural consciousness while connecting to the larger understandings of the culture of pregnancy, childbirth, and disability.

4. **Funding:** I received a SSHRC scholarship to support this research.
5. N/A
6. N/A

## **7. N/A**

## **8. Consent**

My research method is an autoethnography, and therefore is largely autobiographical. My main ethical concern within the work has been individuals in my life that I have written about. These individuals can be grouped into two categories: those who can be directly identified because of their relationship to me (e.g., my husband) and those whose identities can be concealed by having their names and sometimes their genders changed.

I have attempted to create as transparent of a process as possible with the individuals I have written about who can be directly identified because of their relationship to me, such as my parents, my coach, my husband and my children. To minimize harm to them, I have discussed my writing with them and I have allowed them to view sections of the research report that includes information about them. I have been clear that they may ask that sections they perceive as harmful to them be removed from my thesis.

For other individuals that I have written about (e.g., doctors, teachers) I have altered their identities by changing their names and sometimes genders in order to protect their anonymity.

## **9. Methods/Procedures**

Hand-written journals that I have kept for over twenty years are my primary sources of data for my autoethnography.

## **10. Storage of Data**

My journals are stored in my home, as are electronic transcriptions I made of them.

## **11. Dissemination of Results**

My data is intended for the use of the writing of my thesis. I may also use my data in writing that will appear in journal articles and in presentations (conference and otherwise) that I may be asked to give.

## **12. Risk, Benefits, and Deception**

There is minimal, but possible risk of discomfort and harm to those individuals I have written about who can be identified because of their relationship with me. To deal with this, I will, and have, discussed my writing with them, allowing them to read the passages

that include them, and give them the opportunity to ask that sections they are not comfortable with be removed.

There is a possibility that third parties may be exposed to a loss of anonymity because of their profession (e.g., doctors). To reduce this risk, I have changed the names and genders of these individuals where appropriate.

The greatest risk for emotional distress is to me, since this is largely an autobiographical work.

### **13. Confidentiality**

The measures I have taken to protect other individuals with a more indirect relationship to me are changing their names and where appropriate, their genders.

### **14. Data/Transcript Release**

The individuals that I have written about that can be identified because of their relationship to me will be, and have been given the opportunity to read any and all sections of my thesis that apply to them. They are aware that they may ask me to reconsider/remove any sections with which they are uncomfortable.

### **15. N/A**

### **16. Required Signatures**

Student: Heather Kuttai

Supervisor: Dr. Donna Goodwin

Department Head:

## APPENDIX C

### Consent Form

#### **Maternity Roles/Roles: An autoethnography on an embodied experience of disability, pregnancy, and childbirth**

**Researcher** - Heather Kuttai, Master's of Science (Kinesiology) candidate  
University of Saskatchewan (306) 374-3287

**Research Supervisor** – Dr. Donna Goodwin, Associate Professor, Faculty of Physical Education and Recreation and Executive Director, The Steadward Centre for Personal and Physical Achievement, Faculty of Physical Education and Recreation, University of Alberta (780) 492-4397

This is a consent form whereby you indicate that you are willing to be identified by way of your name and relationship to me, in my thesis, *Maternity Roles/Roles: An autoethnography on an embodied experience of disability, pregnancy, and childbirth*. This consent is a requirement of my institution and ensures that an individual, like yourself, knowingly indicates their willingness to be identified.

My thesis is an autoethnography that is based largely on the journals I have written in over the last twenty years, and in particular the journals I kept while I was pregnant and giving birth to my two children.

As an identified person in my thesis, you are free to ask to read any or all the sections of my thesis where you are identified. You are also free to request that certain sections that identify you be removed from my thesis. My autoethnographic research will be used for the purposes of dissemination in articles, conference presentations, and in book form.

If you have any questions at all, you may call the Research Ethics Office at the University of Saskatchewan (306-966-2084).

By signing below you acknowledge that this study and contents of the consent have been explained to you, that you understand the consent form, and that you agree to be identified by way of your name and your relationship to me in my thesis. A copy of this consent form will be given to you for your records.

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Signature

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Date

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Researcher

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Date