

**MULTIPLE REFLECTIONS ON DISABILITY AND REHABILITATION**

**“I WALK, THEREFORE I AM...”**

**MULTIPLE REFLECTIONS ON DISABILITY AND REHABILITATION**

by

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**Abstract**

The term ‘disability’ is laden with medical origins and medical meanings, which contribute to exclusion and oppression for persons labeled as ‘disabled’. Moreover, these processes are amplified by constructing disability as an individual burden or personal tragedy. Medicalizing disability keeps it a personal matter, a personal problem that needs to be treated, rather than addressing the social processes that actually restrict or constrict the disabled person’s life.

Rehabilitation Science and my lived experience of disability and walking serve as contexts that assist me as I explore how my subjectivity as a disabled woman and clinician helps me understand the theoretical tensions of five key themes: independence, power, client-centred practice, ableism, and the social model of disability in relation to disability and rehabilitation. These themes offer me a way to analyze my experiences, and how I have come to access and engage with Disability Studies literature in order to deepen my understanding of the critiques on disability and rehabilitation. As an insider, my research explores three decades of personal narrative. Through critical reflexivity as part of autoethnography, I work to increase my own awareness and that of my readers on the tension and complexities with respect to disability and rehabilitation.

## Acknowledgements

As PhD students we are told that a doctoral program is a lonely journey, but that we can make it a fulfilling journey when we reach out for support. My doctoral journey was possible because of the guidance, mentorship, and support of a group of important people in my life.

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and did not hesitate to to mentor me when I decided to explore the field of Disability Studies. I was a better PhD student because of you, and am a confident Disability Studies scholar today.

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# **Preface**



—July 2013

It has been a few weeks since my surgery and I am lying in bed. My iPad begins to ring, a video call is coming through. I hoist myself up onto my elbows, wincing in pain. As I roll myself onto my left side in order to reposition my right leg in its huge immobilizer knee brace, I tap the screen and say, laughing, “Hold on, I’m here! But it’s going to take me a few minutes to sit up”.

“How’s it going, Sues?” my very good friends Christina<sup>1</sup> and Tina ask me over video chat. “It’s so good to see you’re home”.

“Ugh. I’m doing okay. This is really hard.” I have managed to pull myself into sitting and am leaning up against the headboard. I am exhausted by this ordeal.

“You look good!” Christina comments. I shift uncomfortably in my bed, trying to reposition my leg so that I can sit a little for the conversation. Christina, like me, lives with a congenital disability<sup>2</sup> and is also, like me, a Disability Studies scholar. I open up to her a little bit about my reflections on this experience.

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<sup>1</sup> All characters within this thesis have been assigned a pseudonym. Names that first appear as designated with an \* are anonymized. Names without an \* have consented to appear with their real names.

<sup>2</sup> I intentionally do not use the term impairment, which would be viewed universal language as per modern ICF terminology. The term *impairment* is too simplistic for my use; it ignores how different cultures can underpin concepts such as impairment, disability, and disablism (Goodley, 2011). I use *disability* to take the focus away from impairment as my (our) problem and politicize my disabled experience and those of my disabled peers. Through the critical orientation of this body of work I align myself with Disability Studies thinkers, where disability (and not impairment) expresses “the value of subjectivity, and specifically the value of bringing personal experience of oppression to bear on analysis and interpretation of the world” (Morris, 2001, p. 5). I take the power to reach beyond Rehabilitation Science terminology and represent my reality of disability in line with other disabled thinkers like myself.

“I’ve been journaling a lot.” I confess to both of them. “You’re supposed to be resting” Tina reprimands me. Christina laughs and says, “I think it is good that you are journaling through this”.

“I have all of these feelings about this experience.” I reflect. “Something feels different.”

“Like what?”

“I almost feel like Rehabilitation Science and Disability Studies are colliding in my recovery”.

“You’ve definitely got to journal through that, Sues”.

“Yeah? What am I going to do with this?”

“I’ve told you this before. *This* is what your thesis should be”. Christina leans into the computer screen. I observe how her expression means business.

“What, my surgery?” I laugh sarcastically.

“No silly. Your thoughts about what is going on in your life” she encourages me. “Sues, this is where your strength lies. You need to talk through some of these issues”.

“I wouldn’t know how to do that” I whine into my computer screen. “I can’t do this for a PhD thesis.”

“Yes you can”. Christina encourages again.

“But I have figured out my thesis work already.” The thought of changing my thesis work causes a lot of anxiety right now. My leg is beginning to throb in its brace. I try to shift my position to alleviate the pulsing.

“You keep on coming back to your reflections about what’s going on right now. That’s why we wanted to call you.”

“I know... everything seems so *raw* for me right now. It’s really making me think of so many things, like how we should teach about disability. Heck I am thinking about how I think about disability.” I scratch my head.

“You can do this as your PhD thesis. You need to give Rehab Science something they can understand. Something they can connect to. Your life is knowledge”.

I feel enticed by this concept. I know she is right. I’m much too passionate about this to let it go.

“For now, all you have to do is to keep on journaling about what you’re feeling and work on your recovery. The rest is going to fall into place.” Christina smiles at me. Tina nods in agreement.

“This is all so foreign to me.”

“But it feels right?” Christina asks me seriously.

“It feels right.”

~

— September 2014

“Everything is set for today?” my husband, Derick, inquires as we both get ready for our workdays.

“Yup” I answer. “Part of me still wonders whether I really want to do this today” I add, as I collect my things in my shoulder bag and get ready to head down into the kitchen.

“You’re ready” he encourages me. “You will be fine. And remember, you can always go to your van and grab the wheelchair if it’s too much.”

“That’s true,” I agree. My heart skips a beat and I can feel the fluttering of anxiety make its way up my chest into my throat.

“Please call me if you need to, and let me know that you arrived okay.” He always says that when I drive longer distances. I nod and lean into him for a goodbye embrace and a kiss.

“You can do this,” he says again as he and our senior pug run to our entrance door. He throws a dog biscuit to the pug and then opens the door, and after an “I love you” he is gone.

I sigh as I scan over some of the things I want to pack for today. “What room number do we have our meeting in?” I mutter out loud as I sift through all of my teaching papers and then scan through my teaching email mailbox on my laptop. Is it in 422 like our first meeting was? The butterflies in my stomach steadily multiply. I often mutter out loud to myself, especially when I feel anxious. “Why are you so nervous about this, Susan? I mean you are just doing what you decided to do. The second week of tutoring you are going to walk into school and you’re going to leave your wheelchair in the car.”

I have two choices. Either I call the coordinator and ask for the room number, or I could just take my wheelchair and wheel through the building to find the room. The second choice tempts me for a few seconds. But I pick up my cell phone and dial the coordinator’s number. When she answers, I say: “Hey, it’s Susan”. I look at my watch and realize I don’t have much time before I really need to start driving to the university. “Sorry do you have time right now?”

“Yes I do,” she answers. I think that I should quickly get to the point so she does not think that I am cancelling on her for today’s clinical tutoring of the OT students.

“I couldn’t find the room number for our meeting in my tutor folder. Is it in 422?”

“Yes it’s in 422. You’re right, I haven’t written this down. I should send an email to the others...”

I break her line of thought. “Ugh 422, that’s the 4th floor”.... I really had hoped that I did not have to walk on the 4th floor today. Specifically I had not anticipated that I may ‘come out’ walking to the rehab people just yet.

The coordinator breaks my line of thought “What do you mean by the 4th floor?”

“Well today is the day I said I would walk at school,” I stammer as she replies: “That’s right!

You did tell me about this. Today is the day? Is the 4th floor too far for you?”

I start to laugh, “No, no, the 4th floor is fine. I have no idea why I’m so bloody nervous about it.”

“You’re nervous? You’ve walked at school before.”

“Yeah, but this feels different” I pause. I have walked at school – from my desk to the washroom and back. But I’ve never left my wheelchair in the car before. Trying to explain the difference I say, “This is me walking in school after a year off because of surgery, and you know what everyone is going to think”. My butterflies start to flutter again.

“I mean, I know that I get it, but you don’t think other people will get it?”

“No, I frankly think that other people don’t get it.” I start laughing again. “I mean it’s my choice whether I’m going to use my wheelchair at school or walk and I don’t know why people have so

many things to say about walking. It's like if I walk into the building today everyone is going to feel so happy for me, like I'm some kind of miracle. That I'm somehow better".

"But you are better". She's right, but I don't feel better. I feel different. This surgery opened a whole other door for me. Even I am still coming to grips with what this surgery really represents in my life, from my own perspective.

At this point, I hurriedly start to toss my things into my bag as I glance at the wall clock. I really need to head onto the road. While I pack my things, the coordinator encourages me through my cell phone's headset.

"Listen. I think you need to do one of those audio notes that you tell me you do all of the time. Do one on your drive. A 'before and after' on why you're so nervous about walking at school." I'm interested by this advice. Why am I so nervous about this?

"That's a good idea, I think I will do that".

"And don't worry about what people are going to say. Just do it. See what happens." My inner voice fuels my thoughts.... That is usually the advice everyone gives me. Just do it.

Out loud I reply "Okay, thanks for the chat. I will see you in a bit". I disconnect the phone, swing my backpack over my shoulders and then grab my forearm crutches. I walk to the garage door.

## Contents

<b>CHAPTER 1: Introducing “I Walk, Therefore I am...” .....</b>	<b>1</b>
Where do I Begin?.....	3
“I Walk, Therefore I am...” .....	4
What had I Begun?.....	6
Disability Studies and Me.....	6
Tensions in the Literature.....	9
Where Next?.....	11
The Significance of Normalcy.....	11
Implications of my Research.....	16
<b>CHAPTER 2: “I Walk, Therefore I am...Between two Worlds”.....</b>	<b>17</b>
Paradigms and Knowledge Bases.....	19
Elements of the Research Process.....	22
Critical Consciousness.....	22
Post-structuralist Orientation.....	22
Narrative.....	24
I am Disabled.....	26
Autoethnography: The Why and How.....	29
Rationale.....	29
Research Methodology.....	31
Analysis.....	34
Methodological Tensions.....	38
Reflexive Tensions.....	38

Analytical Tensions.....	39
Tensions of Emotional Labour in Research.....	40
<b>CHAPTER 3: “I Walk, Therefore...I am Independent” .....</b>	<b>42</b>
<b>CHAPTER 4: “I Walk, Therefore...I am Oppressed” .....</b>	<b>62</b>
<b>CHAPTER 5: “I Walk, Therefore...I am deemed to be compliant” .....</b>	<b>99</b>
<b>CHAPTER 6: “I Walk, Therefore...I am Able” .....</b>	<b>141</b>
<b>CHAPTER 7: “I Walk, Therefore...I am Less Disabled.....</b>	<b>178</b>
<b>CHAPTER 8: “I Walk, Therefore I (Simply) am” .....</b>	<b>223</b>
Overall Conclusions.....	226
Why Embark on This Journey?.....	226
Contributions to Understanding Disability and Rehabilitation.....	230
Implications for Future Research.....	235
Implications for Education.....	237
A Path Forward.....	242
A Final Thought.....	247
<b>References.....</b>	<b>250</b>
<b>Appendices</b>	
Appendix A.....	270
Appendix B.....	273



# **CHAPTER 1:**

## **Introducing “I Walk, Therefore I am...”**

At the heart of [a] minority consciousness is a rejection of the reigning medical model of disability. That paradigm has dominated not only medical treatment decision making regarding persons with disabilities, but alas, more broadly, modern cultural definitions of disability, social perceptions of people with disabilities, and the social options and roles permitted to disabled persons. The medical model defines *disability* as the physical and psychological experience of biological defect deriving from any one of a series of illnesses or injuries located within the bodies of “afflicted” individuals. Medical practitioners have seen cure, or at least correction of functioning, as the only possible way to bring about the social integration of people with disabilities.

—Paul Longmore, 2003, p. 205.

### Where Do I Begin?

Throughout my childhood and early adulthood the topic of disability represented a red wooden door that I could approach, but not dare to open and pass through. As I began to study at university and appreciate different world views, the door regularly stood open to me, inviting me to pass through to the other side. But I was afraid to cross its threshold. I respected my current role as a disabled<sup>3</sup> individual in the normalizing world within which I was raised. I would tell myself that someone like me simply did not cross such a boundary. Yet I was curious about disability, curious about the worldview that existed on the other side.

I did not enter my doctoral studies, at first, with an intent to explore disability within the Rehabilitation Sciences although I understood this area to be a tension in my field. When Hammell (2006) published her influential book titled *Perspectives and Attitudes on Disability and Rehabilitation* I did not see myself as a scholar and researcher to explore this topic. I had to take a step back and reflect on the tensions I felt between the clinical role in which I was trained and the disability role into which I was born. My disability experience directly applied to my work, no matter how much I tried to separate it from inquiry, teaching, and coursework. There were foundational questions that I needed to unpack before I could address disability research. How do I view disability myself? Do I identify as disabled? What does disability mean to me, as a disabled woman and a disabled clinician? Where am I situated as a scholar on the topic of disability? These questions represented significant challenges along my journey because they

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<sup>3</sup> I identify as *disabled* and not as a *person with a disability* to reflect disability theorists' argument that people are disabled by society and do not live with a disability steeped in medical origins and interpretations (Oliver, 1996). For a complete explanation of my choice in language see "*I am disabled*" on page 36.

were difficult to answer, but also because exploring these questions meant exploring the discourses on disability throughout my life. My life became data, a narrative and story that linked scholarly literature with lived reality. Again I stood in front of the open red wooden door. I was ready to move to the other side.

### **“I Walk, Therefore I am...”**

This body of work represents an autoethnographic journey that connects my experience of living with spina bifida, to my situatedness as a disabled Occupational Therapist and Rehabilitation Science scholar. My transformation into a disability scholar has been highly theoretical and philosophical in nature. Autoethnography as a methodology offers me a way to reveal my experience of living with my disability and combine this experience with socio/cultural analysis of the literature and discourses on disability. The theme of walking (versus using a wheelchair) represents a lifetime of significant personal and social/cultural tensions. This became particularly apparent after I went through major reconstructive leg surgery in 2013 and its lengthy recovery period. Thus, this surgery represented the catalyst for me to express my voice(s) on walking through a lived, transformative, cultural narrative and an embodied, activist and political interpretation.

This thesis attempts to disrupt silences on disability and rehabilitation and opens with an introduction to Disability Studies as a field, the tensions I have come to understand in the literature, and an introduction to autoethnography as my methodology. I will then discuss five key themes within my life’s story in relation to disability and rehabilitation:

- 1) the concept of *independence* in my life and how independence is articulated within both the Disability Studies and Rehabilitation Science fields;
- 2) my awareness today of oppressive childhood situations and how *power* and *powerlessness* play prominent roles within my life;
- 3) how the idea of power spills over into a discussion on *client-centred practice* within my life story and the Rehabilitation Sciences;
- 4) how my story encouraged me to explore the impact of *ableism* in my adult life; and
- 5) my contribution to a discussion on the impact and significance of *impairment* in addition to *disability*, a vital discussion to Rehabilitation Science and Disability Studies scholarship.

My voice and narrative occur through this entire body of work. Using aspects of my life story I theoretically interpret and critically analyze two main bodies of literature: Disability Studies and Rehabilitation Science, thus making autoethnography a good fit with my theoretical and epistemological foundations. September 16, 2014 provided an epiphany for me, a catalyst with respect to how walking in my life forces me to reflect on the issues of disability and rehabilitation. As a scholar who has theorized intensively with respect to the implications of merging two at times opposing fields on disability, this thesis will use my reflections on September 16th as a way to explore my life experiences on that particular day. Autoethnography offers me the tools to refract my experiences on disability from two separate yet at times complimentary lenses.

## **What Had I Begun?**

The term ‘disability’ is laden with medical origins and medical meanings, which contribute to exclusion and oppression for persons labeled as ‘disabled’. Moreover, these processes are amplified by constructing disability as an individual burden or personal tragedy (Linton, 1998). Medicalizing disability keeps it a personal matter, a personal problem that needs to be treated, rather than addressing the social processes that actually restrict or constrict the disabled person’s life. The distinction emphasizes that disability is a marker of identity that can result in disabled people getting slotted into diagnostic categories used within assessments and classification systems used within the rehabilitation practices (Guenther-Mahipaul, 2015).

### **Disability Studies and Me**

The field of Disability Studies offers a way for disabled persons as well as practitioners to unpack the taken-for-granted and matter-of-course notions about disability, impairment, and normalcy<sup>4</sup> in rehabilitation as well as the overall lived experience (Guenther-Mahipaul, 2015). I was still working as an occupational therapist when Hammell’s (2006) text on perspectives on disability and rehabilitation was published. I began to read her book a few months before applying for my PhD studies. This book represented the first published text that merges critical disability theory with rehabilitation science concepts. At first I felt perhaps afraid – even apprehensive, with respect to how Hammell spoke about rehabilitation science and its associated

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<sup>4</sup> The words normalcy and normality are used interchangeably in Disability Studies literature. Normalcy appears in North American writing, whereas the word normality is often used by European theorists. Both words attempt to challenge the reader to think about the meaning of ‘normal’ in our world, and to consider what normal means to disability and how disability matters to normal (Titchkosky & Michalko, 2009).

practices. In her introductory chapter I have highlighted the following quote with a question to myself in the margin: “Do I believe the rehab profession is doing good or wrong?” Hammell writes the following:

Recent critiques from disability theorists challenge those rehabilitation assumptions... suggesting instead that their rehabilitation professions are not apolitical and that the rehabilitation process is often irrelevant, meaningless and useless (Abberley, 1995; Morris, 1991). The correlation between increased function and independence with perceptions of enhanced quality of life is challenged (Hammell, 2004a) and the relationships between professionals and their patients and clients is perceived not as benevolent, client-centered and helpful, but as hierarchical and disempowering (Abberley, 1995; Barnes & Mercer, 2003; Dalley, 1999; Johnson, 1993; Jorgensen, 2000; Morris 1991), with therapists perceived as sharing a pessimistic, deflating ethos (Cant, 1997). At worst, their rehabilitation and healthcare professions are believed to constitute part of the problem on living with impairments (Barnes & Mercer, 2003; French & Swain, 2001; Oliver, 1996a). (as cited in Hammell, 2006, p. 5)

As I read Hammell’s book, I remember feeling in awe with respect to the multitude of resources she cited with respect to challenges and critique of the rehabilitation profession. But Disability Studies had a much greater impact on me as a person first, and a scholar second. As a disabled person, Disability Studies provided me an opportunity to reflect on my experiences with

the rehabilitation and overall health care system, to make sense of the systems, and to use that learning in my teaching of current and future rehabilitation professionals. All of a sudden I became aware that I was situated within a complex, dynamic social and personal process (Williams, 2001).

Disability Studies provides a profound alternative perspective with respect to human existence in practically every social and cultural sphere (Longmore, 2003). The core of the field propagates theoretical issues such as emancipation, empowerment, and control for disabled persons. As Linton's (1995) definition highlights (as cited in Longmore, 2003, p. 222):

[Disability studies] reframes the study of disability by focusing on it as a social phenomenon, social construct, metaphor, and culture utilizing a minority group model. It examines ideas related to disability in all forms of cultural representations throughout history and examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies both emanates from and supports the Disability Rights Movement which advocates for civil rights and self-determination. The focus shifts the emphasis away from a prevention/treatment/remediation paradigm to a social/cultural/political paradigm. This shift does not signify a denial of the presence of impairments, nor a rejection of the utility of intervention and treatment. Instead, Disability Studies has been developed to disentangle impairments from the myth, ideology, and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social status and the



assigned roles of people with disabilities are inevitable outcomes of their condition.

Disability Studies considers disablement through various theoretical lenses that build from or transcend the social model perspective. These dimensions include “issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection” (Linton, 1998, chapter 5, section 1, para 3). Thus, Disability Studies as a discipline bridges the academic and disability communities (Guenther-Mahipaul, 2015).

### **Tensions in the Literature**

A review of the literature – in both Disability Studies and the Rehabilitation Sciences – highlights several complex and intersecting challenges that fuel my choice for autoethnography as a methodological approach for my study (Jones, Adams, & Ellis, 2013). First, I became aware of the lack of breadth within Rehabilitation Science research approaches that could explore the complexity of the overall everyday disability experience. I realized that disability represents a socio-cultural phenomenon within the wider literature. Yet within the Rehabilitation Sciences most approaches continue to perpetuate the medicalization of disability using positivist, quantifiable data in addition to a preferred orientation to the person dimension of rehabilitation first and the social dimensions second (Hammell, 2006; Guenther-Mahipaul, 2015). I began to feel a shift in my thinking on disability based on Disability Studies literature – the representation of disabled lives, where I realized that I was positioned in an authoritative academic field in which medical and therapeutic representations have real consequences on persons such as myself

(Titchkosky & Michalko, 2009). I needed to change how I spoke about disability and awaken to the underlying tones of normalcy, power, discrimination, and oppression that have profoundly run through my life story, but which I acknowledged superficially, at times consoling myself with a hushed: “That doesn’t really apply to me, does it?” I became curious about the potential for a researcher like myself to use “the personal in research” (Jones et al., 2013, p. 21) to highlight my transformation regarding the theoretical, ethical, and political concerns about understanding and researching disability through evocative story, emotion, and body in research. This aspect of my scholarship makes me feel like I am ‘walking’ a tightrope. Although I attempt to challenge Rehabilitation Science thinking with my work, I also recognize that my very work will equally challenge disability theory and politics (e.g., Shakespeare, 2014).

I agree with writers such as Tom Shakespeare (2014) that the recent published works in disability theory and politics, like their seminal counterparts, continue to shrug off the role of rehabilitation to favour a one-sided, perhaps rigid, socio-political perspective. I believe that Rehabilitation Science is able to withstand and grow from the important and robust critiques that Disability Studies so harshly communicates.

There appears to be no intrinsic reason why a single-impairment organization might not be progressive and helpful, given that people with different impairments experience specific issues and problems, both medical and social. Nor is it logical to think that a focus on social barriers necessitates a neglect of medical intervention. To accept – or even to prioritize – wider structural change does not necessitate the abandonment of

medical research or clinical intervention. (Shakespeare, 2014, chapter 2, section 2, para 5)

There needs to be a dialogue between Disability Studies and the Rehabilitation Sciences. Although the tightrope on which I walk is strung tightly from one field to another, I feel that this rope bridges a path between the two, where my life story illustrates to me how the two fields are in fact connected.

### **Where Next?**

“Disability simply is...and what disability *is* is an indirect spectacle of the power of normalcy” (Titchkosky, 2009, p. 49).

### **The Significance of Normalcy**

It takes a lot of effort on my part to acknowledge the prevailing theme of normalcy within my life and thus also my scholarly endeavours. The theme of normalcy runs profoundly through the entirety of this thesis. The mere fact of my using walking as a thread that weaves together disability issues within disability studies and rehabilitation practice implies that in some way or form I am forcing the theme of normalcy onto the reader and myself. When people see me walk, they can tell that I have a disability. My mobility devices signal my disability, my difference (Linton, 1998). In fact, one of the questions I get asked most frequently in my life after “What happened to you?” is: “When did you first know that you were different?” When I was younger, the word different bothered me, but I didn’t know why. Also, the finite question with “knowing when I was different” is difficult to digest at times, leaving no opportunity to reflect on my identity, perhaps to feel that I was different, imperfect, broken, and deficient in some way.

As an adult reflecting back into my childhood, I recognize that the young me was challenged by not having mobility devices. It was partly difficult because I understood that walking was difficult for me. But also, I was curious about crutches and wheelchairs – in fact perhaps even yearned for them – because they were symbols of disability and thus something with which I identified. Non-disabled individuals do not know how to respond when I say that I identify with my mobility devices, or when I dare to imply that my wheelchair or crutches are a part of me. This is not an unusual statement. For many of us, our assistive devices are in fact symbols of us, of our disabilities (Linton, 1998). My crutches and wheelchair make me feel normal; there is nothing abnormal about them. As a young girl before the age of 10 I did not have crutches and a wheelchair.

My first connection to walking as a theme occurred while my family lived in a small town, population of 5000, in Mittersill, Austria. There were few disabled people like me. I remember that I had a difficult time explaining to people that I had spina bifida. Before the age of 10, I had a hard time wrapping my mind around what spina bifida was. How was I supposed to explain this to curious people? Before I draw my introduction to a close I wish to share this first memory, to recognize the scholar alive in this young girl and how this story has shaped the scholar I developed into.

~

People always can tell that I walk differently. I walk with a limp. As a young girl, there was a time when I began to tell people that I broke my leg. People seemed to understand that I limped because I hurt myself. But I was smarter than just to say that I broke my leg. I told them

“It hasn’t healed properly so now I walk like this”. This was so easy for me and took such a weight off my shoulders. I would just tell people that I broke my leg and then we would go on and talk about something else.

One day when I came home, my mother wanted to know why I was telling people that I broke my leg. I didn’t know what to say. It was just something I did but I didn’t want her to be upset about it. “Susan, you are so smart. You know why you have what you have, right?” I nodded and felt ashamed. She took me by my hand and we walked into my father’s office. We stopped in front of one of his many bookshelves as my mom ran her right index finger across the spines of many books, sometimes tilting her head to read the titles. Her finger paused on an orange book. She took it out of the bookshelf and we both sat down on the floor. As she flipped through the pages I saw many black and white pictures flash by. She stopped on one of those black and white pictures.

“You see here? Can you read what it says?” She pointed her finger at some bolded words in the title. “Spina Bifida” I read out loud and then didn’t know the other words.

“That’s right, don’t worry about the other words, they are written in English. But see this picture?” My mother pointed at a black and white picture that took up half of one page with a baby lying on its stomach. “That’s what spina bifida looks like when a baby is born. That’s what you looked like. But your back looked a little different than on this baby. And then you had that big surgery to fix your bump and now you have your scar.” I studied the black and white picture with the baby that has a pancake sized bruised patch of skin on its back. It looked raised like the

top of the muffin, uneven, with parts of it cracked and bruised. I didn't think it looked grotesque, but I found it hard to imagine that I once had something like that on my lower back.

“Yours was not that big when you were born” my mom said to me. “It was much smaller and maybe that’s why you can walk the way that you do. Many other kids, maybe even the one in this picture, can’t move their legs at all and need to use a wheelchair”.

“Do you have a picture of me like that?” I asked my mom and she shook her head.

“No, Susan, we didn’t want to have any hospital pictures of you.” I felt a little sad because I would’ve liked to know what I looked like before I had my surgery as a baby.

“How long was I in hospital for?” I wanted to know from my mom. She told me that I was in hospital for over a month, and that they had me strapped to a board in my crib so that I would not move my spine. She said that they didn’t want to have a picture of that memory.

“Susan, you should always tell people that you have spina bifida. And if they don’t understand then that’s okay. You know what you have and if they don’t want to take the time to learn about you then this is their loss, not yours”. I nodded and gave the book back to my mom. After she sorted the book back to its proper place on the shelf she grabbed my hand and we walked hand-in-hand back into the kitchen.

I returned often to this bookshelf and sneaked a peek in the orange book with the black and white picture of the baby with spina bifida. In my early teenage years, I rediscovered this bookshelf after we moved to Canada. I found all of the doctors’ and specialists’ reports and journal articles about me and spina bifida on that same shelf and every once in a while my father

would find me in his office, sitting on the floor with information spread all around me, armed with questions for him to answer.

~

I hope that my interpretations shake up the taken-for-granted notions of normalcy that we so quickly come to accept within society and within the rehabilitation sciences (Gibson, Teachman, & Hamdani, 2015; Hammell, 2015; Oliver, 1990, 1996; Titchkosky & Michalko, 2009). There is another aspect of normalcy, however, that I hope to address throughout my thesis. I am a person who deviates and departs from societal expectations in negative and abnormal ways. Thus I am stigmatized by persons Goffman (1963) calls *normals*. That being said, I have tried to be kind to myself, to write and interpret my life's story with the understanding that I myself at times perpetuate normality within my own life and towards myself.

I need to catch myself in those moments, when I say, "That sounds about right", or "This is what it is." I have to challenge my own automatic interpretations of normal and/or abnormal within my disability experience and view disability as a distinct topic area in research and teaching. As a result, I actively resist traditional disability knowledge and ideology that focuses on disability as deviance. Moreover, I critically analyze knowledge that fails to recognize the exclusion, oppression, and devaluation of disabled people (Titchkosky & Michalko, 2009; Zola, 1982). As I separate out and critique the taken-for-granted notions within my stories, whether they are my own or those of the people with whom I interact, a rich overall picture of normalizing tendencies undeniably emerges with drastic clarity. I intend to pull out these

tendencies and themes as much as possible, to disturb the dominant disability ideology and offer alternative empirical questions and viewpoints for consideration.

### **Implications of My Research**

The implications of my research are manifold. I hope that through this work my narration of living with spina bifida will help reveal the complexities of growing up and living with a physical disability that is often so closely linked with rehabilitation and medical intervention. I also intend to highlight the transformative aspect of this work for me as the ‘researcher-as-subject’ (Freire, 2000). My position, or situatedness, on a theoretical spectrum represents a unique journey. I hope to be able to illustrate how I have come to understand my disabled identity (i.e., how I view myself as a disabled woman, clinician, and scholar) more critically. I will explore who and how I was as a disabled child and young adult before I explored Disability Studies as a field. And I will reveal who and how I am today as a disabled theorist and scholar, which is a significant and empowering outcome of this research. Most importantly, I hope that my study and work helps to engage others, whether they are professionals or disabled individuals, their families or beyond, to understand the experience of disability and rehabilitation and to engage in a discussion on how disability is approached and understood within the rehabilitation field. Next I will introduce the key concepts to my research process and describe how autoethnography as a methodology fits with my goal to explore disability and rehabilitation.



## **CHAPTER 2:**

### **“I Walk, Therefore I am...Between Two Worlds”**

If writing beyond recognition is the price we must pay for working at the limits of self-knowledge and mastery, of piecing together radically incomplete accounts as they are performed in the crucible of social relations, let it be you who reads with feeling and solidarity. Let it be you who takes what experience tells and makes it into something you can use, something yours.

— Stacy Holman Jones, 2011, p. 333

### **Paradigms and Knowledge Bases**

Every day, I stand along a path, where on one side lies a disabled world, and on the opposite side a world of the non-disabled. And I have struggled moving between those two worlds as a child and young adult, crossing the margins ever so slightly but never fully breaking through (Hooks, 2015). “I feel like I don’t belong in either world,” I wrote as a 14-year-old girl. I could not pass for normal. I grew up with my disability; my disability, called spina bifida, had always been ‘just there’.

There is little guidance for a scholar like myself undertaking research on disability and rehabilitation. I became aware early on in my research journey that the Disability Studies literature stressed emancipation, critical approaches, and a social relation of research production between rehabilitation researchers and disabled research participants and communities (Barnes, 2004a, 2004b; Frank, 2002; Oliver, 1992). But I myself am a disabled researcher. Where do I fit? What do I have to offer the research process? I found little work by others in situations similar to mine. Thus I timidly progressed through my doctoral studies.

It was during my search to explore how to develop into a credible *disabled* researcher within the Rehabilitation Sciences that I first discovered the complexity of research paradigms and the resulting impacts on knowledge bases of entire academic fields. The work of philosopher Thomas Kuhn (1970) made me reflect on the somewhat opposing foundational knowledge bases of Disability Studies and Rehabilitation Sciences:

*Imagine that Disability Studies and Rehabilitation Science are two trees  
growing side by side in a meadow. Although the leaves may look identical to*

*one another (i.e., both concern disability), the stems and roots (i.e., paradigms - set beliefs and assumptions) make them two different kinds of trees matured on different root systems. Thus, because of the different root systems, each tree has grown with a distinct foundation of knowledge that represents a different way of conceptualizing disability. There is an urgency to explore why disciplines with expertise on disability do not interchange and integrate their knowledge bases. If the field of OT only uses knowledge from within its own scholarly communities, will this potentially lead to an incomplete conceptualization of disability? (Personal Research Journal, Nov, 2012)*

A paradigm represents a researcher's set of basic beliefs and assumptions, and in qualitative inquiry stands for a researcher's worldview (Kuhn 1970; Patton 2002). Research paradigms reflect philosophical assumptions that are epistemological and methodological in nature (Kuhn; Morgan 2007). Epistemology concerns the beliefs about what knowledge is, how we acquire it, and the reliability of claims to knowledge (Hammell 2002; Morgan 2007). On one hand, the paradigms of Rehabilitation Science, as a discipline, stem from the scientific method that is based on empirical and measurable evidence (i.e., positivism). On the other hand, Disability Studies originated out of arts and moral-based paradigms. Paradigms are important for researchers since "some stories enhance life; others degrade it. So we must be careful about the stories we tell, about the ways we define ourselves and other people" (Felske, 1994, p. 190).

Kuhn (1970) argued that scholarly communities had to agree on constructs in order to engage in research. Kuhn illustrated (as cited in Felske, 1994)

...how paradigms dictate worldviews or ideologies in the physical sciences and how researchers become resistant to change. Paradigm shifts or radically different ways of viewing the nature of reality are often led by new researchers holding different ideologies than their predecessors. (p. 191)

If Rehabilitation Science scholars attempt to incorporate the paradigms of Disability Studies, they need to demonstrate the capability to evolve their Rehabilitation Science-specific paradigms, methodologies, theories and models that shape their assumptions about the lived reality of disability.

Emancipatory approaches represent a profound paradigm shift that focused research on the study of disablism – the fight against discrimination and oppression of disabled individuals (Oliver, 1992). However, scholars who explore the concept of disablism are challenged if they are situated within a field that lacks a foundation (i.e., research paradigms) that successfully portrays disablism.

Existing research paradigms have proved inadequate and hence, will not be useful in trying to construct a disability research agenda for the future.

Issues highlighted by disabled people have been identified and it has been suggested that they can only be tackled by building a new research paradigm which fundamentally changes the existing social relations of research production. (Oliver, 1992, p. 113)

## **Elements of the Research Process**

### **Critical Consciousness**

As a disabled researcher, I am encouraged to build a research agenda that is based on my exploration of how Rehabilitation Science needs to rethink perspectives on disability and rehabilitation. My goal is not to produce normative, canonical knowledge, but to interrogate knowledge and to “unveil assumptions embedded within knowledge generation processes, and to make explicit the connection between knowledge generation and human interest” (Kinsella, 2012, p. 73). I wish to unpack the taken-for-granted assumptions and matter-of-fact power relations and structures that are created and supported within Rehabilitation Science. A critical approach offers me a valuable epistemological tool to shift and advance knowledge bases within Rehabilitation Science on disability (Kinsella, 2012). For me, this includes reflecting on systemic power relationships such as normality, ableism, independence, and perspectives on impairment and body, but also to unpack the ‘systemic solutions’ to the above-mentioned inequities such as client-centred practice and care. I connect to a critical approach because it awakens me to multiple discourses and knowledge, to increase my consciousness on disability, and to keep thinking connected to action (Freire, 2000).

### **Post-structuralist Orientation**

Based on my lived disability experience and growth as a disabled scholar and theorist, I follow a poststructuralist orientation that claims or perhaps embeds primarily subjectivism as my epistemological position. Within a post-structural account on subjectivity, the subject is considered “as shifting, contradictory, multiple, fragile, fragmented”, as an ongoing project

(Gannon, 2013, p. 231). I am a subject and researcher who is constituted in language (Gannon & Davies, 2012). I am situated within cultural and social discourses that are circulated within texts but also within our multiple life experiences (Gannon, 2013). I am not autonomous in creating and constructing my own world (disability or beyond) within social relations; rather I am “embedded within a complex network of social relations” (Corker & Shakespeare, 2002, p. 3).

I also choose to situate myself within poststructuralist thought to be able to take a step back from the political stance of social model thinking to open an exploration of cultural relations and the role of discourse on disability (Shakespeare, 2014). I do not wish to deconstruct disability as a category and political issue; rather I wish to explore the disability experience in order to offer an understanding of the disability experience and how we talk about disability, to bring about social change (Hammell, 2006; Shakespeare, 2014). Poststructuralist theory allows me to write about my subjectivity in the context of both previous theoretical ideas and new theoretical ideas, where I can *re-create* myself in process and acknowledge that the research practice is “an emotional, personal journey” (Hubbard, Backett-Milburn, & Kemmer, 2001, p. 124).

My experience with the disability and rehabilitation science cultures is not based on my personal world and reality alone. Rather I have an individual version/story/social discourse that has been formed as a result of cultural artifacts that are always being molded, altered, and discarded (Chang, 2008). Poststructuralism is the “distinction between ‘readerly’ (*lisible*) and ‘writerly’ (*scriptible*) texts, that is, between texts that envisage a merely passive, receptive reader and those that call upon the reader to be an active creator of meaning” (Barthes, 1975, as cited in

Crotty, 1998/2011, p. 204). As a narrator, I narrate for *process* rather than outcome, specifically the process of constructing and deconstructing my *self* who is disabled and a rehabilitation scientist.

In poststructural research, the shift of interpretive focus is from language as a tool for describing real worlds to discourse, as constitutive of those worlds. There are no “right” research methods that will produce a reality that lies outside of the texts produced in the research process because reality does not preexist the discursive and constitutive work that is of interest to poststructural writers. This is important for feminist researchers in that it makes visible the historical, cultural, social, and discursive patterns through which current oppressive or dominant realities are held in place. What might have been taken for granted as natural, even essential to the human condition, and therefore unable to be questioned in any systematic way, is no longer taken to be inevitable, no longer left invisible. The structures and practices of everyday life are opened to scrutiny. (Gannon & Davies, 2012, p. 81)

## **Narrative**

Disability Studies, as an arts-based discipline, uses narratives to construct the reality of what it is to be disabled. Narrative researchers either follow the basic philosophical assumptions that underlie narratives or focus on what and how to approach the analysis of the narrative. Epistemologically, narratives represent a means of knowing and a way of telling about life



(Smith & Sparkes, 2008). Disability Studies views the stories of disabled people as an obligation to reflect on the people we take ourselves to be. Stories are not just personal; they also reflect cultural and social impacts. A scholar who uses the analysis of narrative seeks to discover how the storyteller (i.e., social actor) perceives and ‘stories’ about their own reality. With respect to disability, I reveal and narrate about the complexity of the lived disability experience, to be disabled, and to define quality of life. Thus I describe meaningful participation as an important contribution to credible disability research (Barnes, 2004b; Frank, 2002; Smith & Sparkes, 2008).

My narrative, my life story, makes up the body of this thesis. I *narrate* my self within my life story as the primary character and the primary participant of my research. But I also construct my narrative, my life story, in relation to others with whom I interact, and how these relationships have helped me find a voice, a theoretical lens, as a *subject* throughout my research process. Autoethnography as a methodology represents a good fit with the aforementioned theoretical underpinnings as I attempt to write ‘the self’ – *my* self – and critically interpret this self for the reader who will perhaps hear and retell my story of living disabled within the Rehabilitation Sciences.

...my stories don't aim to satisfy the general curiosity about what it's like to live in a withered body like mine or feed the public appetite for inspirational pap. Like all stories, they are most fundamentally a chance to ride around inside another head and be reminded that being who we are and where we

are, and doing what we're doing, is not the only possibility. (Johnson, 2005, p. 4)

My narrative, my stories, offer readers an opportunity to explore a socio-cultural context to which they can perhaps relate themselves, or to each other (e.g., in a community). I attempt to add this research and body of work, my narrative, to a field that attempts to redefine storytelling into something better, to move it forward. “Narrative analysis can be a significant model for a society that will continue to work out its moral dilemmas in story form” (Frank, 2002, p. 116). I make my stories explicit as part of critical merit, but I also introduce credibility and accountability by making my stories available for external consideration – to seek active dialogue with other people like me, and people in relationship to me (Frank, 2002; Thomas, 2010).

### **I am Disabled**

This research is not about how I define my disability, or to explore disability status. I intentionally identify as *disabled*. The term “disabled person” over “person with a disability” (so-called ‘person-first’ language) is used by disability theorists to denote that people are disabled by social and political responses to their impairments, not because of their impairments or bodies (Oliver, 1990, 2009; Shakespeare, 2014). For this reason I also choose to use the word disability as an overarching concept and do not refer to spina bifida as an impairment (see Footnote 2, p. viii).

I believe that person-first language within academia and personal use reduces my agency as a moral person (Lauersen, in press). This has perhaps been a rather startling realization for me,

as I have come to meet and learn from the writings of disabled peers – many of them with congenital disabilities – in other disciplines. I agree with Shakespeare (2014) that, “quibbling over ‘disabled people’ versus ‘people with disabilities’ is a diversion from making common cause to promote the inclusion and rights of disabled people” (chapter 2, section 2, para 7).

However, there is something to be said about the intentions of using person-first language to emphasize that we are all people who strive for equal rights and opportunities, thereby humanizing disability without the weight of labels (Titchkosky, 2001). As Lauersen (in press) explained, for those of us connected to disability as part of our identities, the use of person-first language becomes problematic. Lauersen discussed a complex theoretical interplay between three personal perspectives that come together to shape every person’s narrative identity. “A disability cannot – and, for that matter, should not – be separated from a disabled person’s identity – which... is precisely what people-first language endeavors to do.” (p. 8).

One of the most fascinating social dilemmas I have with respect to my disability occurs when people comment: “Sometimes I forget that you have a disability”. I never know whether to take this statement as a compliment, or a backhanded insult that it sometimes feels to embody. Lauersen (in press) is one of the few scholars I have met and read who tackles the theoretical underpinnings behind the identity that we disabled individuals develop based on how others talk about us. She convincingly argued that many people do not consider the various personal perspectives within which disabled people are immersed.

Beatrice Wright (as cited in Paul Longmore, 2003) also described similar observations. Wright, an expert on the social psychology of disability, argued that disabled and non-disabled

individuals process and internalize different kinds of information about themselves. Longmore (2003) concludes that, “Outsiders, non-disabled people, latch onto a single trait (for example, paraplegia or arthritic pain), while “insiders”, people with disabilities, take into account the full range of their experience.” (p. 209). Insiders, then, do not evaluate their lives based on the stigmatizing labels that the outside world attributes to them. This goes beyond having learned to deal or adapt to their disabilities. The disability has been incorporated into their identities, “... into their very selves. And they see their experiences as yielding much that is positive in their personal growth” (p. 209). Arguably the personal perspective that influences a person’s self-concept the most is a ‘second-person-perspective’:

When disabled people’s notion of self is intertwined with their disability, people-first language becomes guilty of inhibiting moral agency and autonomy. That is, it fractures a person’s first-personal perspective and the second-personal perspective, promoting a non-unified identity and, as such, a non-self for all disabled people who recognize their disability as a defining part of their first-personal perspective. To clarify, my first-personal perspective tells me that my disability is vital to my self; people-first language, as a social construct and thus a second-personal perspective, tells me that my disability can be easily separated from my self. Thus, my sense of self is radically different from the sense of self that society believes I should have. As a result, people-first language promotes an erosion of my self-respect because it fails to validate my own sense of self worth, and inflicts a negative self-conception on me. Because I cannot rectify this

conflict between two vital parts of my self, my self ceases to exist.

(Lauersen, in press, p. 9)

I thus identify as disabled within this thesis and avoid the use of person-first language within academia. I do not do this because I recognize the medical origins of the word ‘disabled’, but more importantly because I agree with Lauersen that to use person-first language, in a philosophical sense, robs me of my autonomy.

### **Autoethnography: The Why and How**

#### **Rationale**

My rationale for proposing this study relies on my intimate understanding as a disabled clinician and academic, in that fully engaging with the literature means drawing from at-hand knowledge of being disabled my whole life. My first-hand experience with the rehabilitation system brings the literature alive, and in a sense compels me to interact with the literature beyond evidence-based practice and statistics.

“One characteristic that binds all autoethnographies is the use of personal experience to examine and/or critique cultural experience” (Jones et al., 2013, p.22). I use an autoethnographic approach enhanced by a layered autobiographic writing format to help me to portray the tensions and perceptions surrounding disability and rehabilitation (Ellis, 2004, 2011; Ronai, 1995). Autoethnography is a viable form of inquiry and a well-known qualitative research methodology in the social sciences. As an interdisciplinary approach it has yielded important results in understanding culture and challenging the language people use to talk about cultural experiences. As a methodology, autoethnography merges autobiography with ethnography. I am a *full insider*,

a *native* within the group being studied (Hayano, 1979), who systematically analyzes (graphy) layered accounts of personal experience (auto) to understand and interpret cultural experience (ethno) (Ellis et al., 2011; Reed-Danahay, 1997; Ronai, 1995).

...Autoethnography is defined as a form of self-narrative that places the self within a social context. It is both a method and a text, as in the case of ethnography. Autoethnography can be done by either an anthropologist who is doing 'home' or 'native' ethnography or by a non-anthropologist/ethnographer. It can also be done by an autobiographer who places the story of his or her life within a story of the social context in which it occurs.

(Reed-Danahay, 1997, p. 9)

I do not attempt to answer a specific research question as in traditional qualitative approaches, or to provide ways in which society can change its approach to disability and rehabilitation. I attempt to tell my story to provide the reader and me an opportunity and place to be present to one another, to create a relationship "embodied in the performance of writing and reading that is reflective, critical, political, emotional and evocative" (Jones et al., 2013, p. 19). I also attempt to reflect on my story, my epiphany, "to show how the aspects of experience illuminate more general cultural phenomena and/or to show how the experience works to diminish, silence, or deny certain people and stories" (Jones et al., p. 23).

Given that few published narratives are presented from the accounts of individuals living with congenital (i.e., from birth) disabilities situated within the rehabilitation sciences (Longmore, 2003; Shakespeare, 2014), I recognize the unique niche within which my work is

situated. My narratives aim to disrupt silence and to introduce the reader to issues of social justice with respect to the disability experience. As Bourdieu (1989) suggests, I wish to sensitize the reader to the narrative as many points of views represented through the lens of lived experience. This thesis offers a “thick description” (Geertz, 1973, p. 10) of the disability and rehabilitation culture for the reader. I want to portray meaningful personal experience and engage readers with cultural experience and literature (Ellis et al., 2011).

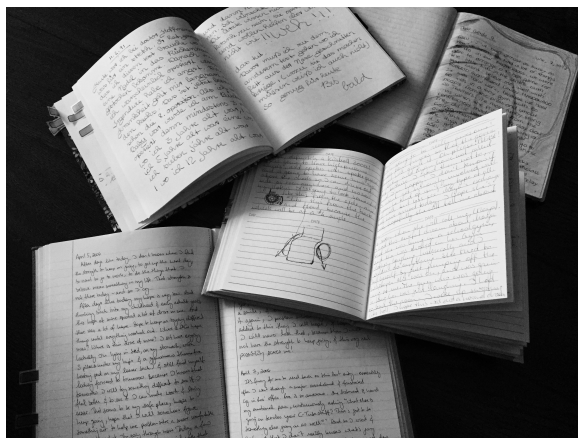
This research distinguishes itself from autobiographical writing styles such as fiction or other subjective personal work through “purposefully commenting on/critiquing of culture and cultural practices, making contributions to existing research, embracing vulnerability with purpose, and creating a reciprocal relationship with audiences in order to compel a response” (Jones et al., 2013, p. 22). Although these characteristics distinguish autoethnography as scholarship, I do not claim my methodology to be more reliable, generalizable, or credible than other types of methodologies. Autoethnography adds to the body of knowledge we have on studying cultural experiences (Jones et al., 2013). I believe that this type of approach is trustworthy and valuable to complement existing knowledge on disability and rehabilitation in disrupting norms of research practices, working from insider knowledge, breaking silence, reclaiming voice, and making knowledge accessible.

### **Research Methodology**

An autoethnographer must retrospectively and selectively write about an experience and pick out epiphanies from that experience, use methodological tools and literature to analyze the experience, and explore ways that the reader may connect to similar epiphanies and thus make

cultural characteristics, already known to an insider, familiar to an outsider (Ellis et al., 2011). I write autobiographical layered accounts of my experience to offer “an impressionistic sketch, handing readers layers of experience so they may fill in the spaces and construct an interpretation of the writer’s narrative” (Ronai, 1995, p. 396). This is an academically powerful way of writing and translating knowledge in which the reader reconstructs a subject area and takes more away from it as they project their own selves into the narrative.

I shift fluidly between my voices from the past and present dimension. This is an iterative process, where I use an evocative present *self* to construct a self from the past, and where my self from the past helps to construct a self in the present. My recall of present and past voices is strengthened by my personal journal collection of diary entries spanning a 28-year period. My first diary entry was written on Christmas 1987 when I was gifted my first journal at the age of 10. I possess 15 paper journals filled with handwritten entries (predominantly end of day accounts and reflections), in addition to an electronic research journal dating from 2008 to present. From these journals I could write evocatively about what I thought and experienced when specific events happened in real time. I chose to write these memories – these data – into my layered accounts.





*Image 1: Samples of personal journal collection spanning 1987 to present*

As the primary character (participant) in the story, I also interact with others as tertiary characters (participants) and call them into my story, into a relationship, at times in unpredictable ways. The tertiary participants (characters) are those persons who are represented and/or directly implicated in my layered accounts because of the relationship they share with me as the primary participant. It is the tertiary participants that help me write a relational story that pinpoints the social and cultural structures and discourses that occur around me every day with respect to my disability experience. I thus employ a purposive and highly selective sampling to arrive at a thick narrative with relational data.

I do not engage directly with my participants about my narrative, with the exception of *potentially identifiable* tertiary participants (e.g., my parents, my husband, and one of my Disability Studies colleagues). For autoethnographers, the issue of consent takes on a broader ethical concept of “relational ethics” (Ellis et al., 2011, p. 281). Experienced autoethnographers recommend that I fundamentally write from an ethic of care and concern for myself first and foremost, and to do no harm to myself or to the people I write about. Relational concerns are a “crucial dimension of inquiry” (Ellis et al., 2011, p. 281) where on many occasions I am obligated to show my narrative to potentially identifiable participants to give them opportunities to respond to what is being written or how I have represented them in text. I have chosen to initiate a member checking process regarding the sections of my story in which these identifiable participants appear (see Appendix A). I use a *recruitment script* (see Appendix B) to connect with implicated participants. This study contains ethical complexities and demands that do not

occur with other types of research involving human subjects. I have to reflect carefully on, and consider, that I hold authorial power over my story, and that I also value the personal relationships I share with some of the people I write about after the completion of my thesis.

Thus for autoethnographic studies, the aspect of ethical relationships assumes a great priority (Ellis et al., 2011). I exercise strict ethical standards in seeking voluntary informed consent from potentially identifiable participants regarding all tertiary participants who appear or are implicated in my self-narrative (Chang, 2008). I draw on protective devices (i.e., using pseudonyms and composite characters, not identifying any personal information or location information regarding hospitals, rehabilitation centres, cities, etc.) and I have endeavoured to treat all persons mentioned and/or implicated in the research as potentially vulnerable to risks and adverse consequences. For example, I recognize that from a relational standpoint, some of the participants may struggle with the socio-political transformations of how I have come to view and understand disability through my doctoral work. Therefore, I recognize that either now or at some point in the future participants may become aware of the stigma and discriminating experiences that I face in everyday life (i.e., private and public) and how I have come to voice and challenge those in a scholarly way. I weigh the risks and benefits to myself as I reveal more of my life story (Tullis, 2013).

### **Analysis**

For the purpose of organizing and structuring my data collection and analysis, I have chosen to write about my experience of one day that I *walked at work*. My reflections and memories of that day, September 16, 2014, are intended to be more temporal, rather than

chronological, as narrowing my narrative to the events of this one day helps me organize and pull together my various memories within rehabilitation throughout my life. My reflections – my internal information – such as thoughts, memories, feelings, reflections, etc. are deepened by my journal entries, recollections with familiar others such as family, friends, co-workers, partners, rehabilitation professionals, doctors, etc. My methodology draws on a thematic analysis of my personal journals over a 28-year period, and my research journals throughout my PhD studies, with respect to the tensions I have experience on the theme of walking. Thus, the scene/plot remains specific to the rehabilitation science environment and practices throughout my life, where the theme of walking provides me with a compelling story line for Rehabilitation Science thinking. Although autoethnography is presented and performed in a multitude of creative ways (e.g., storytelling and writing, film, poetry, plays, art, performance art, dance) (Ellis, 2004; Smith-Sullivan, 2011), I choose a layered account/writing format (Ronai, 1995) as a liberating form of writing that will explain the techniques and process of autoethnographic research along the way. I follow autobiographical guidelines by illustrating new perspectives on personal experience (i.e., epiphanies) that help bridge gaps in existing related storylines. Interpersonal and cultural resources and artifacts – external information/data – complemented my writing in the form of letters, emails, medical reports, and the scholarly literature on the topic.

As an autoethnographer, my goal is to present and reflect on my subjective experience on disability and rehabilitation by being able to step back and express meaning, not truth. As I write layered narratives, I ‘pluck out epiphanies’ and focus in on cultural patterns as represented in the literature. I am in a unique position in that I have access to my journals and diaries dating back to

my 10 year-old-self (1987 to the present). Although I will at times write from recalled memory, I have access to my own thick descriptions that accurately reflect place, time, emotions, and state of mind throughout my life. The layered account format, supplemented by journal/diary data, relevant literature, and a systematic synthesis and analysis, complements data collection and analysis that are suggested to occur simultaneously, often hand-in-hand (Charmaz, 1983).

The purpose of this study – to highlight the tensions on disability and rehabilitation through an aesthetic and evocative autoethnography – can only be achieved by my examining my own story and experiences in relation to patterns and culture as evidenced by the literature on this topic. Rigour and trustworthiness of findings, as opposed to measures of validity or reliability, is the aim of qualitative research. In this case, I specifically choose not to write a chronological story about my life, because this type of autoethnography tends to be met with controversy from traditional social scientists. Often the researcher can be challenged as a ‘naval gazer’, since such narrative works are accompanied less by analysis and connections to the scholarly literature. For the purpose of this thesis, I draw from reflexive ethnography (Ellis et al., 2011), where I will document how my disability perspective has changed and/or been challenged by engaging in my doctoral training. The use of a layered account will connect the personal with the scholarly and illustrate how “data collection and analysis proceed simultaneously” (Charmaz, 1983, p. 110; Ellis, 2004; Ellis et al., 2011).

My autoethnography employs the following *evocative* methods (Ellis, 2004, chapter 2, section 2, para 24):

- I write in the first-person, making myself the subject/object of the research;

- The narrative text is not generalizable beyond myself (I am a single case extended over time);
- I present my narrative as autobiographical fiction with a story line that includes a narrator, characters and a plot;
- I write a story that discloses private life, hidden details that highlight emotional experience;
- The dynamic interplay between relationships in my story dramatizes the connected nature of lives across time;
- I explore the connection between my life and the lives of my participants in a reflexive way; and
- I write about a relationship between me, as the writer, and the reader as participant, not as passive receiver.

The following *analytic* features inform my methods within evocative autoethnography (Anderson, 2006). I am a “complete member researcher” (p. 378), meaning that I am an *insider* with respect to the lived disability experience – *opportunistic* in the sense that I was born into this category – which means that I can come closest to “the emotional stance of the people I study” (Adler, 1987, p. 67). Second, I engage with analytic reflexivity, demonstrating self-reflexivity with respect to the reciprocal influence between myself, my story and setting, and the people within my story. Third, I am visible as a person and active as a researcher within my narrative. Fourth, I engage awareness of others within my research and engage in a critical

dialogue throughout the research process, analysis and findings. Finally, I am committed to an analytic agenda (Anderson, 2006). My goal is not to provide my personal perspective and capture my socio-cultural environment; rather my goal is to “use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves” (Anderson, 2006, p. 387).

### **Methodological Tensions**

#### **Reflexive Tensions**

Within autoethnography, a tension exists for researchers to focus excessively on the self while remaining isolated from others (Chang, 2008). The very meaning of culture suggests interconnectivity between the self and the people around them. “Autoethnographers should be warned that self-indulgent introspection is likely to produce a self-exposing story but not autoethnography” (Chang, 2008, p. 54). There is value in experience and reflection (Wall, 2006, 2008). Autoethnographers feel anxious and are aware of important questions pertaining to reflection, such as: How can I “see given my proximity to the field” (Wall, 2008, p. 50), and that I am an *insider*? How do others value various kinds of data, how would others respond to my story, and how can I work ethically within autoethnography?

These types of tensions pertaining to reflexivity relate to tensions I experience with dominant norms of research practice and production (Wall, 2006). Autoethnography, as a form of new epistemology, challenges me to go beyond ‘token reflection’, beyond “...reflexivity that merely acknowledges the researcher’s perspective or attempts to convey a greater truthfulness or awareness of other” (Wall, 2006, p. 149). My writing about my *self* does not remove the tension

of representation (Hubbard et al., 2001). Moreover, the fact that I am an *insider* does not mean that my research is representative of other disability groups (e.g., those with acquired disabilities, or those who view themselves as chronically ill). Autoethnography challenges traditional writing that attempts "...to validate empirical science and uphold the power that accompanies scientific knowledge" (Wall, 2006, p. 149). As an autoethnographer I am aware of these internal tensions with respect to self-reflexivity (Richardson, 2000). Thus I attempt to develop self-reflexivity that continuously weighs the self between the subjective and objective, and a self-understanding that is committed to self-analytical and embodied political awareness (Reed-Danahay, 1997; Richards, 2008; Wall, 2006).

### **Analytical Tensions**

Analysis within autoethnographies consists of thorough discussion, introspection, and the immersion and incubation of thought until themes and meanings emerge (Wall, 2006). In a sense, the emphasis on narration over analysis can create a tension within my work. I balance my emphasis on story telling with the analytical process by fluidly moving between my personal story and then analyzing external discourses and texts, which in turn refer and connect back to my story. This reliance and emphasis on multiple sources of data provides a foundation for thick description (Geertz, 1973). I also choose to use layered accounts (Ronai, 1995) to help me simultaneously proceed with data collection and analysis. The outcome results in opportunities for me also to co-construct my narratives, as in the case with my parents responding to how I have written about my life, and adding their voice as part of my overall story (Ellis et al., 2011). I

try to employ thematic analysis techniques within this autoethnography, as a flexible and heuristic strategy and not as an outcome-orientated procedure (Anderson, 2006).

### **Tensions of Emotional Labour in Research**

Autoethnography allows me to “write through painful, confusing, angering, and uncertain experiences” (Jones et al., 2013, p. 34). Some scholars may challenge my methods for being naval-gazing, indulgent, even narcissistic, “...though such critiques often ignore the dialogic relationship of self and culture – the *I* and *we* – that autoethnographers emphasize when making themselves vulnerable by making personal experiences available for consideration” (Jones et al., p. 24). This work has been a work of *emotional* labour for me in the sense that I had to practice vulnerable disclosure of my *self* as well as engage with the emotional responses and recall of my ‘familiar others’. I have faced considerable emotional tensions within this work, as well as representational tensions in the methods I chose in order to tell my story of living with disability and rehabilitation. In a sense, the level of emotional labour within this thesis represents a risk to my well-being, and is something that, as the researcher, I need continuously to address and manage (Hubbard et al., 2001).

The challenge therefore is how we can construct meaning and develop understanding and knowledge in an academic environment that, on the whole, trains researchers to be objective and ‘extract out’ emotion. How can we explore and use emotions that appear and are felt so personally, within an academic discipline that requires us to structure our communication in such a way that others can make sense of it? How do we develop



emotionally-sensed knowledge as a way of being and knowing, rather than turning it into just another abstract concept? (Hubbard et al., 2001, p. 135)

My experience with this thesis process helps to share a practical experience with how to use emotional labour as a way to understand the overall research experience and social world.

~

I open my autoethnography with my most recent surgery. This surgery challenged me to sit with my tension with respect to independence within my recovery. I began to journal about interdependence in my life, and in theory. In the next chapter I explore the concept of independence. This is where my story begins.

# **CHAPTER 3:**

## **“I Walk, Therefore... I am Independent”**

We reflected briefly on how America had such an emphasis on everyone being independent...

This reminded me of an incident I had once witnessed at a United States hospital, and I shared it: “A patient was dying and the physician could do nothing to reverse it. He was furious, ‘God damn it,’ he said to no one in particular, ‘it’s un-American.’”

As we talked, the image became even bleaker, and I added, “You know, it’s not merely that people with handicaps have to do their best, they have to do better.”

—Irving Kenneth Zola, 1982, p. 120

I chose to have my left hip replaced at the age of 28. Before that I had a few procedures on my bowel between the ages of 19 and 21. Going back from there, I had orthopaedic surgery at age 17, age 16, six major surgeries on my spine and spinal cord between the ages of 13 and 14, surgery on my bladder at the age of 12, two major surgeries on my bowel at the ages of 7 and 5, several little procedures before that to manage incontinence, and of course my first major spine surgery to correct the neural tube defect or spina bifida at my birth.

In 2011, at the age of 36, I chose to see Dr. Smith\* for advice. I have fought hard over the past 15 years to find surgeons and specialists around me that first, understand what spina bifida is and the complications that come with this disability, and second, see me as an active citizen participating in a quality life where walking may or may not be a meaningful part of this quality life. With frustration I continuously have to swallow the fact that many surgeons are not interested in my case, my body, my deficiencies. But there are a few gems out there who are interested not only in consulting, but also are skilled in thinking outside of the box. Dr. Smith, a specialist in the human knee, is one of my most recent gems and I drive hundreds of kilometres to learn from his experience.

Dr. Smith noticed as soon as he met me that my right leg and my right knee were not aligned properly. He explained that this was likely since birth, but because of how my body grew and developed as a child, and with the limited strength in more than half of my leg muscles now as an adult, my knee was hanging on by a thread. Studying my X-Rays he turned to me and commented, “I don’t understand how you have not blown out your knee yet. You have no knee pain?” I shook my head and answered, “Just lower back and hip pain”.

He nodded and took out a pen and began to draw a straight line from the bottom of my thigh to the middle of my knee cap and then a line from there down the centre of my shin bone. Incredulously I marvelled at the sharp angle. “That looks like my foot and shin are rotated 45 degrees to the right” I remarked to Dr. Smith “Yes they are. In fact I would say that your foot is rotated externally more like 55 degrees. But what I’m interested in is this angle, called the Q angle.” I was relieved when he began to explain this to me since I was not aware of what this meant for me.

“You may understand this given you are a rehab professional” he began. “For a healthy young woman like you I would expect this Q angle to be about 17 degrees. Yours I would guess is 30 degrees. If I would guess, much of your pain in your hip and spine has to do with the fact that your quadriceps muscle can’t function properly at this angle. Also, with every step you no doubt have to constantly rotate your hip inward in order to get your foot pointing forward to walk. Not having to work so hard to twist your hip may actually resolve some of your hip pain.”

My husband, then fiancé, and I looked at each other, then at the X-Ray. The clinic’s PT who has known me since my hip replacement cleared her throat and said, “Susan, this is a very difficult surgery. People who don’t have a disability have a hard time with recovery. I would be concerned whether you want to go through this when you don’t walk very much”.

“Actually”, Derick, my fiancé corrected her, “she walks almost all the time now.”

“Really?” she looked at me and I was not sure whether her look conveyed respect or concern.

“This certainly is considered one of the more painful surgeries” Dr. Smith added matter of fact. I was taken a back a little by this comment, unsure whether I could imagine what he possibly meant by this.

“You will be unable to weight bear for 12 weeks and the rehabilitation protocol is extensive.” Dr. Smith concluded.

“What time frame am I looking at for recovery?” I asked hesitantly.

“For the average, healthy patient, they take 6 months to return to work,” the PT answered.

Stunned, I thought through my options. I would have to factor in at least twice that amount of time if everything goes well. And I would need to allow for a buffer in case things don't go as planned with my rehabilitation. I left the appointment with my fiancé, having put my name on the waitlist for the surgery, knowing that I could back out if I had doubts.

Two years later, June 2013, I went in for surgery, and what this surgery tested the most for me was my sense of independence. All of a sudden I reflected on how independence in my life did not seem clear. My own focus on it created some tension between the theoretical values of independence and the reality of independence in my life.

I recognized that there is a dissonance between perspectives on independence between Rehabilitation Science and Disability Studies. This next section of the story is about how I experienced the concept of independence, as an adult surgical patient, and as a woman living with a lifelong disability.

~

The possibility and perhaps need for surgical intervention is less pressing in my adult life as compared to my childhood years. However, my aging muscles, joints, and bones make me face certain physical challenges that many non-disabled adults do not need to consider until well into their senior years. I was always told that when you are born with a disability, you age with a disability from birth on. Therefore it is not uncommon for us with congenital birth defects to be *surgically needy* as we get older. Whereas my childhood was all about getting me to see the age of 20, my mid-twenties to mid-thirties were about stalling degeneration of my joints and bones due to overuse and unnatural wear and tear because of invasive childhood surgical interventions and unfortunately, my walking.

Next to walking, the concept of *independence* has followed me through my life, attached like my shadow – always there, sometimes small in the background, and sometimes larger than me. My circle of close family and friends frequently share a memory about me as a little (disabled) girl. The adults still recall that during family and friend gatherings, all of us kids would play and run around, and eventually would come to ask for a snack or a glass of juice. When the adults would ask, “Can Susan have a drink?” my parents would respond, “Yes, but she can get it herself.”

Independence and autonomy are highly valorised in the West and these notions are translated into measures that assume the less dependent a person is, the better her or his quality of life. However the research we reviewed suggests that satisfaction with life is not highly correlated with independent function. Thus a challenge for therapists, educators and researchers is to re-

examine assumptions about quality of life and how we can best help clients achieve it. (Gibson et al., 2009, p. 1452)

~

The OT and PT at the hospital gave me a sheet of ‘dos and don'ts’ to take home. This sheet pertained to things like how to get dressed, what movements to avoid, and what to do in the shower and with stairs – for an able-bodied patient! The first day the PT and my nurse got me out of bed to stand my confidence plummeted instantly.

“Why don't we try it with a walker first?” the PT advised me.

“Could I have an under-arm walker?”

“You want an under-arm walker?” The PT furrowed her brow. “You should be fine with a regular walker”.

“I would like to try with an under arm walker so that I can put my full body weight onto it if I need to”. The OR team had placed 3 IVs into both of my arms. Hooked up to IV poles and nerve block machines I wanted to have the safety of an under-arm walker.

The PT left the room and in moments came back pushing an under-arm walker, adjusted it to my height, and placed it in front of me.

“Now remember, you cannot put any weight on your surgery leg.”

“Yup”.

We shuffled my body to the edge of the bed. I placed my left foot onto the floor. I was already feeling weak; my heart beat relatively fast for the little work I just did.



“Ready?”

“Ready”.

I stood up on my left leg. This was a whole team effort – PT to my left, nurse to my right, and husband behind me on my bed. The knee immobilizer brace was heavy and my right leg moved in toward the left and began to cross over. *Shit!* I thought. *I can't hold my leg with the weight of this brace.*

“Don't cross your legs!” the PT shouted at me. “Your right foot is on top of your left foot, you can't do that”. The PT's panicked voice made me panic.

“I can't move it away, the brace is too heavy.” I was so afraid that I froze, shaking with effort as I clung to the walker. The pain from the blood rushing down into my leg was intense.

“Can you move your right leg out to the side?”

“No!” I said back. “You do know that I use a wheelchair, right?”

Silence. I am happy to have the standing walker at this point. On top of this ordeal my leg brace slowly started to slide down my leg. *Argh* I screamed in my mind. The nurse to my right crouched down and said, “Here, let me help you”. She held on to my knee immobilizer and also carefully pulled my leg off my left foot and out to the side. I took a deep breath.

“The brace sliding down is normal. Can you use your right hand to keep it from sliding?”

At this point all I managed to do was to look at her. Clinging onto the under-arm walker with both of my arms I could not remove one arm to pull up my leg brace. It took all my patience to keep an *Are you dense?* expression from my face.

“Listen” I said. “Let’s forget the walking thing right now. Maybe it’s better for me to practice my transfers from bed to wheelchair safely”.

“Okay, sounds like a plan.”

I was hugely disappointed. I had *not* expected the fact that I was going to have to wear a knee immobilizer brace, and that my leg was going to have to be straight the whole time. My muscles didn’t work well when my leg was straight. And they cut my thigh muscles in surgery too. I would have to use my right arm to lift my leg... how was I going to do this and walk with a walker? There was no way...

Back in bed, Derick took my hand.

“We’ll figure this out, don’t you worry”.

I did worry.

~

Four days later I was ready to go home. “I feel silly giving you this” the OT laughed while she lay the sheet on the foot of my bed. “You probably know exactly what I am talking about.” She explained to me the ‘dos and don’ts’ of getting dressed, putting on socks and shoes, and taking a shower. I lay in bed thinking about how at this moment these things were the least of my worries.

Once home, I needed to figure out how I could catheterize myself in bed. Getting to the toilet was just too difficult and was reserved for my “BT’s”, my Bathroom Thing. Close friends and family know that when I have a “BT day” that this means that I spend a large chunk of time

in the bathroom. I spare them the details but they know that this is what I have to do in order to have a bowel movement every second day. I had not thought about what it would be like to sit on the toilet, with a knee immobilizer brace and a leg that could not bend. All of a sudden my amazing raised toilet seat toilets in our home were an enemy to me. For 12 weeks my husband set up our bedroom as my 24/7 living quarters. My mom called frequently because she was terrified that I was going to “go out of my mind” stuck in that room.

~

My inability to take care of *myself* after surgery, my full dependence on my husband and family, and my yearning for interdependence overall forced me to tackle theoretical concepts *in vivo*. I began to reflect that, overall, there seems to be an assumption across the board that everyone knows what independence means. I certainly was not independent after my surgery. But I also was not completely dependent either. What was I? Was I interdependent?

As an occupational therapist, I reflect quite a bit on what an OT would say to Derick and me in terms of making it through these 12 weeks. And then I also thought about what Disability Studies literature would comment. Neither of the two gave me any theoretical answers to my own reality. First I looked up how independence was defined in the dictionary. Looking up the word in a thesaurus revealed the first alternative: ability, then autonomy, self-government, self-determination, self-reliance, self...

Did I not have autonomy or self-determination?

Yes I still have those things, but they are different now than they were before my surgery.

For rehabilitation professionals in the Western world, independence represents a person's ability to live on his/her own without caregiver support, or the ability to get around within his/her environment without 'help' (Cole, 2001; Gibson et al., 2009; Oliver, 2009). I obviously needed caregiver support right now. And I also needed to ask for help... a lot... so did that mean that I did not have autonomy? Reflecting on the Disability Studies literature discussion of the independent living movement, I recognized that independence is about choice.

There is something to be said for viewing independence as the right to choice in life, where quality of life occurs through the choice to use or refuse services or to choose not to dress oneself and be dressed by a caregiver so that one has the time and energy to enjoy a cup of coffee in the morning. Participation reflects self-direction, control, and ability to assume life's responsibilities and benefits (Cole, 2001; Woodill, 2006; Zola, 2001). For me, choosing to drive hundreds of kilometres to consult with surgeons like Dr. Smith represents independence. The idea of not asking for help, to have the physical and/or cognitive ability to use my skills effectively (i.e., normally and independently) (Cole, 2001), seemed to not matter at this point. But with respect to choice and autonomy, my relationship with my husband who was now my primary caregiver, created an upset for me in terms of feeling independent and in control.

~

*July 28, 2013<sup>5</sup>*

*It is difficult for me (right now) to be out and about with family and friends. They don't understand how I feel... They are worried about me because I'm basically in bed most of the time*

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<sup>5</sup> Sections of my narratives that appear entirely in italics and are prefaced with a date represent diary excerpts.

*and I don't go out much. But it's not like I'm lying in bed all day – I am in bed but I am "on" the bed – just like I would have been studying at university. But when I'm out at a restaurant like we were tonight to celebrate the birthdays of four of us in the Mahipaul family, I realize how much this surgery really has knocked me on my ass. I see one of my cousins (who sustained a tear to her ACL and meniscus) hop on one crutch and be able to talk on her cell while she hopped away to talk on the phone... and although her situation is entirely different from mine I still felt inferior for some reason. It made me feel sad! And there is absolutely no reason for me to feel sad! My knee and leg were swollen and quite huge... And sometimes I forget that I had pretty massive surgery. Even though my cousin has a knee injury that will require surgery, her injury is to parts of her knee's ligaments. I had multiple tendons transferred plus several bones broken and pinned, screwed and aligned. Obviously I am more injured and have a harder recovery period... But I still feel that I should be equal to her... stronger... more resilient. Where do those feelings come from? More important, where does my incredible pressure come from? Why am I so incredibly hard on myself? We have a picture of our dinner tonight... And I look at myself in that picture and I see that I don't look well... But I have reason not to look well! I am still recovering! I will recover at my own pace. I wanted to document these feelings tonight because I get insecure too... Even when often I come across as confident, with high self-concept and integrity, I still have moments of doubt and inferior feelings. I don't know what I did (or what my mentors and family members did) to foster my personal self-concept as a child and young adult, but I had a tremendous amount of support and love – which now continues in my adult life by the people in my life now... and one of these people is my cousin. I'm learning about myself and perhaps today I had a glimpse into how I cope(d) with surgery as a young girl (the competitive drive that stirred*

*within me). Thank God I now have a husband who can pull the plug on this competitive drive... Because it makes my journey in recovery risky – I push myself too much and this is not a time I should be pushing my recovery! So I recognize that I'm frustrated... But that's okay... It really is...*

~

Cole (2001) explained how rehabilitation specialists view task-oriented approaches as key factors in independent living because of an overall expectation that disabled clients depend on others. Rehabilitation specialists identify task-oriented approaches as easier to teach, concrete, observable, and procedurally oriented, thus “...convenient for the rehabilitation practitioner to document. The methodological neatness of task-oriented training offers advantages in maintaining records of client goals and in measuring client progress, both of which may be required by sponsors of services, as is the case in independent living programs” (Cole, 2001, p. 190).

This type of orientation towards independence represented who I was before my surgery. Not only did I do my best, as Zola (1982) wrote, but I was doing better than best. I managed to take impeccable care of myself. I was going to all of my doctors and specialist appointments, keeping a household, was married, was doing a PhD, drove, played musical instruments, etc. As a disabled young adult with a congenital disability I had certainly made it in this world. I do not require an attendant to assist me with self-care tasks on a daily basis as do some other disabled adults, however, I do accept and employ help with running my household. As a rehabilitation professional, I was taught that with respect to independence, young adults who require attendant care should focus on skills training that relate to how they would manage (i.e., direct) an

attendant to complete self-care tasks and techniques. This is perhaps the area that disability scholars critique the most with respect to rehabilitation principles. The independent living movement focuses on training the skills necessary in “recruitment, hiring, and training of attendants; negotiation of working agreements; interpersonal relationships and styles of interaction; conflict resolution; discipline and termination; and payment for attendant services.” (Cole, 2001, p. 190).

This stark contrast became reality for me during recovery from my surgery. I would have liked to ‘help’ my husband figure out how to take care of me. Certainly this was going to give me a sense of control and meaning. Helping my husband figure out my care collaboratively would have been how I defined independence during this time. But that did not work for my husband. On a Sunday night we both lay in bed and I was already dreading the Monday morning to come. Derick was going to go back to work and had to be there for 8 AM.

“Tomorrow you have to let me do things my way” Derick said, staring at the ceiling.

“What do you mean?”

“I know that you want to help, but you telling me what to do doesn’t help me take care of you”.

I was taken back by his last sentence. I didn’t say anything.

“You trust me, right?”

“Yes”

“And you know that I’ll take care of you”

“Yeah”, I started to cry. He took my hand.

“I love you, Susan. But you need to let me figure out how to do things my way.” He looked at me. I didn’t say anything.

“It’s already hard enough for me to get myself ready in the mornings and do all of the things that I have to do. Now I also have the dog, and I have you, and I need to do things the way I do them to get it all done by 8.”

I was so surprised to hear his reasoning. I understood what he is saying, but for me to simply follow along and have no say in the matter was really hard too.

“This is temporary,” he reminded me. “We’ll make this all work”.

Lying in bed I reflected on what, as a clinician, I would have told a client in this situation. I don’t think I would have said “Just let your husband take care of you for 12 weeks”. And then I thought about what proponents of the independent living movement would have said about this experience. I had no choice in the matter, but at the same time I was really well taken care of. Communication was incredibly difficult for the two of us during this time. But in the end we figured it out because I could let go of my own ideas of independence and let Derick sit in the driver’s seat for a little while. In the end, this was being independent. My *choice* to let Derick figure out what he could do for me, and for me to go with flow, was giving me independence. But theoretically, this experience still ate at me.

My mom called me over Skype one day and I explained to her about my independent or lack of independent negotiations.

“I was afraid of that,” my mom laughed at me through the screen.



“I know, but isn’t that how you raised me?”

“Yes, but I do not think that Derick knows how to deal with that side of you yet”.

“Are you saying I’m difficult?” I teased her.

“No, not at all. You are fiercely independent!” she reminded me.

~

*July 23, 2013*

*I am fiercely independent... So says my mom. But this surgery that I had four weeks ago has challenged my notions of what independence really means for me. I think for me to be independent means two things. First, it means that I am determined and a strong problem solver. Second, though, independence also means having a choice in the things that I do every day and how I feel that I choose to do these things. My mother taught me to tell people what it is that I need (of course only after I know that I can't do it myself). But what is the difference between a caregiver that you hire and a caregiver that is there to care for you because they want to be there? Independence is actually a two-way street and there are more people involved than just me. My husband, for example, is also independent as an adult with a great job and a house that he loves to take care of. And when I have surgery and I am bed-bound for a long time it's not about how I can problem solve my care. I can't tell him how I want him to do things. I have to allow him to be as independent as he can so that he can take care of me.*

~

Disabled persons always live in the shadow of someone else's definition of physical independence (Cole, 2001). They move through a different social world from the one that the rest of society inhabits. Disabled youth therefore often develop sophisticated cognitive skills to cope within this different world that even their able-bodied peers often do not possess. For example, they learn "to charm, manipulate, or otherwise enlist the help of others... to deal with the split between [the youth's] social worlds: the home, where [the youth] is loved and respected, and the street, where [the youth] is viewed as a biological fact" (Cole, 2001, p. 350). I was an adult product of such ideologies. And this, I believe, made my struggle with my recovery and the concept of independence so vivid, so emotionally destructive.

I am still unsure of what I truly think of the concepts of independence and interdependence today. Independence is imbedded within other discourses on disability such as ableist norms, adaptation, and the will power to overcome, among others (Gibson, 2006). What is successful rehabilitation? What did Derick and I do well? Were we interdependent? Were we connected? The same way that I wanted to exert choice and control in my care, he met my needs with expressing choice and control in the skills that he could offer us, as a unit.

It requires a re-imagining of the contained and sovereign subject of Western discourse as fluid and *becoming*. This postmodern re-conceptualization not only problematizes dependence/independence in disability discourses but also demonstrates how disability expresses the connections common in all human becoming. (Gibson, 2006, p. 188)

What my recovery period caused me to reflect on the most were the varied discussions that go on about independence and dependence within medicine and Rehabilitation Science, and the disability discourses that go on within society and culture. As a healthy disabled child, I was acculturated into a system that rewarded me for doing things myself, for not asking for help, not complaining of pain, being strong and not accepting pain medication; taking control of my own care, my medications, my therapy regimens, and being self-directed and self-determined. As an adult, however, I learned that this type of independence was not sustainable. Yet I was afraid to ask for help, to mention my pain and take pain medication, to seek collaboration in my own care, my medications, and therapy regimes, and to connect to others around me to partner in my adult life choices.

~

*July 28, 2013*

*I needed to figure out how to make the bed every morning – because even though the bed is the most comfortable place for me to rest and to recover I don't need to be under the blankets all of the time. So I make the bed every morning (with me still in it) and then I do my exercises for my leg... I have my environment set up around me so I can reach everything, including the mini-fridge that Derick brought into the room for me. I can grab most of the things with my reacher... And some other things I have to ask Derick to get for me. This feeling of being able to do things by myself is really important for me ... And a lot of people, when they talk to me, say that they're worried about my going crazy because I'm in the bedroom all of the time. I have my moments where I feel lost, but I never feel bored. I have everything I need here – I get to watch*

*TV in the background – and there is never a moment where I get annoyed with being like this.*

*But I think it is because 1) I know that this is short term, and 2) I always have something to do, whether it is making phone calls or doing my exercises. My leg exercises alone are incredibly time-consuming! And I'm figuring out how to increase my tolerance with my exercises even though I have to make sure how to not overdo it. But what I was thinking about right now about making the bed every morning... I have to do things that are meaningful for me.*

*With all of the things over which I don't have any control right now, because it has to do with Derick and what he can manage in terms of taking care of me, it's little things like making the bed and keeping my environment organized that keep the little bits of Susan alive even if she's stuck in bed all day – alone and trying to recover.*

~

The conversation about interdependence is rarely juxtaposed to the conversation of independence versus dependence for those of us who are disabled. There is a large debate going on elsewhere with respect to dependence and independence (see Crewe & Harkins, 2001; Gibson, 2006; Oliver, 2009; Thomas, 2007 among others). I have attempted to open a discussion on independence from my life experience, especially when my daily disability experience gets upset because of illness, surgery, or even aging. It is not as simple as considering independence to mean the ability to do everything by one's self versus the ability to make decisions over one's life and care (Bricher, 2000). It is also not as simple as having an ability to have control over my life (Morris, 1991). The overall concept of independence is fluid and always changing. It is never the same thing twice, and there has to be a lot of room for dynamic growth in our definition of it.

We cannot seek a definition of independence to suit one purpose, to box it into one way of understanding it. Yet, many discourses on independence attempt to do just that. This is what makes the concept so difficult to articulate. Society recognizes that prejudice is based upon race, creed, sex, or class but has yet to recognize the inappropriateness of judging a person on the basis of what they can do (Crewe & Harkins, 2001; Oliver, 2009).

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In the next chapter, I will explore the concepts of power and powerlessness in my childhood. This part of my life has been the most difficult to write and analyze as it represented my, and my parents', first experience of oppression and helplessness within the rehabilitation and medical systems.

**CHAPTER 4:**  
**“I Walk, Therefore... I am Oppressed”**

Great surgeons are not born, rather they are made by a commitment or willingness to pay the price for excellence

— Grant, Mericle, & Hankinson, 2009, p. v

*“Are you going to talk about the things that went wrong for you back then?” my father asks me after reading part of my life story. “I mean you told them that you were not feeling well, you told them that you were living with a lot of pain and thinking back to that time, no one listened to you. They just ignored you”.*

*I am taken aback by the emotional tone in his voice. My father is holding the pages with my life story in his hands. I can feel that he sees a different side of me today because of how I remember this time.*

*“I can’t change that past, Dad...”*

*“But it is clear to me today that in a way you didn’t matter. They just did to you what they felt was right”.*

*We both study the quote above from the Congress of Neurological Surgeons above.*

*“That’s why I decided to write this, Dad. What I can do today is to take back my power. I’m taking back our power, our voice.”*

— Personal Research Journal, April 2015

Fall 1989, I'm in Grade 7 now, and my family has moved from Austria to Germany. We left Austria two summers ago because of my dad's work and now I go to a new school. These are fun years for me. I have great friends, I love my school, I'm on a swim team and I am working on the bronze level of my lifeguarding certificate. In the water I am just like my friends and my brother. I can do everything they do. But outside of the water I feel slow, moving around with my friends is tiring. My brother and I bike to school and back for most of the year. It's about 45 minutes one way. I like taking the bike. But in the winter we take the train. I want to take the train because my classmates also take it. The train is time for us to hang out with each other. My mom offers often to drive my brother and me to school but we want to take the train, so she drives us to the train station. I hate the walk from the train station to our school. It's not a long walk, but we don't have a lot of time. My friends and brother grab their things and backpacks and start running. I feel left behind. I walk as fast as I can and have terrible side stitches by the time I arrive at school. I'm glad to sit down at my desk.

I wish I could have something to help me walk. I see people every once in a while with crutches and admire how they walk by swinging their legs in front of them. *I could do that too*, I think to myself. *Why can't I do this?* Eventually an orthopedist prescribes me one crutch, for the right side. She tells my parents "if she gets crutches she's going to get weaker, not stronger". I can't swing walk with one crutch but it does help me speed along a little faster. Years later my physiotherapist, Jenn\*, would always wonder about this one crutch. Why would any health care provider give a child one crutch with weakness in both legs?

Back in 1989, none of my physicians seemed concerned that my walking was changing drastically. My walking became noticeably laboured and I began to talk about how tired I was at



the end of the days, with my parents, and in my journals. *I'm so happy that I can lie down and rest right now*, I wrote on December 30th 1989. At 12, I learned to listen to my body.

At 12 I also was being trained by my parents to shoulder the responsibility to take care of my health. One evening we sat around the dinner table and my parents talked to me about a surgery I was going to have on my bladder to help with my incontinence.

“You won’t have to wear diapers anymore during the day” my mother smiled at me. The idea of not having to wear diapers appealed to me. It was difficult to hide them from other kids. The plastic lining always made a noise when I moved.

“Okay” I replied.

“We don’t know how much school you will miss” my mom continued. “But in the long run this will be a good change for you”.

“But Susan, you have to listen carefully” my dad said sternly. “You will have to have a strict catheterizing routine. Every 4 hours”.

I nodded.

“If you don’t catheterize every 4 hours your urine will have no way to get out and it will back up into your kidneys and you will get very sick and you may die”.

I nodded again. Kidney infection was a paralyzing fear for my parents. It continues to be a worry for me today. My parents were told and knew that if my kidneys should fail that this was going to take my life. I knew that the urologist didn’t think I could handle this responsibility. But my parents fought for my right to have this surgery. They believed that I could take care of myself.

~

What I enjoy the most about Disability Studies is that I have gained an appreciation of the history of disability within Canada and beyond. Understanding the history of disability within my culture – as a disabled woman and also as a clinician – affords me an opportunity to ask myself two questions. First, what were they thinking back then? But a second equally important question is “do we still think like this today?”

I have received different skills in life from each of my parents. My (non-medical) father was the researcher. He researched surgeons, treatments, and in a sense critically appraised the best evidence for someone in my situation. In a sense he paved a path for me in life regarding my healthcare. My mother, although also a researcher in my care, was focused intensely on the social side of my development. When medical professionals advised my parents to hospitalize me for treatments, she often challenged their advice. She often thinks back to my kindergarten years and recalls that, “They wanted to put you into a rehabilitation centre for a whole year when you were 5. I would say ‘No way, she is not going to miss a whole year of kindergarten. She needs to be with kids her own age’.”

“And then what happened?” I would ask her.

“They thought I was a bad mother,” she says. How anyone could think of her as a bad mother is beyond my comprehension.

~

Today I understand that much of what I experience as a disabled woman within the healthcare system is systemic. When I was younger I did not understand the political nature of

the system; for me it was about the relationship I had with people – my healthcare providers. I needed to immerse myself for a long time within the literature that drew me into issues of power, knowledge, and systemic practice. Foucault in *The Birth of the Clinic* (1963/1975) examines how western society began to build a culture of medical practice. Hospitals, in particular, became in the 19th century a place where patients would go to stay, and specialists could see a large number of patients (examples) with specific conditions. “Medical care tended to fragment identities through ever-increasing specialization” (Marks, 1999a, p. 74).

This ever-increasing specialization was still present in the 1980s and 90s when I was a child. I grew up in a time when therapists and physicians expected my parents to make reaching my *maximum potential* a priority – mentally and physically. Hammell (2006) explained: “In light of the reality that few therapists have ‘maximized’ their own functions – few are elite athletes with PhDs, for example – this would seem to be an unlikely goal” (p. 127). But as a patient, and as a family of a disabled child, you do not reframe the idea of expertise in your mind.

The fact that professionals possess relatively high status and considerable power (real or perceived) can render the parent passive, in the role of solely providing information. This maintains the professional in the ‘driver’s seat’ of control, further perpetuating the individual model (Brett, 2002, p. 837). In addition, as a disabled child, I was often infantilized by my professionals, and also by the education system. I spoke to my mother about some of the memories I had of kindergarten; memories of having to sit and complete workbooks while my peers got to play.

“Why do I keep on remembering these things now?” I asked my mom one time as we were preparing dinner in the kitchen.

“What is it that you remember?” My mom stops chopping vegetables.

“For some reason I remember doing these games where I had to match shapes and I seem to remember that I wasn’t so good at those”.

“Oh you probably remember the psychological testing that you had” my mom comments.

“Psychological testing? Why did I have psychological testing?”

“So that we could prove that you were intelligent enough to go to a regular school”.

I stare at my mom. As a university student I find it hard to believe that my psychological competence was ever questioned.

“Oh yeah. They really did not want you to go to a regular school,” my mom continues.

“Why?”

“Because they said that if there was a fire alarm that you couldn’t run out of the school like the other children”.

I think about how there never was a fire alarm once during the four years I went to school there.

~

I have read, with interest, historical documents written with a critical Disability Studies lens of the birth of surgery, particularly orthopaedic surgeries as a field for *crippled children*<sup>6</sup> in

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<sup>6</sup> I use the phrase “crippled children” here to recognize, as does Hanes (1995), that the label *crippled* was used to refer to children with orthopaedic disabilities in the early 20th century.

the early 20th century. The history is an extensive one (see Hanes, 1995). There was a time when surgeons appeared to greatly shape the social meaning of children living with orthopaedic disabilities. In fact:

Many professionals, such as orthopaedic surgeons, educators, and social workers maintained the stigma of disability through their activities and interventions, which perpetuated many stereotypes about crippled children including the doctrine that crippled children were not only physically disabled but they were intellectually impaired as well. (Hanes, 1995: p. 35)

Albrecht and Levy (1982) highlight that much of this thinking still prevails today. As the 20th century progressed, surgeons came to represent a powerful group with self-interests who possessed the power to shift and influence social policy with respect to disability. As the medical profession as a whole was perceived by society to hold scientific basis, medical professionals began to spread their expertise into all areas to do with disability. Medical opinion became, and persists today, as the basis for social and disability compensation. Stone (1984) who wrote that, “Although the applicant for social aid would actually be undergoing a mandatory examination for the purpose of determining his motivation and ability to work, the test had all the trappings of a voluntary, patient-initiated, therapeutic encounter” (As cited in Hanes, 1995, p. 37). Yet, orthopaedic surgeons and their profession as a whole are described as bold as they stepped outside of their realm of medical care and intervention, and decided to branch out into reconstructive and rehabilitative components.

The orthopaedic care and treatment of crippled children went far beyond the straightening of bones, the cutting of muscle, the severing of ligaments and tendons, and the application of splints and braces. Orthopaedic surgery exploited the social concern for the self-sufficiency of cripples and made economic independence a central theme in its approach. (Hanes, 1995, p. 42)

Through speeches, lectures, and publications, these very orthopaedic surgeons successfully enhanced their credibility as specialists. They boldly proclaimed themselves as the answer to solving the social costs and physical problems of crippled children. As a childhood patient within the orthopaedic and neurosurgery systems in the latter part of the 20th century, I was trapped within this air of power. I have consciously to recognize this power and learn to resist it within my adult life.

~

My PhD work has forced me to face the idea of power differentials in my life. And my work forces me to name power, powerlessness, helplessness, and oppressive situations that shape my disability experience. Within this section and the next I talk about one of the most difficult and influential situations that I went through as a young girl and young teenager – a very difficult situation that my family as a whole went through. And as I write about this part of my life I have to respect the theme of power that emerges in my relationship with healthcare providers and the overall medical and rehabilitation systems. To name it as power – as oppression – is new for me... and uncomfortable.

Even though more than 20 years have passed since my childhood, my parents will ask me “What do you think would have happened if we would have not gone ahead with the surgeries?” “I don’t think about it that way”, I always answer. We will never know *what could have been if...* But my scholarly challenge has been to reframe these insecurities and recognize the feelings of having failed, powerlessness, helplessness, and oppression, among others. My parents feel that they *may* have failed me because they *may* have made the wrong decisions, the wrong choices. Just as I was powerless, so were they as my parents, within a system where there is a sharp divide between the healthcare professionals who have the authority to make decisions, and those like me and my parents, who are in a subordinate status to those with decision-making power (Barnes & Mercer, 2010). The fact that my parents feel that they may have been the problem, or that they may have failed me, leaves an emotional imprint on me that I cannot shake. That’s wrong. I need to explore this here.

~

*February 1991*

*It’s been half a year since I have written in [my diary]. Since we live in Canada a lot has changed. Somehow I still don’t feel settled in my new class... Today I saw Dr. Milton\*, what a stress. He said that I need this test where they stick a needle into my spine. I probably will have to have surgery after that. Somehow I am afraid. I’m starting to get annoyed with all of this. I’ve had something like 8 surgeries since I was a baby... I wish that I was healthy. Those doctors don’t know how it feels. They operate and want to help but they don’t know how much it HURTS!*

~

They called it a *myelogram*. It was a horrible day. I also got my period the morning of the test and I had bad stomach cramps and my back was stiff and sore. The idea of them sticking a needle into my back did not make me happy. But I was good and listened and did everything they told me to do. As I lay flat on my stomach on the table I could see the terrifyingly long needle lying on the tray. It all felt like eternity and then they strapped me onto the table and told me to relax while the table tilted, turned, and dropped as an X-Ray machine rotated around it. Sometimes the table tipped so low that I was sure to slide off onto the cold tiled floor. Clamping my fingers tightly onto the edges of the table slab, I clung and hung on, I shut my eyes and lost all sense of time. Then I was transferred to a CT scanner, and instructed to lie on my back, straight, for another long... still... time. All I wanted was to curl up into the fetal position... to relieve the pulsing burning throbbing pain in my stomach and back. I had never been so happy to see a hospital bed as I had when they brought me back to my room.

Dr. Milton, my neurosurgeon, came to my room that afternoon. He told my mom that I had something called a tethered spinal cord and he insisted that I have spine surgery immediately – the next day. It was almost March Break and we were supposed to go back to Austria in three weeks to visit family and have a vacation. He assured my mom that I would be out of hospital in seven days and would make the vacation. My mom said yes. I didn't really understand what was happening when my mom was talking to Dr. Milton.

Afterwards my mom sat on my bed with me and talked about my surgery next day. A nice nurse kept on coming into the room, chipper and cheery. The nurse was telling me that I couldn't eat anymore and that I would have to take a shower with a special soap. I knew all that already



from surgeries I had before. I wanted to know what they were going to do tomorrow. So my mom started to explain to me what the surgeon had told her. When someone like me has a tethered cord, they have to do a surgery called a *laminectomy*. They make an incision on your lower back and with microscopes they can see all of the bones and spinal cord and the membranes around it. I have some fatty tissue growing around my spinal cord and scar tissue from the surgery I had when I was a baby. That scar tissue is tugging on my spinal cord, which is why it hurts when I walk and why my legs are weak.

“It’s because you’ve grown so much in the past few years” my mom explained. I understood that Dr. Milton would try to cut that all out and then I would be back to normal in no time.

~

I used to talk to medical students, psychology majors, rehabilitation and nursing students about growing up with a disability, but in hindsight I’m not sure how they interpreted my story. To the average outsider this story may read like a nightmare that you want to awaken from but simply can’t. As the person telling my story I become inspirational, brave, courageous. I become a survivor. People even comment “It’s amazing that you are so well adjusted and grounded given all of the things you went through as a child”. Back then I was unsure what I could say to those comments. I have never felt like I overcame or survived. My family grew through these experiences. But that is not what people want to hear. My life was/is not *normal* to people. If I say that I feel normal and had a normal childhood, people tend to feel that I am either more inspirational (Zhang & Haller, 2013) or that I am in denial over what happened (Hammell,

2006). I can see the theoretical foundations of why society would gravitate toward such interpretations now.

Back then there was also an atmosphere of ‘us versus them’. My mother often says that, “We believed in them. They were the experts so we didn’t question their decisions”. What is interesting about this statement is that this is what I believed as well as a child. I was socialized into a system where I didn’t really get to have a say in what happened to me. I learned to be collaborative, to listen, to be respectful, and to not question. For a long time I truly felt like I was a problem. And all I could do was to work really really really hard within this system to prove to everyone that I was a fighter. Speaking up did not make me a fighter. Within the hospital environment I quickly learned that compliance and being a good little girl got me further than advocating for my needs and my feelings. I knew from a young age that if I complied, I would fit into the system. I should not show fear, yet be brave, and I shouldn’t cry, but be happy. As Chloe Atkins (2010) wrote in her book about her relationship with medical staff, “I not only wanted but needed them to like me” (p. 19). More often, disabled people are depicted as pained by their fate or, if happy, it is through personal triumph over their adversity. The adversity is not depicted as lack of opportunity, discrimination, institutionalization, and ostracism; it is the personal burden of their own body or means of functioning” (Linton, 1998, chapter 2, section 7, para 1).

I am learning, slowly and at times painfully, that I have been trying my whole life to understand and interpret my disability experience within an environment that sees disability as a predicament to do something about, to control it, and to reduce its potency in my life (Linton, 1998). I said earlier that both of my parents have asked me the question: “What do you think

would have happened if we would have not gone ahead with the surgeries?” This is an immensely difficult question to answer because we simply do not know. But sometimes I wonder what my parents would have done with a “We do not know” from my surgeons who so determinately rushed into surgery to save my abnormal body without second thought for my normal future. As Hanes (1995) explored, surgeons were trained on the notion that they wanted to remedy suffering, pity, and dependency. This type of approach is value-based, created on a one-sided perspective towards service orientation (Marks 1999a), and my parents certainly did not dare to be sceptical towards professional recommendations. Surgeons and healthcare providers represent powerful groups that rarely challenge or make explicit their theoretical claims, thus perpetuating the status quo (Hammell, 2006). What happens to us patients and family within the status quo seems trivial. However, we need to account for the roots of disablism within the system (Marks, 1999a):

Having recognized the need for a certain amount of scepticism towards professional claims regarding their ‘disinterested’ service orientation, it is important not to go too far the other way, and reduce all professional activities to narrow self-interest. Simplistic denomination of professionals fails to recognise the external constraints placed on them or to distinguish between ‘good intentions’ and damaging cultures and practices. (p. 106)

~

I got woken up in the middle of the night by my night nurse, Ms. Guyer\*. “You need to shower now,” she barked at me. “Then you can go back to sleep”.

I followed her into a dark room with a large metal tub in the middle. I followed her orders to strip, and then she lifted me into the tub and began to scrub me down with an antiseptic smelling soap. I felt my skin burn. After the shower was done Ms. Guyer lifted me out of the tub again and handed me two towels. I dried myself off and then put on a hospital gown on the front and then one around my back. We walked back to my bed, I climbed in and Ms. Guyer lifted the railings on either side until they clicked. Then she walked out of my room and the lights went out. I grabbed my watch from the bedside stand and tilted it until the dim hallway light illuminated the display enough for me to read it... 3 AM, it says. I lay awake in bed until dawn appeared on the horizon. Ms. Guyer walked in one more time, likely before the end of her shift. “Oh you’re awake already?” she said to me. I didn’t dare to tell her that I hadn’t slept since she got me up for the shower.

“They’ll be coming for you soon”.

They did come very soon after Ms. Guyer left my room. Things progressed like routine. I had had surgery before so the steps and the process did not scare me. I always thought that it was funny how movies and television shows make the characters have dreams during surgery. They hear their favourite music and dream about their family or something that they want to change. And then they wake up well rested and happy. For me it always feels like a split second has passed. You fall asleep and then all of a sudden you wake up again, except that you are in a lot of pain and you do *not* feel like you had a good sleep.

~

“Susan, you are in the recovery room” a warm voice says. I feel the sheets lift off my legs. “Can you wiggle your toes for me?... Good... now push your feet down like you would on a gas pedal”.

I don't know what to do. How do you do that? I don't know how to drive a car. I feel a hand touch the bottom of my foot.

“Can you push against my hand?... Good”

I fall asleep again.

My mom comes and sees me in the recovery room. She does this thing after every surgery where she touches my cheek with the back of her cool hand and then I know that I'm okay. She tells me that my surgery was longer than three hours, almost six hours. I get moved into critical care for a few days and then moved to a regular room.

Once I was in my regular room, I met Nancy\*. Nancy was the unit's physiotherapist; she was tall and athletic-looking, matter of fact, and full of plans. Her plan was to get me to sit up in bed. It had been a week since my surgery.

“This is probably going to make you feel a bit dizzy, but that's okay. We'll go slow,” she encouraged me. As I tried to right myself up, I became intensely nauseous. The aroma of my mom's coffee in the room insulted my sensitive sense of smell, pressure built within my head and I threw up. The convulsions from the gagging making my back and scar burn like red-hot ashes. I was sure that I had burst stitches. I told Nancy that after she lay me back down in bed.

The next time Nancy attempted to sit me up I didn't vomit but I felt dizzy and had a splitting headache. The blood rushed around my ears so violently that I could not hear anything, I could not see anything. I remember hearing Nancy ask me whether I was okay but she seemed far away. I concentrated on not throwing up again. After a while Nancy lay me back down in bed.

On the third day, Nancy started to get impatient with me. I felt a change in her interaction with me, a palpable opinion that I was being difficult, stubborn, uncooperative.

"You need to try" she would encourage me. I often did not say anything. I did try. I was not trying to be difficult; I suffered to please her. Nancy, upon the demand of Dr. Milton and his residents, made me sit up several times a day. Each day Nancy and a nurse would lift me out of bed and sit me up in a reclining chair next to my bed. I would start to dread this routine.

The worst was when I had visitors because the insult of pain, nausea, and pressure on my body often would make me wet myself. Every day I was put into that recliner and I would sit there in my own urine. Often I felt myself floating away from my body as if that part of me would sit on the bed and watch the "real me" sit in that chair. I would watch 'her' try to interact, try to smile, drenched in sweat and exhausted by the time they would put her back into bed. Back in bed they would say that I would have to be able to sit up to go home. I wanted to go home. I didn't want to stay there. Why would Nancy and the nurses think that I would act sick on purpose? I tried sitting up myself but I couldn't do it. It was torture – torture inflicted by them and torture inflicted by me onto me. I cannot call it anything else. I am claiming the truth. I have never talked about this before.

~

As I write this passage I feel incredibly uncomfortable, on edge, I want to walk away. It's as if the 37 year-old me wants to tell the 13 year-old me that I understand that she was not being difficult or a failure. I was such a compliant little girl, so eager to please in a situation that at times felt hopeless and out of many people's control. I understand why she was afraid to speak up for herself. No one believed her but she also did not want to worry or upset the people around her. She needed to be strong. She couldn't cry. She had to be happy and optimistic. She had to try. I want to tell her that I'm proud of her... I know how she began to reflect on those experiences, and as a 13-year-old how she would start to analyze people, situations, and how she could find a niche in a world where she felt utterly misunderstood... a world to which she did not feel she could ever belong.

~

This hospitalization was my first experience with institutionalization. I label this experience as institutionalization with purpose, not because I link it to the experiences that disabled people would have had living in residential institutions (see Goffman, 1961); rather, I bring up institutionalization as an underlying theme related to control, power, and oppression as systemic practices (Ben-Moshe, 2013).

The health professions rather successfully portray themselves as benevolent, altruistic and client-centred – especially to themselves – yet little research has been undertaken to determine whether this equates with clients' experiences of rehabilitation and hospitalization. Macfarlane (1996, p. 13)

notes that many disabled people define the care they have received as being ‘oppressive, often of a custodial nature and provided in a controlled way’.

Notably, those in residential institutions or rehabilitation facilities often have no control over who can touch their bodies or provide their personal care (Westcott, 1994). Indeed, powerlessness is a defining characteristic of institutional care (Goffman, 1961) (as cited in Hammell, 2006, pp. 119-20).

I occupied a “marginal status” within the hospital, first as a patient, and second as a child (Hammell, 2006, p. 120). I experienced powerlessness because I was unable to advocate within this environment where therapists like Nancy and nurses like Ms. Guyer represented authoritative figures to me who clearly wielded power and had jurisdiction within the hospital walls to make decisions over my care.

I had been hospitalized before and had surgeries before, but this experience was different. This time around I wasn’t getting better. I wasn’t progressing to going home. Each day my situation worsened, and with each worsened situation my learned helplessness grew. I wanted to get better for my mother, my father, Dr. Milton, and Nancy. But I couldn’t do it. And I sensed, deep down from my interactions with Dr. Milton and Nancy that in my current situation, my problem, was disappointing to them. I helplessly went along with what was *ordered*. I was stuck in limbo, a concept called *liminality*, where I was “caught in an ambiguous and transitional state that [was] not under [my] own volition or control” (Hammell, 2006, p. 120). Why was I being left sitting in my own urine? I knew that for me to wet myself, my body would have had to be in great physical distress. Under normal circumstances I did not leak after my bladder surgery the



year before, which is why I was on a strict four-hour catheterization regimen. I was cooperative, compliant, and passive. I was powerless to change my own situation. I wanted to be what everyone expected me to be. “The liminal, or transitional, period of institutionalization that can follow impairment has been characterized as a time of helplessness, dependency, powerlessness, loss of freedom and loss of control” (Hammell, 2006, p. 122). I pushed myself to the point of torturing myself.

~

It was during the dressing change... the day they took the huge puffy surgical dressing off my back. The nurse, Mary\*, gave me a mirror so I could see my scar. I remember holding the mirror and noticing how bruised it all looked. I remember thinking that if I could sit up straight the staples in my back would make a perfect ladder from the mattress up to the tips of my hair hanging just below my shoulder blades and a little gnome could climb up into my hair. Holding the mirror I watched the nurse dab a saline soaked gauze pad over the staples. She stopped and studied my back. “I’ll be right back,” she said. I lay there, half naked with the door open to the hallway, my back exposed to the cool air. I remember how cold the room temperature air felt on my scar. A few moments later Mary walked through the door with another nurse in tow. It was the floor nurse, Shelly\*. I liked her very much. She had such a deep calming voice and she was super tall. “Hi Susan, let’s see what’s going on here”. After Shelly must have studied my back for a little while she looked at me and said, “It’s puffy... has it been like this for a while?” I remember looking at her and thinking how should I know? It’s been covered for the last five days. Touching my shoulder she said “No no, don’t twist, here.” She adjusted the mirror in my

hand. “See how it’s puffy? This should be flat.” I nodded looking at my bumpy back. It looked like little mogul hills with a gnome ladder in the middle. I watched Shelly poke my skin again, just like the Pillsbury dough boy. “I don’t know” she said to Mary “we need to have the surgeon look at this”. “Let’s just cover this up again, shall we?” And they walked out of the room. I pulled the blankets over me... my mom wasn’t here yet. I wanted my mom.

My puffy back began a revolving door of doctors that day. Matter-of-fact Dr. Milton, as he did every day, spoke to his students and the nurse holding my chart in her hand. “Let’s tap her,” that’s what he said. “Let’s tap her”. And that is what they did. Instead of a spinal tap, they just tapped the puffy part. First a lot of blood came out into the syringe. But with each day the bump grew, and with each day the liquid became clearer. I learned from listening to the doctors speaking to each other that it was cerebral spinal fluid in the syringe. And now that the pressure dressing wasn’t on my scar anymore, the fluid gushed out under my skin. It became the size of a football. Coincidentally the day they found out about my “leaking”, all sitting up and getting out of bed stopped. In fact I wasn’t allowed to move at all. They bandaged me up so tightly that I couldn’t breathe. Day in and day out I was kept in a Trendelenburg position, where they lowered the head of the bed and raised the feet. All this did was make me slide down and have to be pulled back up every few hours. I wasn’t allowed to move, I had to be turned by nurses. I was a prisoner in my own bed.

Every day another medical student would come in to “tap me”. It was always a different person. Back then I didn’t think much of it... some were nice, some were not so nice. Some didn’t treat me very nicely. They got to learn on me... every day, because each day my bump got

bigger and bigger no matter how often they sucked the fluid out and how tightly they wound the pressure bandages around my torso.

One morning I had a floater nurse, Harriet\*. I had been there for almost a month now. I knew all of the nurses, knew the ones I got along with and the ones I really liked. When Harriet came into my room I wasn't feeling well. I was sick to my stomach, somehow I felt weak and unwell. I felt my blood rushing around my ears. I felt like something was crawling under my skin. I felt pressure all around me... I felt a pulsing. Pulse... pulse... pulse... like a heartbeat in my head. Harriet didn't know me very well. We talked a little bit as she went through my morning routine. That night I had sweated a lot in my sleep – my clothes were drenched in sweat. Harriet changed the bed sheets and turned me onto my other side. This had become more and more difficult... It was very painful. Every time I was turned, I had to roll over my back... my bump. I clenched my teeth so hard each time that one time I felt as if one cracked. Today I didn't want to do it. I pleaded with her to let me stay on my side. I told her I was feeling sick. “No worries,” she replied, “we'll get you changed and new sheets and turn you and you'll feel better. We've got to make you look nice for when your mom comes in today”. What could I do? I had to go along. But after the whole turning ordeal I told her again that I didn't feel well, that I was in pain. I said, “Something doesn't feel right”.

“I know dear,” she trilled as she walked out the room, “you'll feel better once you eat something”.

Harriet returned with a food tray and the smells made me gag. I didn't want to eat. I felt so unwell that I didn't know what to do. I must have been moaning because Harriet said,

“Someone is having a rough morning isn’t she?” and walked briskly out of the room. The morning cartoons were playing on the TV. Care Bears, then Inspector Gadget, and then the Power Rangers. I heard the shows but didn’t really pay attention. All I felt was my body. The pressure was growing so intense in my head and my back that I had an instinct to climb away from it. Instinctively I started reaching for the bed railings and starting pulling myself towards them – anything to get away from this pressure. I tried to pull myself up over the railings but my body weighed so much I couldn’t bear to lift the weight. With effort I wanted to get a leg over the railing. Maybe that way I could leave the pressure behind in the bed?

“Oh my God what are you doing?” Harriet screeched as she ran to the side of the bed and grabbed my leg. “Susan, what are you doing?” I moaned in response. “Susan? Susan?” I heard her calling my name but each time it sounded more and more faint like a name that echoed back and forth between the walls of a cave. Harriet rolled me back into bed. Her aloof demeanour was gone and there was concern in her voice. Holding on to my shoulder she reached for the call-bell. Each ring seemed like an eternity. “Yeeesss?” An impatient voice droned through the intercom. “Sue, it’s Harriet. I need Shelly to come immediately”. The intercom clicked off and then back on “She’s in room 511”. “It’s urgent” Harriet urged.

At that moment, my mom walked through the door. “Hi Susan” she says like always and then stops, observing Harriet holding on to me in bed. I heard hurried footsteps coming down the hall and a swoosh of scrubs rushing through the door. Harriet spoke to Shelly in rushed tones “... I caught her trying to climb out of her bed... She was half hanging over the railing when I came in...”

“Susan? Really?” I felt a cold hand on my cheek and forehead. “She’s burning up”. My mom moved towards the bed.

“Her temperature was normal this morning when I checked. She was complaining of not feeling well but I thought that she was in a bad mood”.

My mom spoke up. “If she is complaining then something is wrong. Susan is not a complainer”.

“She’s right,” Shelly said. “This one here is tough”. She patted my shoulder. I moaned because her touch made my spine pulse and spasm. Shelly let go of me.

“She’s been complaining of a headache and nausea. She was soaked in her own sweat over night. She didn’t want to be turned this morning”.

“That’s not like her at all.” Responding to my moans, Shelly crouched down over the bed and asked “Susan, are you in pain?” I nodded. “Okay we are going to get you something for pain. Hang in there, don’t move. But first I need to have a doctor come in and look at you.”

A fellow came into the room with Shelly a few moments later. Lights were flashed into my eyes, temperature was taken, questions were asked. Mostly I had become unresponsive. I was too tired to speak. My vision was coming and going. The heartbeat in my head was constant... all that I really was aware of. Pulse... Pulse... Pulse... Blood work was ordered, another spinal tap completed, pain medication administered. Then I was moved to another room, an isolation room. I was afraid that my mom wouldn’t find me. But Shelly assured me that she would bring my mom to me. I fell asleep.

After a while I woke up to my mom walking out of the room and talking to Shelly in the hallway. I opened my eyes, but I felt like I was looking through a tunnel, the end barely in focus. A nurse came in with two IV poles hung with lots of different colourful IV bags, one for each arm. As she started to find a plump vein to plunge the IV needle into, I could hear whispers in the hallway.

“...we think it’s meningitis... serious... we don’t know until the results come back”

I heard my mom gasp “no” and then sob.

“Evelin\*... this is going to be okay... we caught this early.” Shelly comforted my mom.

My mom came back into my room and pulled up the chair next to my bed. Again she touched my cheek with the back of her hand. I was so glad she was here with me. I opened my eyes...” I can’t see anything” I started to cry. The pressure in my head is intense like a heartbeat of a drum beating a regular slow timpani boom every few seconds.

“She can’t see because her brain is under a lot of pressure. The skin around the brain is inflamed. We are also giving her a lot of medication.”

“Is she shaking?” My mom asked Shelly.

“She has a high fever,” Shelly replies. “Evelin, this is going to be okay. We caught this early. We got to treat it earlier than if she was at home”.

“Thank you, Shelly”.

Shelly grabs my chart and strokes my hair. “I’ll be back in a bit, okay Susan? You rest. You need lots of rest”.

“Are you cold?” My mom asked me as she touched my arms. “You feel hot”.

I lay there. I couldn't see but I felt safe. My mom was here with me. I heard shuffling as Harriet came into the room. “Mrs. Miller”, she addressed my mom, “I'm Harriet, I was Susan's nurse this morning. I'm so sorry, I didn't realize that she was so sick. I'm not usually on this floor”. My mom talked with her for a bit, always being kind and not upset.

“She's a sweet girl,” Harriet said to my mom.

“Thank you”.

“Is that a spasm?” my mom asked Harriet. They must be looking at me, watching me. “I don't know,” Harriet responds. “Looks like a twitch.”

I realize that they can see the pulse that I feel inside my spine and head. The pulse of the cerebral spinal fluid as it is being circulated around my nervous system. Meningitis is an inflammation of the membranes around the spinal cord and brain. With each pulse of the fluid the membranes respond. Each pulse is a surge of pain that rushes through me, a pulsing pressure that explodes in my head, a shooting snap that jolts my neck and spine. Each pulse is there and as I feel it, they can see it ripple through my body.

~

“Perhaps the most terrifying form of epistemic invalidation involves doubt about the patient's claim to be in pain” (Marks, 1999a, p. 55-56). Marks described epistemic invalidation as the process by which doctors and specialists use patient records, assessments, and tests to make treatment decisions with little opportunity for the patient to have input. The patient's

experience with their body is not “considered rational and is not therefore considered to be an appropriate guide to treatment” (p. 54).

I have often wondered about Harriet and her initial interaction with me. With time, Harriet and I got to know each other well, and I came to like her very much. I had her often after my first experience with her as a floater nurse and she treated me with much respect and empathy. What happened here? Why would she have told my mother and Shelly that she thought I was in a “bad mood”?

At first I did not want to look at my experience within the hospital through a Disability Studies lens, because using this lens forced me to see that most healthcare professionals involved in my care only began to relate to me, believe in me, and empathize with me once they got to know me (Marks, 1999a). Nurses in particular, according to the literature, struggle with becoming too involved with patients.

Waking up patients to give them their sleeping pills, ritually taking temperatures and generally treating patients as if they were cogs in a machine may not be the most effective way of delivering care, but it appears to deal with the potential anxiety generated by intimate contact between staff and vulnerable people. Nurses are moved around wards, and follow shift patterns designed to further prevent the risk of becoming ‘too close’ to patients. As such, sympathy (and its converse, sadism) rather than empathy comes to be the key form of relating. (Marks, 1999a, p. 57)



As a child, I learned that I needed to be grateful for the assistance I was given. This is perhaps best explained by Parson's sick role (Parson & Fox, 1952). First, a sick person is to seek medical treatment and cooperate with prescribed regimens in order to return to a normal state of health. Second, a sick person should view their condition as unwelcome and unwanted (Barnes & Mercer, 2010). Although Parson's sick role has been criticized in recent years for failing to "... address the dysfunctional effects which some parts of the social system may have for some members of society" (Marks, 1999a, p. 60), it does apply to my experience as a hospital patient. Moreover, I had gone from 'healthy disabled', where my physical condition and functional abilities were relatively stable, to someone who was 'unhealthy disabled' and thus entered a world and category of diagnosis that people have a harder time accepting (Wendell, 2013). I tried not to push the nurses' buttons. Except when I was sick, then it was difficult to be grateful and cooperative. When you are sick you go into survival mode. Being cooperative is difficult to sustain.

The words *violence* and *abuse* have only recently entered my vocabulary. One cannot discuss power and powerlessness without identifying abuse and violence within social interactions (Hammell, 2006). Disability Studies literature is full of accounts of violence and abuse of patients by their healthcare providers (e.g., Atkins, 2010; Goffman, 1961; Kraemer, 1994; Marks, 1999a, 1999b). When I teach occupational therapy students, I purposefully seek out writings by people such as Atkins (2010), coupled with my experience, to open the door to discussing the topic in the safety of our problem-based learning groups. To explore what emotional and physical abuse may look like, to understand how it can happen and the

implications it has on patients, are important factors for all healthcare providers to understand (Barnes & Mercer, 2010; Hammell, 2006; Marks, 1999b).

~

I recovered... it was a long time on many IVs and a struggle to get better. I lost lots of weight. Instead of “tapping me” every day, my surgeon tried to put in a lumbar shunt. I know that children with spina bifida have shunts going from their brains into their abdomen because they have extra cerebral spinal fluid in their heads. I understood that I had no extra fluid in my head but that I had *lots* of it leaking out of my spinal column. That surgery seemed easier than the first, and for about a week I seemed to improve. I had a flat back. But as soon as Nancy came to work on sitting me up, the puffy bump returned. After only a few days my bump again was the size of a football.

I didn't know it then, but my mom was worried. She didn't let me eat hospital food. She brought in all of the rich home-cooked German food favourites and yummy huge hotdogs from the street vendors. But my back didn't get better. I needed another surgery. They couldn't get my fluid to stop leaking out. And so I got used to this football-sized bump on my back. It became a part of me. I had to learn to live with it. Nancy, the PT, came back into my room when I was allowed to try sitting up again. She said, “I guess you gave everyone quite a lot to worry about?” As if this was funny. Like I was supposed to laugh and make her feel better for torturing me every day with getting out of bed. This time Nancy acted differently though. She sat down next to me and said “Listen, I've never had someone like you before. So I didn't know that this could happen. Now that I know what you have”, she looked at my huge fluid filled skin sac on my

back, “I’m not sure how we can work on sitting you up. We need to work as a team and figure this out together”. I nodded. I felt for her. I didn’t want to be someone who’s difficult. I didn’t want to be a problem for her.

Every day we worked on sitting up more and more. But I never managed to sit up straight. I made it to 45 degrees and then the pressure in my head was too great for me to continue. The difference was that now Nancy listened to me. And she began to see the signs of when it got too much for me. She began to understand that I tended to push myself too far, to get that extra degree or try to do it myself. That I would not stop when I perhaps should stop. I didn’t mind working with her, but I also felt that I was a failure.

“You can’t go home until you can sit,” my surgeon said to me one morning. “Sitting is the only way we can discharge you. It would be best if we could get you to stand and walk a few steps. You are going to have to try harder”.

I was really hurt when he said that. I was already trying so hard. I wanted to go home. That day my mom came into my room with an excited smile. “Look at what I have for you” she said and she handed me a picture of our dog, Tobi. He was a brown spotted Dalmatian and I missed him so much. I wanted to pet him and cuddle with him. I missed his long sleek tail that whipped so hard when he was happy that it hurt your thigh when it hit you. She grabbed a hospital tissue box and propped the picture up in the frame, making a makeshift photo stand. I wanted to go home. I wanted to see Tobi. I tried to sit up and had to lie back down. My mom stroked my hair. All in time, her eyes said. She was such a patient mom with me. I loved her. I loved her for knowing to bring in a picture of Tobi.

In the afternoon Nancy came in with a funny looking bed on wheels. “A banana cart”, she called it. “You can lie on your stomach and wheel yourself around on it. Wouldn’t you like to get out of your room?” The first time I lay on this cart felt weird. I smashed into everything, and months later I got the nickname “crash” from one of the fathers on the ward – but for now my mom and I got to stroll down the ward together, past all of the other rooms with kids lying in beds. I got to put faces and room numbers to the noises I heard when I lay in bed. There were the teenagers in comas, or the kids who had brain injuries and their screams for chocolate milk would echo through the dim lit hallways every night. My mom and I made our way down to the end of the hallway by the elevators with a big window you could look outside. Down below I could see lots of people walking, the trees were starting to bloom... It was April already. People were buying hot dogs from the hot dog stands under the red and yellow striped umbrellas. We wheeled back to my room, passed the nursing station. I knew all of the nurses now, some of them looked up and smile at me. “Look at you,” Shelly said, “wheeling in style!” She laughed her deep hearty laugh. I was getting the hang of this. I could actually turn into my room without hitting the walls or scraping the doorframe.

We got back to my bed and I said, “Mom, I want to go home”.

My mom sighed, “I know Susan. I want you to go home too.”

“No mom,” I repeated, “I want to go home”. Looking at Tobi’s picture in the tissue box I grabbed on to the railing and hung on to it at the point where I feel that the pressure was too great for me to continue. I felt how tight my lower back was. Everything felt under great tension. My mom held on to my arms, urging me to lie back down. I said, “Pull mom.” My mom

hesitated. Her eyes signalled that she wanted me to do this with Nancy but I urged her to pull me up. I knew I couldn't do it myself, the pain wouldn't let me do it myself but I trusted my mom. My mom pulled me further into a sitting position... slow and hesitant... afraid of going too far. A shooting pain seared down my legs and I screamed. My mom hesitated again. I nodded and she pulled me a little further. All of a sudden, nothing. No pain. I sat. I felt dizzy and light headed.

“You're sitting,” she shouted. “I'm sitting” I smiled. “Call the nurse mom. Call someone to see”. My mom happened to find Nancy on the floor and Nancy came jogging into my room.

“Well look at that” she smiled. “I thought we were supposed to do this as a team?”

“I didn't do anything” I explained “My mom had to pull me past the painful point. Now I'm not hurting so bad. This I can do.” I didn't mention to Nancy that I was afraid of going to lie back down though.

“That is interesting” Nancy pondered. “We will try that again tomorrow. But for now let me help you lie back down. You look a bit pale.”

I practiced every day, and soon I was able to stand up and walk a few steps with help. But I could never get past the painful part on my own. When I would sit, my mom would have to pull me into standing, fast and assured because I would sometimes scream in pain. She would grab my hands and say “One... two... three...” and then yank hard and fast to get me to stand. When I would lie in bed she would have to help pull me into sitting, past my painful point. My mom and I were a team. I was discharged home, football sized bump and all. But I was able to go home. To my dog. To my family.

~

I must have appeared as *motivated* to Nancy, my mother, and my Dr. Milton. Motivation, as a concept, still follows me through my adult years as much as it did through my childhood. I always wonder what it means when clinicians comment, ‘*client appears to be unmotivated...*’? It is a type of communication between professionals that stereotypes a client into a role, that offers a professional a mental picture of who the client is, before you give the client a chance to figure out for themselves what motivation is – their own locus of control (Hammell, 2006). One of the first things that I came to understand through the Disability Studies literature was that rehabilitation professionals might inadvertently be part of the problem, and not always part of the solution for disabled people (Abberley, 2004; Beresford 2004; Hammell, 2006; Krupa, 2008). I had always understood this to be a reality within my own experiences, but to see it reflected in the literature caused me to feel apprehensive – as a disabled client and as a clinician. Abberley (2004) explored how the relationship between occupational therapists and clients, for example, creates power imbalances because of factors such as the occupational therapists having to “offer evidence of ‘success’ in order to validate their work” (p. 240). Clients, in turn have to work with these requirements by meeting the criteria set out by the therapist. If a client does well, therapists have a tendency to relate this performance to their treatment efforts. If a client does poorly, therapists tend to attribute this to the client being unmotivated and not able to work hard enough to resolve the issue. Hence, rehabilitation professionals can reinforce negative therapeutic stereotypes. They can also inadvertently create a negative spiral where a client’s world gets

divided into the ‘good’ and the ‘bad’ – and this only increases a client’s feelings of powerlessness (Kraemer, 1994; Marks, 1999a, 1999b).

I have found in my experiences that there is always a period of adjustment. When I was in hospital, I faced a time where I certainly was not unmotivated, but I had to determine for myself what was personally meaningful for me to work towards. Going home was the reward. Sitting and walking, for me, were not a reward – even if it meant that I could go home. I wasn’t able to sit up the way Nancy was trying to teach me to do it, but I was determined to figure it out my own way. I was becoming an expert in my body, my own care. I realized that I was going to have to find my own solution to this situation, and hence I forced myself to try to sit, to figure out what it could feel like to sit – under my control, from my own sense of agency (Thompson, 2013). If I was going to be like this, if my new body, my changed physical impairment, meant that I now must live with a fluid filled sac on my back, then I was going to work this into my identity, my life. I was going to make this work.

I don’t know how long my mom and I managed at home with my bump. One month? Six weeks? The reality was that I had to go back to the hospital and another surgery was to be tried – another laminectomy, but this time my surgeon was going to give me a pig’s spine membrane. I thought that was cool at the time, that they could do something like that.

~

One week after surgery, I was doing well. This surgery was a success. But my body was weak, my spine angry, and I was discharged home in June in “fair health”. My back was flat, no more football sized bump on my back. Life seemed normal. It was summer. We were at the

cottage a lot. I swam and played and got stronger every day. One day in August I was walking into the cottage after a mid-day swim. Walking past the large glass sunroom windows I caught a reflection of myself as I reached for the screen door. I was wearing my green bathing suit with large black stars printed in symmetrical lines across the front and back. I saw it then, a hint of a small bump on my back. It was very small, so faint that I thought the window glass was playing a trick on my eyes as the clouds rushed past in the sky and the leaves rustled in the wind.

Carefully and slowly I reach back and lay my hand flat on my back. Gently I poked my back... it was soft and squishy. My heart skipped a beat and I flushed in panic. Anxiously I reached for the door handle, pulled open the door, and after a last fleeting glance at my back I walked into the cabin. "Mom?" I called out.

"In the bedroom" she replied. I walked up to the door, turned around, and said, "Is this a bump again?"

We both sat down on the bed and started to cry.

~

"How are you doing, Mademoiselle Suzanne?" my French teacher asks me one late October day after grade 9 French class. I walk up to her desk as my peers head downstairs for lunch break. "Any news about your surgery yet?"

"My surgeon left it up to me. He said that when the pain gets too bad that I can come in for surgery. It's getting pretty bad. I think I'm ready to go back to the hospital".

"Already? How many surgeries will this be?" I see that she wears concern on her face.



“Four”

“Four” she repeats and takes my hand. “You’re brave, Suzanne. You are handling this so well”.

“That’s okay. I’ve had lots of surgeries. This is just another one for me.” I smile at her as I head to the door. “Au revoir Madame.”

~

The human body has a profound ability to exert its own forces on a person. You can intervene as much as you want to... but the body will find its own equilibrium in the process (Marks, 1999a). I was forced to respect this during my adolescent years and I continue to respect this today. I am beginning to understand that you cannot discuss disability without discussing the body. I will come back to this discussion later within this thesis.

As I draw this chapter to a close, I can connect more deeply with how I experienced powerlessness in many forms: powerlessness with my situation and the power I needed to draw from in order to accommodate my identity and physical limitations as an adolescent girl. I experienced powerlessness and oppression from within the medical system, helpless to change my physical well being, unable to return to who I was *before*.

Who has the right to deal with my body?

My parents?

My surgeons?

Me?

Am I a failure?

Am I responsible for what is happening to me?

~

I want to show them that I can do it. I have the willpower to do this. The social and the medical worlds collided for me that year like the waves of a large boat's wake crashing over me at the cottage. If you dive under the water's surface, you can see the turbulent water currents crash upon each other as you float peacefully below, gently being rocked by the water. I know that I need to surface for air, but I'm unsure if I can stay afloat amidst those currents.

~

Power and powerlessness are essential to the experience of disabled people, and perhaps also the definition of disability (Barnes & Mercer, 2010). As professionals, we do not want to act as powerful, to have power attributed to us within a hierarchical system within which we work. But disabled people experience powerlessness, especially in situations where medical and rehabilitation professionals have the authority to make decisions. I needed to raise issues of power and powerlessness first, in order to lead into a discussion of client-centred practice. Power is not a peripheral concern for us as rehabilitation specialists. In fact, power and powerlessness emerge as central tenets of disability and rehabilitation. In the next chapter I add a discussion of client-centred practice as another layer to discourses of power.

**CHAPTER 5:**  
**“I Walk, Therefore... I am Deemed to be  
Compliant”**

Shifting the focus from “what can I do for this person” to “who is this person and what do they need” may be a strategy that promotes a client-centred partnership with shared power.

—Bright, Boland, Rutherford, Kayes, & McPherson, 2012, p. 1002

“Okay let’s get you out of bed” my new PT, Jenn, says as she sits next to me on my hospital bed. Nancy has left the hospital since the summer. Now I have Jenn. It’s been a week since my latest surgery. Jenn has been teaching me how to get past my painful point all by myself and I can sit up on my own without my mom’s help. We’ve been both sitting on the edge of the bed for a while. I like Jenn.

Jenn jumps off the bed and takes up stance in front of me. She places both of her feet in front of mine, after she has strapped my feet and calves into my Ankle Foot Orthotics and laced up my sneakers, and helps me shuffle to the edge of the bed. “Okay, all we’re going to do is stand up, okay? If you need to sit down again you just sit back on the bed”.

I nod.

“You put your hands on my shoulders, here. Just simply stand up and then sit down again”.

I nod.

Slowly I stand up. I feel weak. My leg muscles are shaking. Jenn is laughing and teases, “I have a problem with you”. Shocked I look at her. “How is it that you are 14 years old and you are already taller than me?” She ends her mockery with a smirk. I sport a faint smile. Is she for real?

“I mean is this too much for me to ask for? For me to have one patient who doesn’t make me feel so short?”

“Maybe I’m just super tall?” I reply insecurely. Jenn starts to laugh a heart-felt laugh.

“Hahaha... just sit back down will you?” I sit back on the bed and look at her. Did we just tease each other? Jenn is so cool. “Not bad, not bad.” A high five comes flying my way, I just manage to slap her hand with mine. “You’re awesome”.

“But too tall?”

“Just don’t hold it over my head,” she teases. “I’ll be back”.

~

When I met Jenn, client-centred practice as a ‘practice’ did not exist yet in standard rehabilitation environments. Within occupational therapy, the practice of client-centred care (Law, Baptiste, & Mills, 1995) and family-centred care (Bamm & Rosenbaum, 2008) emerged in the early 1990s. However, the concept goes back to before WWII when Carl Rogers (1939, 1951) identified the important interplays between cultural values, the active interaction between a client and therapist, where clients desire to participate fully in their therapeutic environments and have a say in the goals about their care (Law, Baptiste, Mills, 1995, p. 251). For the field of occupational therapy in particular, the relationship between client and therapist remains of utmost importance (Bright et al., 2012; Canadian Association of Occupational Therapists, 1991, 2002; Polatajko & Townsend, 2007). Today, client-centred practice is taught in every professional rehabilitation program, research strives to meet and understand it, and clinicians take it seriously and mention it frequently within their assessment and intervention arsenals. Yet, Hammell (2013) adds that:

Client-centred enablement is a concept developed without evident reference to clients’ perspectives. Moreover, the concept of enablement – defined by

dictionaries as a process of allowing, permitting, making able, giving power, making possible – implies a hierarchical relationship in which the powerful allow opportunities and bestow abilities on the powerless. (p. 175)

The issue of power, as I have identified in the previous chapter, continues to encompass a deeply rooted problem within the rehabilitation practices as a whole (Oliver, 1996a).

When I wrote this part of my life story, I did not anticipate that the themes of power and client-centred practice would emerge as strongly as they do. The two themes are interrelated, tethered to each other where one cannot exist without the other (Bright et al., 2012; Hammell, 2013; Law et al., 1995). As I read back over the journals from my teenage years, I had a very one-sided relationship with the healthcare team. The surgeons would come into my room at 7 am and talk about my care. I do not think that they ever considered that my 13 and then 14-year-old self understood much of what they talked about. For me, this was a critical time in my development. I was an adolescent, and according to psychological theory (Erikson, 1950) adolescence is a time when people get to know themselves and make choices about themselves (Thomas, Levack, & Taylor, 2015). I was going through some traumatic experiences during a time when my identity was also changing, naturally. Jenn treated me like a teenager and that was new for me in my interactions with healthcare providers. There were those in my life that exercised power over me, and then there were also those who could give it to me – when I needed power to be given to me. But I was afraid to take this power. A compliant patient went along with things. *“I don’t want to be a shit disturber,”* I wrote in my journal.

There was power in the humour that Jenn and I shared in our therapeutic relationship. It wasn't purely a clinical approach. Did my interaction with Jenn just happen by chance? Was Jenn really practicing consciously in a client-centred way? Thinking back, perhaps it happened by chance in the beginning. I remember that Jenn grew as a clinician through our time together and actively began to manage her clinical role and therapeutic relationship with me to improve my rehabilitation outcomes (Kayes, Mudge, Bright, & McPherson, 2015).

I remember Jenn being able to say, "I don't know".

~

As the adult Susan, I would like to give the younger Susan in this situation some credit. In a sense, younger Susan possessed power in observation. In a sense I observed *their* world, a world I couldn't cross over as a patient, and I was beginning to understand my disability – my body. But I was too young to see this type of knowledge, or awareness (Davis, 2012). I was thrust into a system where one of the "central assumptions of the medical/tragedy model is that disabled people want to be other than themselves" (Davis, 2012, section 2, para 6). Few people in my life outside of my family recognized that I had abilities and a positive identity even while facing this type of adversity. But some did. I always asked the nurses about my medications and dosages. When a procedure was ordered I would ask the resident to walk me through it.

"You are so smart," one of the neurosurgery residents said to me one day.

"Yes she is" Shelly replied to his comment, "Susan's going to write a book one day, you just wait".



She looked at me, smiled and said, “and when you do write this book you let me read it okay?” I nodded, incredulously. She asked me if she can write her address into my journal and I nodded again. The opening line reads something like *I don't feel like writing anything in here today...* with a giggle she scribbled underneath, *You lazy buns*, and then added her address and name and ended her entry with a capitalized *WRITE ME!!!* I did write her for a few years and then we lost touch. Twenty-five years later that memory feels so distant, yet always revivable on that single page of my journal. Today I am writing my thesis. After 25 years, I am taking *my* power to write something that a few influential healthcare providers have encouraged me to do for a very long time.

~

After Jenn was able to get me out of my hospital bed, I got to go home after 10 days... discharged with my ‘bump and all’. That’s what my family and I called it, *bump and all*. Why did we call it that? I was *that girl*. I was the girl with the very large football-sized cerebral spinal fluid collection on her back that just wouldn’t go away. For each of the morning rounds my hospital room was so packed with medical students and residents crowding around my bed that I felt that I was part of some kind of a spectator sport. What is striking about referring to me and *my bump* is the natural way that my family and I incorporated my *bump* into our lives, and how I incorporated my bump into my overall identity. To link my bump to my overall disability identity seemed a natural way for us to cope as a family unit (Garland-Thompson, 2013), but perhaps not so much for the medical team that tried so desperately to find a way to make that part of me go

away; to sever that part from my body. As a family we were coming to terms with my metamorphosis when the people around me did not seem to view this as a choice.

Disability invites us to query what the continuity of the self might depend upon if the body perpetually metamorphoses... disability reveals the essential dynamism of identity. [It] attenuates the cherished cultural belief that the body is the unchanging anchor of identity. Moreover, it undermines our fantasies of stable, enduring identities in ways that may illuminate the fluidity of all identity. (Garland-Thomson, 2013, section 6, para 7)

My *bump and all* became the new normal for me. I identified it as part of me, in a physical and attitudinal environment where this [my] adjustment simply did not fit with the expectations of my surgeons. Feminist disability theory "...presses us to ask what kinds of knowledge might be produced through having a body radically marked by its own particularity, a body that materializes at the ends of the curve of human variation" (Garland-Thomson, 2013, section 6, para 8) and my resulting agency and identity to live with it.

~

"Mom?" I ask today as we are driving together in the car. "Why do we call it 'my bump and all?'"

"We were trying to cope" my mom reflects. "No one seemed to know what to do with you anymore. They would send you home and we managed even with your bump."

We both sit silently for a while and then my mom adds. “You know, they had no idea what we were dealing with. We just made it day by day and we had no help. Somehow we managed.” and then she smiles and says, “We just managed, bump and all”.

~

I was too young to understand that my life teetered on a thin edge. My parents understood this. In a way I went home as a failure. I simply went home, not back to school.

*September, 1991*

*I can't go back to school, I'm not doing well. It's a hard time at home because I know that I'm going to have to go back to the hospital, I just don't know when. My surgeon again says that I should come back when the pain is too great for me to bear. I live with pain all the time, when am I supposed to know when my pain is too great?*

I write the above passage into my journal. I think about how my mom and I go through a daily routine. She helps me get up in the morning, I get to have breakfast with my brother and then we drive him to school. After dropping off my brother we go to our therapeutic appointments and medical appointments. Sometimes I just feel like we are waiting, but waiting for what? Should I say that I should go back to the hospital? I worry that my mom is going to be sad. My dad is sad too.

As a teenager I was not aware of the type of stress that my serious complications brought onto our family life. Bamm and Rosenbaum (2008) explained that

Serious illness or injury brings with it an inevitable distortion of family dynamics and fine equilibrium. The ability of the family to reorganize and

reduce the stress, to provide a healthy environment for all members of the family and initiate the healing process, differs from one family to another.

This unique pattern has to be respected and addressed appropriately (p. 1619).

How would my family have managed if family-centred care had been the status quo during this time? As an adult, I am coming to understand that a lot of things to do with my care happened behind the scenes. My parents were often pulled into consultation rooms to talk seriously with the surgeons about their choices for me. The power differential must have been immense, as my father recalls even 25 years later every name of the residents and surgeons with whom they communicated. I reflect on how powerful this moment is, how it illustrates my father's powerlessness as he recalls one of the moments that he says he can never forget.

"Don't you remember what they said to us about your spine? How Dr. Watkins\* tried to explain the force of water in nature?" My father asks me as he is reading through this part of my life story.

"I wasn't privy to those conversations, Dad. I think that you and Mom must have talked with him outside of my hospital room."

"I will never forget what he said." My dad shakes his head.

"What did he say?"

My father takes a deep breath, meets my eyes, and confidently says, “Trying to fix Susan’s problem is like trying to patch up a bicycle tube filled with water and under pressure.” I silently meet my father’s gaze.

“I recall you saying this before, Dad”. I eventually say.

“They are the so-called experts. What were we supposed to do?”

“Now looking back we know that things turned out okay, right?”

“Did they?”

“Yes they did. I believe they did.”

“They did not know what to do with you. I think they were about to give up,” my dad reflects. “And then they took your case to Boston I think?”

“Actually it was New York,” I correct him.

“How do you know that?” my dad laughs.

“Because I wrote it down in my journal in 1991.” I smile back at him.

I am taken aback by this crisp recall on my father’s part. I have had time over the past few years to reframe some of my interpretations from that time. I have to force myself often to rethink things that happened or things that were said because it’s easy simply to accept them without questioning. The “exercise of the powerful... are shaped by an ideology of normality, which, like most ideologies, goes unrecognised, often by professionals and their victims alike” (Oliver, 1996, p. 104). I do not see my father as a

victim, I do not see myself as a victim. I do not want to see us, our family, as *victims*. But we certainly were victimized (Barnes & Mercer, 2010). And I realize that just like I was oppressed under the shroud of ‘normality’ (Titchkosky, 2003), my parents were also caught in a spiral where the surgeons actively reinforced what they felt was normal and abnormal and forced their expertise onto my parents, who were helplessly left alone with incredibly difficult decisions – that in the end did not feel like a choice (Hammell, 2006).

~

In November 1991 I had been living with my bump off and on for 8 months... At least Jenn made sure that I got a special cushion for my back before I went home. It was a horseshoe shaped insert for the back of my wheelchair so that my bump could hide in this cave that it created. That way I could sit in the car and in any chair. I do not know what my mom and I would have done without Jenn. Jenn was different from all of the other healthcare providers. Jenn understood me and had a sense of my family life and particularly my home life. Today as a clinician I can understand that she saw herself as a *resource* and not as an *expert*. She did not “attempt to dominate, to take control or to manage” me (French, 1994, p. 115). Jenn had an ability to work with me at solving my own problems (Davis, 2012). Jenn had a “way of working [which] might include, for example, an approach to practice, interpersonal skills, or the almost intangible, yet distinct “something” that marks out one practitioner from another with regard to how they connect and engage with a patient” (Kayes et al., 2015, p. 254).

When I am asked today, in 2015, the question “Why did you decide to become an OT?” I believe that my interaction with Jenn planted the seeds of my goal to become a clinician. My lens has shifted with the help of the Disability Studies scholarship. Through the literature on childhood disability and on understanding disability in families (e.g., Davis, 2012; McLaughlin, 2012), and in discussing our family life with my parents, I have come to understand that the healthcare system viewed me and my *situation* as a burden on my family. As a disabled and very sick young teen I certainly fed into the stereotypical image that I was a ‘burden of care’ and that my parents should be celebrated for being able to “cope with that burden” – me (McLaughlin, 2012, section 1, para 1).

~

My mom, my brother, my dad and I decide to go one Saturday to the winter fair at our school. It’s nice for my dad to come and check out the fair with us. He pushes me down the hallways in my wheelchair and we look at the photos hanging on the walls, the photos of all the Grade 12 students who have graduated before me. “One of these days your picture is going to hang on these walls” my dad says as we strolled along the corridor looking at all of the black and white photos. I don’t really know what to think, I’m in grade 9 now and I’m not even in school. My classmates have started a book, a kind of journal, and we write back and forth to each other with this book. I don’t always know what to say in this book. I tell them that I’m fine, I tell them about the hospital and the people in the hospital. They tell me about the math tests that they hate, and who did what on this day and that day and what teacher was unfair and what teacher was

awesome. My world is so different right now, but I still connect to my peers and write to them about my life in the hospital.

My dad and I come up to a jewelry table in front of the bright window. There's lots of neat jewelry there, lots of earrings and bracelets and rings and beaded necklaces. My dad stops in front of the table and studies it. He looks at the rings and then picks one up. It's a pretty ring, with a black and white stone in it with a S-shaped line that divides the black and white part. "You know what this is?" He asks me as he shows me the ring. I shake my head. "It's a Yin Yang," he says. "It's a Chinese symbol, where the white part stands for good and the black for evil." I study the stone, interested in the meaning. My dad continues "but it doesn't have to be good or bad, for you it could be health versus being sick". I am surprised that my dad is sharing this with me. I didn't realize that he felt symbolically about something the way he does describing this ring. "I think we should get this for you." I looked back at him as he handed the ring to the merchant. "Really?"

"You'll see, this ring will help you fight." With a ring in tow, we head off in search for my mother and brother.

~

A few short weeks later, I'm back in hospital. All I can do, as a 14-year-old girl, is to follow along with the institutional practices (Barnes & Mercer, 2010). We go along with the "systematic, all pervasive and almost unquestioned" professional control of what was consulted, decided, and recommended (Strong, 1979, p. 129). This all began with my tethered spinal cord that my neurosurgeon said needed to be *fixed*. I don't think that anyone could have predicted that



this was going to happen. So then what? Can I return to a better self? Or do we focus on the battle to keep me from dying?

“You better talk to her!” my mother yells unexpectedly at my surgeon during morning rounds. Lying in my bed I observe the wave of shock ricochet through each of the resident’s faces as they perceive her tone of voice. Even I am taken aback. *Ooh she is sooooo mad*, I think to myself. She is growing impatient with them. I feel ashamed. I don’t want to be trouble – a burden to the doctors.

“She needs to understand what is happening here.” My mom continues with her rant, all the while pointing towards me in my hospital bed. “You *need* to talk to her about what you want to do. She needs to hear this from you! I don’t know what to say to her anymore”. I hear the quiver in my mother’s voice, yet I’m unsure if it is anger, frustration, or whether she is going to burst into tears. One of the nurses moves next to her and pats my mother’s shoulder. To my surprise, my surgeon turns to me and begins to address me as ‘Susan’ in front of all the residents.

He calmly and respectfully explains to me that they need to open up my back again to try to fix the leak from the spinal cord. But this time I’m supposed to get a human dural membrane transplant. They call it a cadaver transplant.

“Is this type of dural membrane going to heal quicker and keep the fluid from leaking out?” I ask the surgeon and look him square in the face.

“We certainly expect that it will”.

“Okay?”

I nod. All of the white-coated people exit the room, leaving my mom and me behind. Alone we both marvel at the transformation we just saw in my surgeon.

“I guess he is human after all.” My mom smirks about the abrupt display of bedside manners.

“You yelled at him, Mom,” I say insecurely.

“That’s okay. He needed me to yell at him.” That was the moment where the relationship with my mom changed. We began to draw on each other for agency and support.

~

My mom represents a powerful and influential mentor in my life – someone who showed me how to fight in this system that sees me as a burden; the system where I was supposed to be a good little girl, a compliant girl, who follows along with what everyone wants to do *to* her – not *with* her. My mom was able to show me power imbalances in the system, and to empower me to understand myself. I believe that this is where my parents truly shine, still today. This time is so complicated for me. It represents perhaps the first inkling of the medical and the social worlds colliding for me. What happens when there is a thin line? I can’t stay like this, with my bump and all. I know that I will likely die if I stay like this. The instinct for my parents to fight is profound. I sometimes do not know if I should fight along and be a good patient or if I should let go. I might be okay living like this?

~

I beg and plead with the OR team to let me take my Yin Yang ring into surgery, but they won’t let me. They assure me that my mom is going to hold on to my ring and give it back to me

after my surgery. But they don't understand, I need to have the ring on me, my dad told me never to take it off. I don't mean to cry, I feel like the nurse and the anesthetist think I am throwing a tantrum, that I am unnecessarily attached to this object. But the ring means a lot to me. I've researched about the Yin Yang symbol. It is supposed to restore harmony or balance to a person. It takes the good and the bad and makes a person whole. I swallow my tears and try to be strong for my mom. She always cries just before I go into surgery. I tell her that I'll be fine and that I'll see her soon. She hugs me and stands there as they wheel me down the corridor through the "authorized personnel only" doors. Then I don't see her any more.

~

I wake up in excruciating pain. It's the one and only night my mom asks the nurses to set up a cot next to my bed so that she can sleep with me – I know she is worried. "She is in a lot of pain," she says to Shelly. I drift in and out of sleep. I like it when I have Shelly as my nurse. By this point I know all of the nurses and I have figured something interesting out over the past 9 months. When you get the better nurses, then you're not doing so well. I must not be doing well....

"I don't understand," Shelly says. "Her orders on her chart say that she only be given rectal Tylenol for pain. I mean this kind of surgery requires more than acetaminophen." Shelly sighs as my mom asks, "Can I talk to someone about this?"

"No worries, Evelin, you leave this to me." I hear a swoosh of scrubs leaving the room again.

I don't know how much time passes by. It's still dark. My mom lies on the cot next to me asleep.

"Hi Susan" Shelly leans over the bed rail and whispers close to my ear. "I got you something. This is the good stuff." I try to move my head to thank her and a shooting pain runs from my back into my head. "I know, I know, this will make you feel a lot better." Shelly starts to shuffle my IV bags around, the plastic tubing making cling-cling sounds on the IV pole. My mom wakes up and sits up in her cot.

"She's awake" Shelly says. "I got her morphine, am just hanging it up".

"Did her surgeon order it?" my mom asks

"Him? No!" Shelly scoffs. "His fellow is on call tonight. If you ask me he is a total ass. Tried to convince me that these types of surgeries are not painful".

"Unbelievable" my mom replies. "She's trying to climb out of her bed she's so delirious with pain".

"That's why I went to another floor. I know another doctor and I explained Susan's situation and he prescribed morphine for her".

"Oh Shelly, aren't you going to get into trouble for this?"

"Honestly, I don't think anyone would argue with me on this. Even the doctor who wrote this script called rectal Tylenol barbaric."

"Thank you Shelly. You don't know how much I appreciate this".

“No worries, Evelin. Go back to sleep and get some rest.”

Before my mom lies back down in her cot she reaches her cool hand to touch mine. Hand and hand we lie together until dawn.

~

Had they given up on me?

Had I become an experiment?

Was I not human anymore to them?

I wonder whether *they* thought that it was my fault, that all of this was my fault because I didn't work hard to get better. With each failed surgery, I internalize my disappointment when my bump inevitably returns again, and again, and again, and....

~

*November 4, 1991*

*I'm in big trouble at the moment. Exactly 2 weeks after my surgery my back opened up again. I had a lot of headaches and forgot to tell my doctors. I'm going to a CT tomorrow. I hope they don't have to use dye. I have a new roommate. She's going home today. I'm never going to get out of here. I'm probably going to see the new hospital wing they're building in '92. Now I'm again on bedrest. I wonder when I'm going to get well again. Mom said she would get me the board game Mall Madness. Jenn thinks it's stupid. I don't !!!*

*I am getting discharged to a rehabilitation centre. I want to go home but Jenn says that I need rehabilitation. She says that I need a place where I can work on getting stronger, bump and all.*

~

*December 18, 1991*

*I'm very badly off in the moment. Tomorrow I'm going to the hospital again and the doctors are going to drain my back one more time. I hate this so much, in February it's going to a WHOLE YEAR SICK. My dad gave me a Yin Yang ring for luck. Up until now it hasn't brought me any luck but it'll come! Please cross your fingers for me. I spent a few days in the rehabilitation centre. It was fun, finally after months I'm going to school again but that's all gone by tomorrow. I met some nice friends. I'm going to miss them!*

~

*May 24, 1992*

*Well, the ring did bring me luck. I believe strongly in it. I've been fine for almost 5 months. Only 4 more weeks of school, I can't wait. I'm probably going to get long-legged braces because of my legs. They twist too much. I am getting stronger every day, which is good, but my pain, ouch!*

*But it is going to get better, with the new medication it has to!*

~

There is an interesting concept within this part of my life story that it took me a while to tease out for myself: the fact that I made it *despite* professional involvement. When I started to explore Disability Studies as a field, I would come across statements like this:

Regrettably, those disabled people who have managed to accomplish their goals claim to have done so ‘in the teeth of opposition from professionals’ (Campbell & Oliver, 1996, p. 187); ‘in spite of, rather than because of, the involvement of social workers and other “caring” professionals’ (Priestley, 1999, p. 73). This is discouraging. (as cited in Hammell, 2006, p. 148)

This is discouraging indeed, and based on much of my life experience I must say that this statement is partially true. This type of perspective, or the reframing of this part of my life story – from the difficult disaster that it feels like it was, to something that shaped me and my family in unique ways – is not something that I come across in the literature. But this is also where I become torn. As I wrote previously (see Guenther-Mahipaul, 2015), “Some clinicians naturally understand disability as part of the wider social context and are mindful of how their practices and assumptions impact clients” (p. 210). For me, and my parents, Jenn represented a clinician who “... saw opportunities for me in life and she helped shape a vision of these opportunities for me and for my family. I therefore credit clinicians like Jenn... in addition to my parents with making the strongest impact on my self-concept as a *person*” (Guenther-Mahipaul, 2015, p. 204).

Any physiotherapist I meet in my adult life has a lot to live up to. They have to live up to Jenn. It seems funny for me to write this here, but Jenn was/is the epitome of physiotherapist for me. She represents a therapist who was an ally as much as a challenger. She was a partner in my life and I recognized this already at the age of 14 when I met her the first time in the hospital. I was then very fortunate to also have her as my physiotherapist as a rehabilitation inpatient, then outpatient, and for several years as follow-up coaching. If she were to read this now she might be surprised to hear these words, but perhaps I think she would not be. We became very close in the six years that we worked together. She is a big reason why I succeeded at university and she is always in the back of my mind when I think of rehabilitation as a practice.

As I write this I wonder whether my words read like I have a bit of an infatuation with Jenn. But this would be an unjust interpretation by the reader. There are things that Jenn did, and things that she modelled for me that shaped my self-concept as a person just as much as my family did. It is therapists like Jenn, perhaps, that I struggle with when reading the Disability Studies literature. Rehabilitation professionals can be our allies. They can do good in our lives. But this distinction has to be made with a little bit of an open mind. Just because a rehabilitation specialist does good in our lives does not mean that their perspective matches our own when it comes to disability. The difference between a clinician as a resource versus an expert is something I am keenly aware of (Finkelstein, 1991). There were many moments when Jenn, like my parents, was willing to increase my power on one hand and weigh how much of her power she had to reduce on the other (Priestley, 1999). As an occupational therapist today who understands the purposes behind client-centred practice, I respect Jenn for fighting for me like



this. However, the system had also gotten to me. At 14 I had become quiet, passive, and determinedly *compliant*.

I can appreciate Jenn's struggles within the system today. Within a system where people work within and are assigned roles and interests, it is difficult to determine whether therapists do in fact relinquish some of their power within practice (French, 2004b; Hammell, 2006). Jenn worked hard to meet the goals and expectations of my surgeons, and admittedly also the goals of my parents. Just as much as my surgeon(s) struggled with my changed abilities after all of my *failed* surgeries, how absurd is it for me to write them as such here – *my* failed surgeries?

~

“Oh God” my mom cries as she reads this part of my story. “I’m so afraid that we failed you. We failed you as parents.” I look up from my book and move over to the table where she is sitting, my narrative laid out in front of her on the table top. I am struck by what she just said and appreciate the amount of growth that I have had working on this thesis; the knowledge that I have gained, to be able to always look at multiple truths. I understand that my mom, sitting next to me and my story, is still situated in a time and frame of thought where it was expected for my parents to search for strategies to produce normality in my (our family) life (McLaughlin, 2012).

The reality for many disabilities is that medicine is part of life. The social and political implication of this for disabled families is to ensure that this involvement with medicine does not become the key factor in shaping the person's life and identity (McLaughlin, 2012, section 3, para 3).

What I find interesting to understand as a disabled adult today is that my mother (who was with me in hospital every day) was caught in a situation where just like me, she was subject to stereotypical assumptions by my healthcare providers of what a mother of a child like me should be like. We were in an environment where I was pitied, yet we ‘coped’ rather well.

Mothers, in particular are assumed to want to be involved and to participate fully. But they can also become “choosier about medical interventions and appointments... in doing so they seek to reclaim their child and provide a space for a range of the child’s development to occur more freely” (McLaughlin, 2012, section 3, para 4). My mother was particularly good at keeping our family life strong. She participated with me in hospital, but then she also went home each night to my father and my brother. I credit her wholeheartedly for her ability to “redefine [our] family life in the context of disability” (McLaughlin, 2013, section 3, para 4).

“We were all alone” my mother says to me.

“I know Mom. But you know that I would never say that you failed me”.

“I don’t know.” My mom runs her hands through her short white hair. Twenty-five years later I understand that my story has brought alive again the insecurities – *that* time.

“What would you say if I felt that a lot of this was also the failures of the surgeons?” My mom looks up at me. She is thinking.

“It’s okay to say that, Mom,” I continue. “You felt alone because they failed us. It’s like you and dad always said, that all you could do was follow their advice. They were supposed to know what to do and you needed to trust them to do the right thing.”

“Yes”

“I’m reading an interesting chapter right now that talks about how much pressure there is on parents in our western world to raise the perfect child based on what the medical experts say.”

“Really?”

“Yes, and you know what?” I grab my textbook and open it to the chapter I was just reading.

“Let me read you this sentence and you tell me what you think.”

*“All parents in the West are under a heightened gaze through increased levels of medical advice and guidance on how to raise perfect children.”* I pause to give my mom a moment to digest the first part of the sentence. Then I continue to read the conclusion: *“The more this is emphasized and wished for, the more parents of disabled children and the children themselves are constructed as failures.”* (McLaughlin, 2012, section 3, para 2).

“So this is what this Disability Studies field says?”

“Yes. Sometimes it’s okay for you to see things as they were. You don’t have to blame yourself. I don’t blame you. But I am kind of mad at the system back then. I’m actually kind of angry now that I think of it”. I walk into the kitchen to grab myself a glass of water. My mom gets up from the table and joins me in the kitchen.

“Thank you for writing this for us, Susan” she says and takes me into a tight embrace. “You have given us a voice”.

~

“I would like for Susan to have a wheelchair so that we can go on outings. Her cousin is coming to visit and there isn’t much that we can do with Susan outside of the house.”

“I understand, Evelin,” Jenn replied “but I don’t think this is a good idea. Kids like Susan stop walking when they get a wheelchair.”

“Not Susan,” my mother argued. “She isn’t like other kids. She needs to get out. She’s going to need a wheelchair when she goes back to her school.”

That is the only challenging memory my mom and I have of Jenn. It is perhaps the one time that I observed her to slip into the role of *gatekeeper* (Hammell, 2006) where she felt that she was acting in my best interest, but perhaps lost sight of the social dimension of rehabilitation over the personal first dimension of rehabilitation. I find the paradox between walking and wheelchair an interesting one in my life and in my profession. The resistance to wheelchairs as agents of freedom – that we as disabled people view them to be, versus mobility devices, as rehabilitation professionals like to call them – can create significant tensions for us. When rehabilitation professionals mistrust their clients instead of working with them as partners in their own care, common problems can easily arise and can breed mistrust, can become counter-productive, and can often lead to self-fulfilling prophecies. Rehabilitation professionals thus are viewed as becoming oppressive, and perhaps focused on dictating the lives of clients. I often bring it up in teaching as a question: *What would you do here?* I find a quote from Karen Whalley Hammell (2006) highly provocative:

In light of the reality that the rehabilitation professions perceive themselves to be altruistic and to be acting in the best interest of their clients, I have

been advised to avoid provoking resentment and hostility by contesting these beliefs and to focus instead on exemplars of good practice that might enable our professional self-images to remain intact. To do so, however, would be selectively to ignore the biographical reports of former rehabilitation clients, research evidence and the critiques of disability theorists... It must also be acknowledged that locating evidence of excellence *from clients' perspectives* is inordinately difficult. (p. 148)

Jenn did end up prescribing my very first wheelchair. It was red and sporty and awesome. I understand why she struggled with this decision. I hate to admit it, but many of us kids with spina bifida do stop walking when we get *that* first wheelchair. The wheelchair is just so much easier. It was so much easier for me to get around in. In that sense we get labelled and categorized by our health care providers who then “fail to see that [their] definitions are instruments designed for specific purposes and start to think of them as universal and all-purpose” (Bickenbach, 2012, Section 1, para 6).

There were a lot of changes for me physically at the age of 14. Although I was born with spina bifida, the complications of this tethered spinal cord resulted in my going from a girl who walked with a limp needing no crutches and leg braces to a girl who needed crutches and leg braces to walk even a few steps. When I was able to go home, I often would crawl in the house on hands and knees. My parents made the house as wheelchair friendly as possible but there were areas I couldn't get the wheelchair to go. Crawling, for me, was an easy way to get around. And it also kept me moving. I could carry things, and I could get places on my own without

worrying about falling. Crawling was a kind of freedom for me that walking just didn't offer. For my parents and close family and friends my crawling represented a shocking defeat to what I was going through. "I will never forget when you crawled at home," a family friend wrote in a letter last year, "the image of your crawling is something I cannot shake from your childhood".

Jenn admitted to me a few years later that I proved her wrong. Jenn did hold a considerable amount of power in this situation. She could have said 'no' to my mother's request for a wheelchair. Reflecting back on this time, Jenn likely did believe – as many physiotherapists do – that she knew what was best for me in terms of mobility (Jorgensen, 2000). But where Jenn excelled was in talking to me about my social and cultural life and understanding that, first and foremost I was a teenager with *surging hormones*, as she would tease me, and someone who had important goals in life (Jorgensen). But what Jenn also did was to teach me about my health, to help me understand my pain, and to help me understand how to solve some of my health concerns. For example, Jorgensen (2000) writes that "Physiotherapists must work at all levels to establish a practice in which the patient's own understanding of his/her situation, body, and health get a far higher priority" (p. 114). Again this is an example of Jenn handing me power on a platter. And I took it. I didn't stop walking when she prescribed my first wheelchair. In fact I worked on walking. But my walking was far from easy and normal. My pain from my spine interfered with everything Jenn and I tried to work on. Today, I believe that because of the kind of therapist Jenn was, there would have been a strong likelihood that she would have been supportive of Rehabilitation Science, as a field, to change and dialogue with Disability Studies.

~

“You are a physioterrorist!” Mark\* taunted Jenn as we both lay on our backs on the king-sized plinth with Jenn pushing Mark’s bent knee as far as she could into his chest. Although Mark was an amputee, we both had a similar problem. We had tight pelvic and hip muscles. Mark and I had therapy together each day in the afternoon after our science class at school. He’s funny, I thought to myself. That’s funny. But I didn’t feel comfortable saying it out loud.

“You can call me what you like, I’m still going to stretch out these muscles” Jenn grunted as she literally pushed her body weight into Mark’s leg.

“Ugh...” he moaned, “seriously, this is child abuse! I’ve got to call Children’s Aid on you!”

Jenn sat back on her heels and laughed out loud. I laughed out loud with her. “You think this is funny too, do you?” she winks at me while she wipes her brow with the back of her hand. “I’m doing all the work here people while you’re just laying around”.

“Hahaha,” I snort, “do you want us to sit on you for a change?”

“You’d like that, wouldn’t you? Okay you can call me whatever you want. You guys are such complainers”. Therapy may have hurt a lot but it was also fun. Jenn called Mark and me her Europeans because I was from Austria and Germany, and Mark from Greece. Although I did not speak with an accent I made typical German grammar mistakes that she found hilarious. For example, she always corrected me on my use of “carrying my hair open”. That’s how you say it in German, “but here you say that you wear it down” she would tease. That absolutely made no sense to me.

She came over to my side of the plinth and started leaning her full body weight on my right thigh. This was not my favourite thing to do, but it helped with my pain. When Jenn was able to stretch out the tight muscles I could stand with a little bit more flexibility in my lower spine. But every day it was the same thing. Jenn stretched and stretched and stretched my hip flexors but nothing changed. I couldn't stand straighter, I didn't walk better. And I was nearing that dreadful clinic date, the date where I would see my surgeons for the first time after being discharged from the hospital and admitted into rehabilitation. It felt as though Jenn and I were both under pressure to pass some kind of test. I felt bad for Jenn because I knew she worked very hard with me on my mobility, but I had plateaued. I wasn't getting better, I wasn't getting worse. This was the way I was. And I felt this pressure. Somehow Jenn had also changed in our interactions; she was quieter, somehow different. That night I lay in bed lost in thought, pen in hand and my diary open to a new page. Summer was almost here. What was I going to do? I had been in hospital and rehabilitation for almost 18 months now and Jenn told me that I was going to get discharged soon. "So that you can have a nice summer," she explained.

"But I'll see you in the summer, right?" I felt lost. I saw Jenn every day and now I wasn't going to see her anymore?

"You'll still see me, but we both need to take a break for a bit. You'll see, you'll like having a break from me".

That's not true! I wanted to shout, but I stayed silent.

This conversation rang through my mind while I lay in bed. I picked up my pen and started to write.



*May 25, 1992*

*3 weeks to exams, oh no! I hate the tests. I am kind of afraid to go back to my old school because it is so hard. I don't even know if I'm going to manage. My pain is so hard lately that I could cry sometimes.*

*I think Jenn and I are slowly falling on our nerves, I even don't think she likes me anymore.*

*Every time she sees other patients, she is more happy than seeing me. It kind of hurts me but I can't change.*

~

I don't think that Jenn did not like me. Rather it was the contrary. Jenn was beginning to pull back from me a little, no doubt using a combination of clinical reasoning, expertise, evidence, and my own knowledge as her client in shaping the recommendations that she was about to advocate for. All of us – Jenn, my surgeons and doctors, my parents, and most importantly me – had reached a fork in the road. I was committed to working on physiotherapy goals with Jenn, and I remember being very disciplined and independent with my therapy regimen. My father remembers Jenn as being a physiotherapist who could get me to be active, to want to walk and to work on getting stronger. During this time my father certainly reinforced the assumption of normality for me as a goal. For him, the goal of restoring me to normal – to walking – was very important, whether this was an objective goal or not (Gibson & Teachman, 2012; Hammell, 2015). This drive for normality through walking created a wedge between my father and me for most of my teenage years. Although walking was also important for my

mother, she remembers that Jenn seemed to “get me as a teenager. She connected to who you were and what you wanted to do with your life” my mom recalls.

I spent the first third of my teenage years in hospital. Today I appreciate that Jenn had such a big impact on my self-concept as a person – as a young adult – because she worked with me on my self-identity as a teenager with a lifelong disability that had taken a dramatic turn. And what was happening here, while I was journaling about Jenn, was that she had an ability not only to hand me power and to encourage me to take it, but also to *let me go*. Some therapists excel in letting their clients drive the decision making process... even if the decision-making does not fit with the rehabilitation goals set out by the therapist or rehabilitation team (Kontos, Miller, Cott, & Colantonio, 2015). During a time where I was supposed to push boundaries, to break free from my parents’ rules and authority (Erikson, 1950; Thomas et al., 2015), and to find myself, I had landed in an environment where all of this was not an option for me. The more compliant I was, the more I was able to work collaboratively with the rehabilitation team. Rebelling against my parents, surgeons, and Jenn did not seem to be right. I had become submissive, passive, and compliant. In a sense I was the perfect patient. I followed willingly the advice of the rehabilitation team. I didn’t question my situatedness at the time. And what I realize today is that Jenn wasn’t “having any of it”.

How often do we as practitioners want to change something or work on something so that we feel that we can report on an outcome? Were we to report that we will not *intervene* and rather build a person’s sense of self that incorporates abilities and competencies beyond physical function, we would certainly represent the relinquishing of power (Hammell, 2015, 2006).

~

Clinic day arrived and my mom and I waited patiently in the waiting room to see all of my different specialists. This time, clinic day was kind of fun, because I got to hang out with some of the kids I knew from the rehabilitation centre, other teens that I roomed with while I was an inpatient here or that I knew from my time in the hospital. I had made some friends over the past year and a half, and it was nice to see them again and catch up.

I felt kind of nervous about this appointment. My mom sat next to me reading a book while I read a chapter in my Canadian History textbook. My Grade 9 Canadian History test was coming up next week. When they called my name, my mom and I made our way to one of the larger clinic rooms. As I wheeled through the door I saw Jenn and Dr. Mavis\*, the clinic's neurosurgeon standing by the room's large desk, and the orthopaedic surgeon, Dr. Reese\*, by the plinth. A few fellows stood off to the side. I sensed that my mom was taken aback with the number of people in the room, just as I felt. Jenn moved towards me, patted me on the shoulder and then leaned off to the side against the radiator with her arms crossed. *Were they having an argument?* I wheeled up to Dr. Reese. After all this was his consultation room.

"Here's trouble," Dr. Reese teased. He always said that when he saw me. "And what is this young lady reading today?"

"I'm studying for my history test next week".

"This one's always studying every time I see her." He shakes my mom's hand and comes over to me and pats me on my shoulder as well. I reflect how this 'patting me on my shoulder thing' is going around today. "How are you doing, Susan?"

“Oh I’m fine,” I reply and look at my mom who is giving me the ‘*you are not fine*’ glare. In our car ride to the rehab centre my mom had pleaded with me not to say I was fine to my surgeons and asked me why I always said that when it wasn’t true.

“What do you want me to say, mom? I am fine.”

“You’re not fine, Susan!” she complained. “You have a lot of pain, you want to go back to your old school, you’re having a hard time walking. You - are - not - fine”. She said the last sentence with major emphasis on each of the words. My mom and I had these discussions frequently. I honestly didn’t understand why and what she wanted me to say. I didn’t want to wheel into clinic consultations and start to lay all of my troubles onto my doctors.

“But that’s what they’re there for,” my mom pressed on. “They need to know how you’re feeling, they want to know how you’re doing. When you say that you’re fine, they think that everything is good. And then when you come home you still have pain, and trouble to walk, and you have questions. So you need to ask them your questions”. I know she’s right, although I don’t exactly admit this to her in this moment.

Back in the consultation room I noticed that Jenn is rather quiet, which is uncharacteristic of her with the doctors. The atmosphere in this room is so tense that I feel uncomfortable and small.

“Susan, what do you see yourself doing next year?” Dr. Mavis asks me. He pulls up a stool on rollers and sits himself down in front of me. I’ve always liked this about him; we can talk eye-to-eye. He takes my Canadian history textbook from my lap and flips through it. “I remember

reading about this when I was in high school” he laughs and adds “and I don’t want to tell you how many years ago that was”. I smile into his kind face. He knows how to cut the tension.

“Well.” I pause as I think about what I want to say. “I’m going to go back to my old school. To my high school” and looking at my mom I add “and I want to go back to playing the piano and my mom even said that I can work on getting my driver’s license.”

“Uh-huh, hm,” he nodded. “And your school, is it wheelchair accessible?”

I shake my head. My mom steps in: “She can get into the school and the first floor, the gymnasium, and many of the classrooms. Her grade 10 classroom is upstairs but I will help her. She can walk steps and I can carry her wheelchair”. Again there was silence in the room.

Jenn steps forward and adds, “I have recommended that Susan perhaps transfer to a wheelchair accessible high school. But Susan is adamant that she return to her class. Her friends. She’s missed half of grade 8 and all of grade 9.”

Again silence. Jenn continues to speak.

“Susan and I have talked about walking at school. I feel that she should be able to walk and not need her wheelchair”. I’m really mad at her for saying that. But I don’t say anything. I just stare at my shoes in my footrests. She won’t get off me with this walking thing! I look at Dr. Reese. My mom and I talked about Dr. Reese and Jenn in the car today. I feel like my walking is not good enough right now to walk at school. And I’m mad because no one seems to understand how hard walking is for me except for my mom and Dr. Mavis. He gets that I’m in pain. Walking hurts me right now. I just want to go to school. Mom thinks that Jenn is trying to please Dr.

Reese. That's why she wants me to walk. "Just don't listen to her" my mom encourages me as we talk in the car. "You're leading a happy life and you should be happy".

This clinic appointment just seems horrible....

"I feel that Susan should go back to her old school and that we should give her time to settle into high school life." Jenn concludes her thoughts by adding, "She needs to stop being a patient and start being a teenager. Coming to therapy 3 days a week is doing her no good at this point". I'm stunned. Absolutely shocked. What? But I like coming to work with Jenn. My mom and I sit next to each other while we watch a heated argument unfold.

"I disagree with this plan. You discharge her from therapy she'll lose everything she has gained."

Dr. Reese paces the room.

"She hasn't gained anything. As a matter of fact she has lost a whole lot" Dr. Mavis interjects.

"She needs to keep up the stretching and strengthening routine. She's not going to do that without coming here. If she sits in her wheelchair all day long she will get contracted and stop walking all together," Dr. Reese argues.

"She needs to live a little, be a kid..." Jenn tries to explain but is cut off by Dr. Reese who throws his hands up in the air and sternly says, "She needs to be motivated to walk. She's going to lose everything we've worked hard to get".

My mom and I exchange fleeting glances.

"With all due respect, Roger" Jenn addresses Dr. Reese by his first name, "this is one of the most motivated girls I have ever met in my life. She has been working hard to regain all of the things

she has lost. We have been working hard together. And on top of that she has caught up most of grade 8 and all of grade 9 schooling in 5 months while going to therapy, so that she can go back to her old school and join her former class. If you cannot see that she is the very example of motivation I don't know what to tell you." Jenn shrinks back into her corner. My mom and I exchange glances again. This is a very uncomfortable environment at the moment.

"She needs a break from this centre, Roger." Dr. Mavis speaks softly into the silence. Dr. Reese looks my way and I reluctantly nod in agreement. My mom pats my hand with her hand on top of my thigh.

"This girl is 16 going on 37." Jenn speaks again as the atmosphere lightens up a little. "Do I think that she will lose the functional range of motion we have gained? Probably. I feel like I'm forcing her in therapy. I know her now, quite well. And I can tell that she is burnt out. She's had enough. She needs to reboot".

My mom and I leave the clinic room together with Jenn, who takes a deep breath.

"Wow, Jenn." My mom is the first to speak.

"I know," Jenn laughs. She walks across the hall to a few empty chairs and signals my mom and me to join her. I don't know if I should be happy or cry.

"You know that I like you very much, Susan?" She grabs the front part of my wheelchair frame and pulls me closer.

I nod, holding back tears.

“It’s time for you to live a little. You’re more mature than I am. And you are so smart! You’re going to go to university one day and I’ll help you get there. But for now you’ve got to live a little”.

“But I’m okay with coming to therapy” I say.

“I know you are,” she smiles. “That’s what makes you so amazing to work with. But you have to focus on other things too. I would love to see you go to a party for change”. I don’t know if I like that idea. Parties are just not what I’m into right now. As if she reads my thoughts, Jenn says, “You are so mature that I’m afraid that you’ll miss out on your childhood. If you can’t party for you, then at least go to one for me, okay?” I start to laugh. I notice my mom is smiling too.

“Tell you what, you come back when you are ready to come back”. I look up at her.

“That sounds like a plan, Susan” my mom agrees.

“I’m not going anywhere. I’ll be here when you’re ready to come back”.

~

And I did go back after a year off, a year in grade 10. I went back when I could drive myself to my own physiotherapist appointments with Jenn. Today as a disabled woman and a clinician, I understand that Jenn gave me an incredible amount of power that year, and perhaps this was the best gift that anyone could give me for my 16th year. She told me a few years later how Dr. Reese and her argued over the decision to discharge me for a long time.

“He was outraged with my opinion.” She told me the story during one of our PT sessions.

“Really?”



“Oh yeah! I think I almost lost my job that day.” I look at her with shock and I feel a pang of regret that I caused her that much trouble. “Don’t you worry about that. I knew what I was doing”.

I don’t know if as a clinician today I would have as much courage to advocate for a client as Jenn did for me. But having lived through a real-life example of it, I intimately can appreciate the power of client-centred practice. Client-centred practice may represent a convincing answer to the tensions between rehabilitation practices and Disability Studies critiques, but the meaning of client-centred practice can potentially mislead clinicians (Guenther-Mahipaul, 2015; Hammell, 2006; Hubbard, 2004; Phelan, 2011).

Client-centred models still locate disability within the person and his/her body, whereas a Disability Studies perspective clearly situates disability within society and calls for accountability at a societal and not individuals level. A clinician who can reflect on client-centred practice at a societal level is one who is aware of how society constructs disability, and how in his or her practice he or she may unintentionally perpetuate negative disability perspectives. (Guenther-Mahipaul, 2015, p. 203)

Jenn could have gone along with the pursuit of normality by the doctors, and the tension between my parents wanting me to reach normal while still protecting my sense of self and the family unit. Jenn was one of the first clinicians in my life who showed me that I had a choice, that I didn’t need to go along with the hierarchical authority that wanted to make decisions about my body, and about my life.

If it had not been for Jenn and my parents showing me how to advocate and speak up for myself I would have continued to be the compliant teenager, the patient who is good and motivated, the patient who never says ‘no’, the patient who is *fine*.

At 18, as I prepared to graduate from childhood rehabilitation into the adult world Jenn said to me one day:

“You need to become a therapist and I think you should work here one day”.

“No way!” I laughed. The idea of working here, of being a therapist seemed outrageous to me.

“I’m going to set this up for you. I’m going to see if you can volunteer with some therapists and get some shadowing experience”. I lie on the plinth and continue counting my exercises. One of the Speech Language Pathologists pops her head into the treatment room.

“Hey Jill. What would you think about Susan doing some shadowing with you?”

“Sure, I’d be up for that” she replies. “Give me a call”.

I’m stunned.

“Excellent” Jenn laughs as she returns to me on the plinth.

“You really think I could be a therapist?” I ask Jenn.

“You can be anything you want to be.”

“Wouldn’t that be weird though?” I have to admit that I am excited by the idea.

“You need to disrupt things a bit.”

“I’d feel like such a shit disturber.”

“You are a shit disturber. You just wait. Now get on with the counting”. We high-five each other and I go back to my exercises.

~

I am still a compliant client within my therapeutic relationship. But today I look for a partnership in this relationship. Partnerships in my care are highly motivating for me and I seek out a therapeutic relationship built on partnership without compromise (even when this means that I go a few months between care providers). I have also never reflected on the impact that some of my past healthcare providers have had in shaping my self-concept as a person. Some therapists, like Jenn, had as much of an impact on me as my parents have. This is powerful for me to recognize. Especially since some therapists like Jenn, for example, may not realize how skilled they are in client-centred care, and how skilled they are in helping clients with a perspective that is oriented within the social as well as personal dimensions of rehabilitation. It was important for me to share client-centred practice and to talk about my experience with Jenn because as a clinician I recognize today that client-centred practice cannot necessarily be taught. This practice develops with reflection and clinical experience. Some therapists connect to client-centred practice more easily than others do. Jenn gave me control and power within our relationship. But more importantly she also modelled it for me. Finally, she encouraged me to take some of that power for myself. She showed me that as a client I was allowed to take some of my power back. I thank her for this gift.

~

Next I shift gears in order to explore the concept of ableism. I did not expect my narrative to take me in this direction. However, ableism continues to emerge prominently throughout my life. I have chosen to unpack it in the following chapter.

## **CHAPTER 6:**

# **“I Walk, Therefore... I am Abled”**

Disabled people may want to problematize the ableist assumptions that underscore their interaction or meetings with able-bodied people. But we are unable to articulate or communicate our position because often we have to attend to our disability rather than voice our opinion. At other times we are too tired... In any case, others interpret disabled people's silence as tacit agreement.

—Overboe, 2009, p. 82-83

We share the 'code' and readily understand that able-bodiedness is to be assumed unless we are specifically told otherwise. That we understand this, it might be argued, is because ableism is institutionalized in the very fabric of our culture.

—Hammell, 2006, p. 83

In my introduction, I commented that I hope that this body of work will shake up some of the taken-for-granted notions of normalcy that we so quickly come to accept within society and within the rehabilitation sciences. I then added as a second thought, that, as a person with a difference, I am often stigmatized by normals, as termed by Goffman (1963). Ableism, like normalcy, follows me throughout my life. But I have only recently discovered that I have internalized ableism as part of my overall worldview on disability. I choose to talk about it within the latter part of my thesis because I have begun to grapple with ableism as a concept in the recent part of my life's journey. And I have come to understand that ableism, like normalcy, assumes different faces in different situations.

~

On September 16th, 2014, I parked my white modified wheelchair-ramp van in my designated wheelchair parking spot behind my university faculty building. As I turned off the van's engine, silence engulfed me. I felt as though my heart tried to beat out of my chest and I swallowed by reflex. I looked out over the parking lot and watched students rush by my car as they walked to or from their places of study or work. This was a hot September day and felt more like summer than the approaching fall. I regretted wearing a black dress, leggings, and a cardigan. As long as I sat in my van, I felt safe. Sitting in my car on this sunny day I felt just like everyone else on campus: a student, staff, researcher, professor. I turned in the driver's seat and stared into the back of my van, glancing at my wheelchair, which I call Ti, and my crutches I call Stix, leaning up against the backrest. For a split second a voice calmed my beating heart: "You could just take Ti". Going to teach in Ti would be normal for me. I seriously considered it; seriously wanted this road out of my plans to walk into the university building where I have

taught and studied for the past seven years. “No!” I talked out loud into the silence. “Susan, you can do this. You’ve prepared for this for eight months now, you can do this. And you need to do this because if you don’t walk today you’re going to pay for it tomorrow”. I knew that if I sat all day long in my wheelchair and in my car I would be stiff and in quite a bit of discomfort for a few days afterwards. I didn’t much look forward to those consequences. My heart started to beat again, peaking my nervousness and anxiety as I thought about leaving the safety of my van. “You can totally do this,” I said again.

I remember the day that Derick drove me home from the hospital after my surgery. It was a 2 1/2 hour trip and I sat on the back seat with Ti turned around so that I could rest my newly operated leg on the seat cushion. I remember that for almost three months after my surgery I couldn’t sit in the passenger seat every time we traveled to and from appointments. What would I look like, walking at school today? Would people see that I walked differently?

Before my surgery I felt like people could see that my spine and legs did not look and move normally. I walked with a cane in either hand, with my right foot rotated out to the side, my round and misshapen knee joint buckled ever so slightly with each step and with the weight of my upper torso. I went into my surgery with lots of rotated angles. Looking down onto my legs, I could see my left leg looking straight and aligned. But my right leg was rotated so much that I would see the inside of my thigh and the back of my knee. For me that was how the ‘front’ of my right leg always looked. When I awoke from surgery I saw two straight legs, and two knees. Lying in bed my knee was shaped like a knee. Both of my feet pointed straight up, parallel to each other. I looked, dare I say it, ‘less misshapen and disfigured’. This thought startled me



because I had never thought about what I was going to look like before the surgery. I had focused on reducing pain, and helping my 36-year-old body, right leg knee and hip, make it another decade.

It was so odd, that first day after my surgery. Dr. Smith came in and said to me, “I rotated your leg 40 degrees. That is the most I have dared to do. But you needed that much.” Looking at my leg, it felt alien to me. I kept studying this alien extremity. So drastic was the change that I took a picture of this *straightness* and sent it to family and friends with the caption: “I’m doing well, look at my new leg”. How absurd was this caption? My leg was still my leg. Was it a better leg, a straighter leg? Was it going to be a cooperative partner in my goal to walk? Was it going to make me happier?

~

My ‘new leg’ caused me to grapple with my ‘self’ on a theoretical level. I was theoretically troubled. I wrote quite a long journal entry on September 3, 2013. I started by writing: “*I feel guilty about my "new" leg.*” And I would like to explore this journal entry through the literature, as I understand today the undertones of normality and ableism that troubled me back then.

*It's a feeling I cannot put into words, because my leg is not new, it is perhaps more aligned in a way it is supposed to be. My leg now has the mechanics of what a human leg was evolutionarily designed to be like. This guilt, I realize, may more resemble the ideal that my "look" in terms of ambulation, balance, and standing approaches that of "normal" and this is something I'm not sure whether I should be happy about. The look, although it did*

*bother me before, was not a problem for me. It was who I was. This is what my leg used to look like. But now that I see my new leg and how my spine, my pelvis and hip and knee and ankle are approaching “normalcy” I am happy about how I look. It's not a vain thing for me, but it signals to me that I perhaps did have some challenges with my body image.*

*I got ‘fixed’ this summer. My surgeon fixed my crookedness, my misalignment, my abnormal stature...*

Can I deny that my surgery had an aesthetic outcome? No. Did I choose this surgery as an “aesthetic surgery”? No. The thought truly never crossed my mind until I saw the completed work. When you grow up with a disability, the normalizing discourses of reconstructive surgery hold more power than reconstructive surgery’s twin: cosmetic surgery (Garland-Thomson, 2013). To do something for the sake of normality, “...the political aim of privileging normalcy, expressed in the language of the body as natural and conditional” (Michalko, 2009, p. 105), is an ingrained ableist assumption in our culture. However, “...cosmetic surgery’s twin, reconstructive surgery, eliminates disability and enforces the ideals of what might be thought of as the normalcy system. Both cosmetic and reconstructive procedures commodify the body and parade mutilations and enhancements that correct flaws to improve the psychological well-being of the patient.” (Garland-Thomson, 2013, section 5, para 4). Viewed through a feminist and disability studies lens, people with disabilities and appearance impairments can feel pressured to “... become what Michel Foucault calls ‘docile bodies’ (1979, p. 135). The twin ideologies of normalcy and beauty posit female and disabled bodies to be shaped infinitely so as to conform to a set of standards called *normal* and *beautiful*.” (Garland-Thomson, 2013, section 5, para 4).

I was socialized into a world where reconstructive surgery is normal, and in fact desirable. My desire to have my reconstructive surgery emerged from Dr. Smith's argument that my leg was not normal. I find comfort in Garland-Thomson's (2013) conclusion, "I do not want to oversimplify here by suggesting that women and disabled people should not use modern medicine to improve their lives or help their bodies function more fully. But the critical issues are complex and provocative" (section 5, para 9).

*Sept. 3rd, cont'd: I cannot remember ever wanting to look normal as a little girl. But my feelings of being different had more to do with the objects that I was using. As far back as I can remember I wished that a fairy would come and grant me a wish with her wooden magical wand. My only wish was to be able to walk with "klick-klack" shoes and my obsession with shoes ... normal shoes ... still persists to this day. My feet never fit those klick-klack shoes; my ankles could not stabilize my body in those shoes. I wanted to be able to wear the shiny white Mary-Jane shoes that all of my classmates wore in those early elementary school years. They were the shoes with the black hard sole on the heel that would create a klick and clacking sound as they carried their feet down the school hallways. But I could simply not walk in those shoes, especially with my right foot since my leg, knee, and ankle always made my foot and ankle prone to rolling over. It's a miracle that I never seriously sprained my ankle while walking. I should probably thank my mother for always putting me into sensible footwear... no matter how much I didn't think that they made me look normal. Even today, Birkenstock are the only shoes that I can wear and I proudly wear them (although even with this brand I am forced to stick to the types that are*

*made for normal wide feet that can fit my plastic ankle foot orthoses). And... Birkenstock are the one shoe that make a clog-type sandal, and I to this day love the look of clogs.*

I think about the one time that my mom did give in to my shoe fetish and bought me a real pair of clogs when I must have been in grade 2. I still have the left tiny white leather clog today in my glass cabinet by my bed, for my left foot. The right clog has been missing for almost three decades. Recently, my mom admitted to me that my father feared that I would trip and break my leg. My right clog simply disappeared one dark night, into our fireplace. She remembered how much I cried when this happened. Oh, how much I loved those clogs!

Why was I so attached to shoes? Because there were objects in my life that connected me in a fundamental way to normalcy, objects that reinforced the normal state of moving, looking, acting, ...belonging. Many Disability Studies scholars critically analyze and counter the cultural rules and mandates that make *normal* and *beautiful* so important in our Western society (Garland-Thomson, 2013). Already, as a little girl, I struggled with how I was going to fit myself and my difference into the cultural values of normal and beautiful. For me, shoes meant normal and beautiful.

Perhaps this is the place and time for me to grapple with my connection and identity with my adaptive devices? When walking became increasingly hard for me as a teenager, I wished that I could have crutches to help me walk. But the idea of crutches also meant that I could imagine a fit with my identity; with me as *disabled*. Crutches meant that I could keep up, but crutches and later my wheelchairs also signified my difference (Linton, 1998). It could be

viewed as “a matter of semantics” where I connected to, rather than depended on my mobility devices (Gibson, 2006, p. 187).

It is here where I find myself living in an ableist world. What makes my tension between walking and wheelchair so incredibly difficult is the fact that I can do both, and I can do both well. My choice to use both modes of travel for different purposes throughout my everyday life make the ableist discourses around me so much more challenging. How often do I hear: *Why do you use a wheelchair when you can walk?* Or, people will gasp when they see me step out of my chair and walk off with crutches. I can read their confused expressions as they try to work out what I am doing; to work out whether I am *allowed* to do what I am doing. I shake up their taken-for-granted notions that it’s better to walk than to use a wheelchair. But what is also of interest is the matter-of-fact understanding that once people are stuck in a wheelchair, they’re not going to get out of them again (Linton, 1998). So split are these ableist assumptions that they make me uncomfortable in my own identity (Overboe, 2009). I am in a constant spiral of being observed. *Will she overcome her disability? I wonder how she will do that?*

When we overcome our disabilities, as in the case of “disabled heroes” (Wendell, 1989, 116), we necessarily feed back into this loop by not validating our previous sensibility and by accepting the great equalizer – normality, the benchmark for humanity. (as cited in Overboe, 2009, p. 81)

*Sept. 3rd: cont’d I write this down as a way to illustrate the complexity of what normal means to me and how conflicted I can be – even still in this day and age – about what normal means to me as a woman who has always been “normal as disabled”. It is*

*something that separates congenital from acquired disability and it is worth writing about this. And my recent experience with this surgery... that has made my legs look more normal... has brought out these thoughts in me again as I am able to wear shoes that I usually couldn't because I can now walk without a lift under my right leg and this has been a huge gift for me.*

*As I learn how to walk again, however... I will have to come to terms with what these feelings of guilt mean for me...*

Almost two years have passed since this journal entry, and these feelings of guilt continue to surface regularly. Perhaps this guilt represented my anxiety the day that I planned to walk for the first time at the university? Perhaps I felt guilty because my everyday disabled life shakes up the social and cultural rules society has for tolerance (Garland-Thomson, 2013). In a sense I threaten society's rules for disability, in a culture that expresses reduced tolerance for human variation and vulnerability (Garland-Thomson, 2009). I am not blinded to the fact that people would more likely flock to admire me for walking and thus having reduced my physical and dysfunctional flaws over focusing on the social systems in dire need of fixing. *That is ableism.*

~

No matter how much I try to resist society's normalizing rules, ableist assumptions, and undervalued disability identities, "...the temptation to be safe and fall back on the familiar ability/disability continuum and its understandings is seductive" (Overboe, 2009, p. 84).

"I don't understand," one peer remarks when I explain my thoughts about walking and disabled identity in relation to my thesis work.

“You mentioned that you identify as disabled, and that using your wheelchair matches that identity. But wouldn’t you say now that you walk at school, that you are less disabled?”

I take a moment to reflect on what my colleague has just said.

“What about my walking at school with crutches makes me less disabled than using a wheelchair?”

We all laugh uncomfortably as my words sink into the thoughts of the people in the room.

“That’s interesting,” my colleague concludes. “I haven’t thought about it that way”.

I write down what she just said because I hadn’t thought about it that way either.

~

I first dabbled with the idea to walk at university with my physiotherapist, James\*, eight months before today, in January. Back then, September seemed distant, with lots of time for preparation and planning. We talked about it quite a bit, James and I. We both created a solid plan. Tuesdays and Fridays I would walk on the half-days I taught because I only had to walk to and from one room on one floor, but on the busy full days of meetings, research rounds, and networking I would bring my wheelchair into the building. My wheelchair made me more independent and gave me the freedom to carry more items and keep up with the busy work pace.

“I think this is a very reasonable plan,” James said to me at one of my August appointments.

“Why don’t you return in October so you have time to try this out?”

I felt safe with James because I could be myself. I could ask him any question about my recovery and my rehabilitation, any question about my body and how it worked. James patiently

addressed my ‘how will I do this?’ fears. And this day I remember how I came about finding him. Recently married, and having moved to a new city, I found myself looking for a new holistic health care team closer to my home. After my surgery I was pressed to find a new physiotherapist in my new home town. My in-laws recommended a PT specializing in sports injuries and reconstructive surgery rehabilitation. I was looking for a PT with whom I could establish a long-term therapeutic relationship. I sent an email ahead to explain my disability and surgery and inquired whether I would be a fit with the practice. “Absolutely” came the reply, “looking forward to meeting you”.

When I called the office number a warm and friendly voice greeted me on the other line. I explained my situation and my surgery and inquired about an appointment to meet the physiotherapist and discuss the protocol.

“Are you always using a wheelchair or just now because you had surgery?” the receptionist asked me. I replied, “I have spina bifida, so yes I use a wheelchair regularly”.

“Oh” she said over the phone.

“Why, is this going to be a problem?” I expected her to make an apologetic comment about inaccessible washrooms or missing door openers. Instead she said, “Well, there are quite a few steps up into our building. Can you walk steps okay?”

My mind came to a jolting halt. Stunned, I replied, “No, I just had major surgery and I’m under restriction. I’m not allowed to walk stairs yet and I couldn’t even if I wanted to the way I feel now”. Tears welled up in my eyes. My face flashed hot. Disappointed, I thought through my



options. This was not going to work. I felt hurt. In a state of disappointment and hurt feelings, acute pain, and medicated exhaustion I began to cry on the phone.

“How can that be?” I sobbed into the phone. “How can it be that you are a physiotherapy office and you are not wheelchair accessible?”

“I’m so sorry” the warm voice tried to comfort me. “I really don’t have an answer for you. I wish there was something I could do”. I could hear in her voice that she really did not know what to say. I empathized with her helplessness but at the same time felt outraged. As I cried over the phone, apologizing to *her* for *my* emotional reaction to the inaccessible office, she said,

“It’s just that we don’t have that many parking spots, and to put in a ramp would take away quite a few parking spots from our patients.”

Although I understood that she tried to explain why I could not enter her office space, her words fuelled the flames of my hurt feelings. In disbelief, I took a deep breath and somehow mustered the energy to thank her for her time and hung up the phone. I sobbed for a few minutes, feeling robbed of my choice to see this PT. “Well, this PT just lost herself an awesome patient,” I mumbled to myself. I wanted to write someone, to shout out to the world of the injustices of this phone call. But instead I sank back into bed, slept and waited until my husband arrived home from work.

“Why don’t you call the physiotherapist close to our pharmacy?” he encouraged me. “I was there today to pick up your surgical dressings”.

“I just want a good physiotherapist” I whined to him as he crawled onto the bed and took me into a tight embrace.

“I think this guy might be good,” he said. “And do you know how I know this?”

“How?” I looked at him.

“Because I asked one of the staff at the pharmacy, ‘Do you trust him?’ and she said back ‘I trust him with my son’.”

That’s how I found James.

~

Ten years ago I might have shrugged off this experience as normal, as an everyday encounter when you live the disabled life. It happens to me all the time. I meet up with physical obstacles and barriers all the time within my environment (Imrie, 2004). And I do identify with Overboe’s (2009) statement that I am often either not able to, or feel up to, fight for how I see the world because I am either dealing with my disability or other times am too tired. I also full-heartedly know that if I do not fight, people feel that what they are doing is okay – the norm. I couldn’t help but feel that through this interaction, by the mere fact that this physiotherapy office was wheelchair inaccessible, that as a disabled woman I had lost out to *normal* clients and their parking spots. My entering this clinic was not considered a “reasonable accommodation”, but helping me “...strive to ‘correct’ the disabled body, to produce corrected bodies that fit in with the existing shapes and expectations of non-disabled space” seemed more reasonable (Hansen & Philo, 2009, p. 260).

Now, I could tell you (in my optimistic nature) that things worked out for me because James was a better choice for me overall. And I could also tell you that I heard six months later, from my in-laws, how badly the PT felt for having an inaccessible office. But feeling bad, and doing something about why you feel bad, are two very different things. I now know that the difference is a political choice. You can be a therapist who keeps going with the status quo, or a therapist who is going to do something about changing that status quo. Both are political decisions. Either way you pick a side.

The fact that this experience is fraught with ableist assumptions has also not escaped my reflections. Mackelprang and Salsgiver (1999) define ableism as "...the belief that disabled people's differences make them inferior; and those social practices resulting from this belief that privilege "normal" ability and serve to marginalize disabled people and to limit their opportunities" (as cited in Hammell, 2006, p. 203). This physiotherapy clinic, and the rehabilitation professional running this clinic, were orientated towards implementing rehabilitation practices, not inclusion (Titchkosky, 2009). What surprised me the most about my encounter with my phone conversation with the secretary was her assumption that I was *abled*. Throughout this exchange I felt less human, inferior, lesser than. By its choice not to have access via a ramp, the clinic effectively excludes clients like me, perpetuates ableist assumptions, and sends a clear message to someone like me – a wheelchair user and someone who does not walk stairs – about the clients they *prefer* to serve. Those who work towards a priority of changing the very dimensions of a person that help them better fit within their segregated environments, are those who perpetuate ableist assumptions.

...Adhering to modes of intervention that are focused on changing individuals and avoiding confrontations with the structural and attitudinal barriers that discriminate against disabled people is not only politically conservative but attracts to the rehabilitation professions those people who are more interested in modifying individuals than achieving social justice.

(Hammell, 2006, p. 143)

I cried after the phone conversation not only because I was hurt, but also because this oppressive encounter added another cut to the many deep cuts I have already experienced. I was surprised that a rehabilitation clinic could so actively and blatantly perpetuate this kind of a disabling environment. And I knew that this type of clinic was not going to be an appropriate fit for the kind of disabled lifestyle I lead. I did not want a therapist who was more likely to teach me to walk stairs; I wanted a clinician who could advocate for them to be taken away. Finally, I wanted to choose the services of a clinic that would respect me for who I was and not exclude me because of my type of disability. I cried on that day because ableism in attitude hurts me more than the physical barriers they create.

~

“Okay it’s time to get out of this car,” I encourage myself. I have shuffled through the contents of my grey backpack and thought carefully about what I actually need to carry with me for the three hours I am teaching today. My bag seems to weigh more than I thought it would. I never have to worry about weight when I take the wheelchair. Again I glance at Ti and for a fleeting second am tempted to just jump into my chair. I look at the two water bottles I want to

take with me. Taking an extra bottle will spare me having to walk to the water fountain. Weight of bag? Water fountain? My bag has two side compartments for a water bottle, that's where I put the bottles. I smile as I don the backpack, because my family teasingly calls me Dora the Explorer. It's actually quite fitting I find, but the backpack is perfect for me. I can carry all of my necessities on my adventure I'll call 'walking at school'. I laugh out loud as I visualize me as an explorer. Before I step out of my van I look at the building I'm about to walk into. I have two choices. I can walk a short distance and go into the back entrance and then take the back elevator. But then I have to walk one of the long hallways on the 4th floor past the majority of faculty offices. If I walk a longer distance along the outside of the building I can enter on the main floor. "There's a washroom right across the entrance doors," I problem solve. "You just walk the long way now and then go to the washroom right on the first floor". Resolved, I begin to make my way, step by step.

It's hot, my heart is beating fast, my pelvis and lower spine are very tight from having sat in the car for over an hour. My first few steps do the opposite of what they should, they make my muscles spasm and get tighter. I have to walk through this pain before my muscles and joints will loosen up. James calls this flossing. Like flossing my teeth, I have to floss the nerves through their sheaths in the joints and muscles, back and forth and back and forth until they can move freely with no restriction. With me this always takes a little while – sometimes even my whole walk. And right now, at this time in my recovery, the first few minutes of walking are unpleasant. I'm gunning for the few minutes after that. For now I just have to make it through this discomfort.

On my right, I pass a red pole with a large white emergency word painted along its length. I glance at the phone and intercom system on the front. I also notice two poles with streetlights on top. As a teenager, my dad and I used to walk and count telephone poles. Every weekend my dad would come into my room and say “Aufi” (the German word for ‘Let’s go’), and I would oblige. I didn’t really feel like I had a say in the matter. We would get dressed, weather appropriate, and my dad would drive me in his car to one of the side roads in our neighbourhood. We lived in horse farm country, with lots of side roads and large farm fields. Once we parked we would walk along the dirt road and we would count telephone poles.

I hated the telephone pole walks! They seemed so tedious, long, and boring. And they were painful. I went along to please my dad. Going for walks together was something that made him happy. Making him happy was meaningful for me. Usually we would take our Dalmatian Tobi with us. Tobi would run and sniff along the road, sometimes even pee on the poles that we would walk by and count. I guess that is how Tobi claimed the poles for himself. On most of our walks my dad would talk with me about things happening in life. Most of the time it was about me and my health. I found that very annoying. He was always very interested in what the doctors said and what I was doing with medications and therapy. The time my dad and I would walk and count telephone poles the most was the time I had a break from Jenn. My dad really liked Jenn and always asked about what Jenn and I were up to. When it came to walking I think my dad and Jenn thought alike. Firstly, walking was very important for me. And secondly, walking was good for my body. It was hard to enjoy our walks and count telephone poles when walking was so difficult for me. Over the years, however, I got stronger, and eventually I was able to come home

and report to my mom that I walked more than 10 poles in one walk. My dad would remind me how in the beginning I could only walk the length of two.

On my walk to school the poles to my right make me think of this distant memory.

A few years ago my dad and I talked about that time. Now that I am 20 years older, my dad and I regularly go for walks. We don't count poles anymore. We just walk together, and still talk and reflect about life. And now my dad doesn't have to force me to go. I ask him to join me. "Dad," I initiated the conversation as we walked around my parents' neighbourhood, "Why was walking and counting the telephone poles so important for you?"

"It wasn't important for me" he corrected. "It was important for you". I looked at him with a raised eyebrow, not sure if I am following his logic.

"But I hated walking and counting those poles, Dad, didn't you know that?" He didn't reply for a while. We just walked in silence, step in front of another step, in front of another step.

"You know," he reflected. "It was a bad time for you. I wanted to help you to fight. It was either take you out of the house and walk or you dealing with death. You had nothing. Your spirit was low. You had stopped fighting". I reflect on what he has just said. Back then I didn't feel that I had stopped fighting just because I had stopped walking. Walking, back then, was low on my priority list, compared with school and getting on with my everyday life.

We continue walking, step in front of another step, in front of another step. My dad does this thing where he hums under his breath with each step. He was doing this right now and I found it comforting.

“I think I understand how you felt back then,” I comment as we near the house around the corner. “But I did not understand this back then.” My dad continues to hum his tune, our steps creating a rhythm to the hum. “Good, good” he says. It’s his way of telling me that I’ve done well, that I’m doing well now.

~

I often reflect back to the time I walked the telephone poles because I was never truly able to analyze what this experience meant for me. I need to voice here that this experience with my father has profound ableist undertones. His ableist assumptions created a pressure for me to walk. Walking gave him hope, resulting in my being, and perhaps feeling, more ‘normal’, and clinging to the daughter I was before all of my surgeries. However, what this memory forces me to grapple with, more than the ableist undertones, is that this type of experience also creates a conflict where social model thinking fails my disability experience. Walking telephone poles reflected an overall struggle that my father and I had with my impairment (Shakespeare, 2014). Walking at that time was an important part of my well-being, which was greatly impacted because of impairment, not disability. What if my parents, with their (at times) ableist and normalizing discourses, did something positive for my impairment experience? “Disabling barriers make impairment more difficult, but even in the absence of barriers impairment can be problematic” (Shakespeare, 2014, chapter 2, section 5, para 18). My pain, and my body recovering from five major surgeries in one year, created impairments that disabled me equally – perhaps even more – than social barriers. Not moving and not walking increased my pain and increased the weakness in my muscles. Not walking regularly disabled me as much as the social



barriers and attitudes disabled me. These reflections make this experience far more complex and problematic beyond the discourse of ableism. These reflections create a tension for me that divides Disability Studies and Rehabilitation Science, because the two are connected to each other within my life (Shakespeare, 2014; Thomas, 2007; Wendell, 2013). Thus I will raise this tension here, and will return to the discussion of impairment in my final chapter.

Walking the telephone poles, and counting each to measure my walking success, may seem like an oppressive decision by my father to force his ableist view of walking as *normal* onto me. If disability is just about societal barriers (Oliver, 1990; Oliver & Barnes, 2012), where is there space to say that “It’s hard” to live with the reality of disability (Titchkosky, 2007)? I am left with the thoughts of Rod Michalko (2009):

The individual who now finds himself or herself disabled, or the one who is born so, will be traumatized to some degree and will now have to “accept” the disability, “cope” with it, and “adjust” to it. This difference, in its twofold character, is useless insofar as it is “passive”, to borrow from Levinas, and inserts nothing essentially different into the world. Everything remains the same – the world still sees, despite blindness; the world still hears, despite deafness; the world still has places accessed by stairs, despite people in wheelchairs; and parents still count the fingers and toes of their newborn. Blindness, deafness, and paraplegia are still unfortunate conditions that some of us have to suffer and are not (yet?) worthwhile and legitimate alternatives. They are not alternative ways of sensing the world

and moving through it. Thus, disability becomes a difference that should be prevented, not “lived in.” We should see clouds for what they are, posts and people; we should not live in clouds, let alone be intrigued by their mystery. The political aim of privileging normalcy, expressed in the language of the body as natural and conditional, is what lies buried beneath and is masked by the empirical distinction between disability and non-disability. (pp. 105-106).

My identity as a disabled adolescent was shaped in response to the expectations of the people around me, most of which belong to a non-disabled culture. I learned to respond to these situations as a “passive disabled bystander, the grateful recipient of others’ support, the non-problematic receiver of others’ disabling attitudes” (Goodley, 2011, p. 92). The impact of these situations, the fact that I am still reflecting on them decades later, illustrates to me how tested I already was at this young age (Shakespeare, 2014), and the fact that “maintaining this emotional labour can be psychologically testing” (Goodley, 2011, p. 92).

~

Christina and I speak about my memory with counting and walking the poles.

“I’m still not quite sure what it means,” I reflect honestly. “I feel like I’m stirring up a can of worms – a really smelly can of worms”.

Laughing, Christina replies. “You know what this reminds me of?”

“What?”

“It’s like a Montague and Capulet metaphor. It’s not like we can say ‘there there’ and then continue on with life”. I smile at the analogy.

“I so don’t have a solution here,” I comment on the analogy. “I just want to be able to open a conversation at the dinner table”.

We both laugh at the thought of the Montagues and Capulets having a conversation at the dinner table.

“I think that’s a good way to start it off,” Christina concludes.

~

I make it to the front of the building. People file around me through the double doors, one young student in flip-flops squeezes in front of me to hold the door open. I don’t recognize anyone, I just focus on the washroom door straight ahead, happy that it is not occupied. I duck into the washroom and lean against the white tiled wall as the door shuts behind me. I hear the click of the lock engage and take a deep breath. I’m in the building. I made it. Now what?

I take off my backpack and look into the mirror. My face is very red, my hair wispy around my cheeks. I look like I just ran a marathon. I turn on the cold water and let it run over my wrists and hands. That feels nice and cool. I study myself in the mirror. A feeling of defiance drifts over me: a feeling of “look at where you are right now” that I get every once in a while when I reflect on a milestone. I am a grad student, a teacher, educator, and advocate. I am also a wife, sister, daughter, and friend. How could I want to be anything else at this moment? I think about my first young-adult physiotherapist, Lauren\*, and her predictions of me at age 35.

Lauren came highly recommended by Dr. Reese.

“You’re at a crossroads right now,” Dr. Reese said to me at one of my appointments. “You’re walking more now and your spine is showing wear. I feel that you are heading into a spine fusion”. His words had a heavy tone to them. I felt as though he looked at me like a statistic – like a spine fusion was something everyone like me had to go through and now it was my turn. He turned to both of my parents who were with me for this consultation. “*But*” he emphasizes this word, “I feel that you are a candidate for a more conservative approach. You may be able to stave off a spine fusion with physiotherapy.”

“It’s worth a try,” my dad said. I wondered what Jenn would say about this.

“I want you to see a specialist in this area,” Dr. Reese explains. “Her name is Lauren White and she is a specialist in spine rehabilitation.”

“Jenn can’t work with me on this?” I hesitantly ask.

“We need someone skilled in the spine.” Dr. Reese persists. “And this would also be a good opportunity to transition you out of pediatric into adult therapy service.”

“Don’t you worry about Lauren.” Dr. Reese smiles at me and my parents. “She is brilliant.”

I recalled this conversation with Dr. Reese and my parents in the bathroom. I wondered what Lauren would think about where I am now. About my walking at school, about doing graduate studies. It had been years since I spoke with her. I remember Lauren’s demeanour, always smartly dressed in business attire. She did not get onto the ground or onto the plinth with me during PT sessions; rather she was more like a coach, coaching me from a distance. Most of

our therapy session occurred in silence, except for the coaching. Lauren and I did warm up to each other after years and years of working together, but my sessions felt like a business meeting to me, with an agenda to pack the business of rehabilitation into my physiotherapy session.

Something fascinated me about Lauren. She seemed to know a lot about research and was connected to clinicians who just dealt with spines. I think what fascinated me the most was how Lauren was not intimidated by my medical and surgical history. I had become used to clinicians flat out refusing to follow my care, one neurosurgeon making the joke that he would not want to “touch my spine with a 10-foot pole” and then laughing uncomfortably. Yet Lauren dove right into her assessment of my body, drawing from unique and unconventional therapeutic approaches that would train my muscles and spine in ways that created significant improvements for me. I was rather intrigued by her problem-solving abilities. Back then, in 1995, Lauren and I figured out how to tailor exercises to my abilities using the large exercise balls that one can find today in practically every gym’s exercise arsenal.

In everyone’s eyes I was a true success story. I had *made it*. I had exited the paediatric medical system and become an adult. I had survived past my 18th year, attended full-time undergraduate studies with my health relatively stable. But I was plagued by pain. I was aging with my body at a rapid pace and by my mid-twenties my future health picture appeared rather fuzzy. Lauren talked with me a lot about these uncertainties. I feel that she held considerable respect for my discipline and motivation to work on my physiotherapy regimen. Sometimes a heaviness came into my therapy sessions, a heavy reality about my *situation* – my *problem* – that at times felt black and white with no notice for the shades of greys in between. Lauren’s black

and white perspective teetered between my challenges with a body that constantly needed to be fixed and maintained, and pointing out that I was one of the lucky ones because I possessed a lot of willpower to fight.

I was nearing the end of my undergraduate studies. Through Jenn's encouragement and advice I allowed myself five years to finish up. "Whether you take five years to finish your undergraduate degree or four it does not matter," she said. "The most important thing is that you get good grades and that you take the time to put your health first. That's how you'll make it". And I did make it, with a double specialty in Psychology and Exceptionality in Human Learning.

One therapy session with Lauren, she asked me what my plans were after graduating. At the time I considered clinical Psychology as a possible choice. During one of my stretching exercises Lauren sat down next to me and said:

"Don't have babies, your body won't be able to handle it". I looked up at her.

"I'm not thinking of having a baby now." I didn't realize that she meant to *never* have a baby.

"There's always adoption" she added, "but if you really want to pass on your genetics to a child there is also surrogacy".

I was caught, in that moment, in an oppressive situation, where a healthcare provider was laying her ableist assumptions onto me for the sake of being helpful – benevolent (Guenther-Mahipaul, 2015). As I think about her words today, she likely came from a physical perspective, seeing me and my body as unable to carry out the challenging task of pregnancy and parenting. There is another viewpoint, however. The idea of my wanting to carry my own child, to pass on my genetics, to make the role of mothering real for me, seemed to also not be an idea Lauren

entertained at the time. I think that Lauren never knew that those words that day seriously affected my self-confidence for many years after that encounter. Every relationship I was in, all of the adult milestones I met, were clouded by her opinion, the fact that “our society only understands disability as a hindrance that makes parenting truly impossible” (Minaki, 2014, p. 40). What disturbs me more today than her words was how this younger me, almost 20 years ago, simply absorbed Lauren’s words without reacting to them. Especially when Lauren commented on my dreams to go to graduate school. Instead of her realizing that I was beginning to dream about the life and career I wished to have, she said, “You might want to think about whether graduate school is a good choice for you. It’s physically demanding even for a person who doesn’t have your issues. You’ll be lucky if you make it to 35 without any disc problems”.

I remember thinking “Why?”

I had a *right* to feel insulted. But I didn’t. As a young adult I was fully immersed within a normalizing system full of ableist assumptions about me and my life. Lauren was “...involved in a process of co-opting [me] into her view of the situation, defined as ‘reality’, as an essential condition of carrying out the work” (Abberley, 2004, p. 241). This reality, to Lauren, meant that I should view my life just like she did, as a consequence of my impairment. If I were going to go to graduate school and fail, this would be because of my disability, because I was challenged by my impairments. My agency to dream about my life, to make happy plans toward a fulfilled life with a career, possibly marriage and having a family, did not factor into her idea about me as a disabled young woman. Lauren was not about offering me the tools I needed to understand and

balance the normative discourses that are part of my marginal status in society. Lauren belonged to a majority of healthcare providers who focus on the "...process of 'getting real' [which] comprises an effort to adjust clients' expectations downwards" (Hammell, 2006, pp. 123-4).

Perhaps Lauren believed that this type of support would help me adjust and adapt to the marginal status I would surely have in the adult world. Did she see me as a naive disabled girl? A disabled girl with a false consciousness, a denial of her situation, or what Campbell (2009) and Snyder and Mitchell (2006) call 'internalized ableism'?

I try to think about what I would have done if I hadn't become an OT, if I hadn't decided to pursue doctoral studies. The thought of having taken a different path in life seems unrealistic to me right now. I do not think that my not pursuing graduate studies would have changed my life for the better. But I've been very aware of the importance to take care of myself, and I haven't always been successful at this. Even if I do not want to admit it, I know that Lauren, in some ways, was right in her predictions....

"Can things be otherwise? Some writers referring to the activities of those in the disability movement and the struggle for the full citizenship rights of disabled people argue that it can." (Abberley, 2004, p. 243).

I reach for my backpack and say, "You've got to get going now." I reach to push the door opener. As the door opens I muster the courage to venture, as a walking person, through the hustle and bustle of the people in this building. "You're almost there, Susan."

~



“Hey!” I heard a familiar voice behind me. My friend and colleague Sam\* caught up with me. I took the opportunity to stop and stand for a while to catch my breath.

“How’s it going?” she asks me.

“I’m almost there,” I smile. “Actually it has been good so far. I haven’t really run into anyone who has said anything to me.” I am fully aware that I have only started my day in this building. Probability dictates that I will, in fact, run into someone who will comment on my walking. I have told Sam about my anxiety of ‘coming out’ as a walker in this building. Although she patiently listens as I nervously catastrophise I could always feel that she didn’t quite believe that people would make a comment. It is a testament to who she is as a person, and as a friend. Sam would never publicly comment or make a fuss about a person. But on this part of the journey, in this very building of rehabilitation professionals and researchers, I do feel that my experiences with invasive commentators on my private space and body are simply something she has not had to deal with.

“I’ll walk with you,” Sam says as we head toward the elevator.

“Oh my god,” a voice echoes through the atrium’s open space. “Look at you! Is it really you, Susan?” I look at Sam and sigh. Under my breath I say, “Welcome to my life.”

“I can’t believe it,” the voice trills toward us. “I’m so proud of you,” the excited shouts continue.

I continue to walk, Sam by my side. “Good for you, I’m just so proud of you. It makes me so happy to see you like this.” An elated, bustling quick-stepped woman hurries towards Sam and me, no doubt on her way to her office after a coffee break.

“Seriously?” Sam whispers. I smile, incredulously watching the happy, shouting, revealer of my walking, come closer and closer. I look around me, worried that everyone is staring at me now.

Wendell (1996) explains that people are afraid of disability because they won't be able to participate in life. But Thomas (1999) explains that it is impairment rather than disability that drives this fear. My impairments surface much more, for me, when I walk than when I use my wheelchair. But the ideology of disability as *bad* and *undesirable* make my wheelchair seem more damning than when I walk. The tension is so great for me in the rehabilitation building that I have avoided it at all cost so far. Perhaps it is this very reason why I have used my wheelchair at work because I close this very door to false interpretation by the people around me. Walking tends to open a can of worms for me and my everyday life, and in my work life. Every worm I take out of that can reminds me of something I'm not when I walk. Each worm represents the changed identities I need to assume as I *walk* into different environments. My wheelchair therefore represents a confidence boost for me. When I use Ti, I take gait analysis out of the interpretation equation. My wheelchair is a tool, a friend, in mobility that does a lot for my self-concept. It is freedom in body, and freedom in mind. I feel less objectified and my person/body space is less invaded.

“I decided to walk today”, I defensively say to the overly excitable outer as she rushes past us.

“Well it just makes me so happy to see you like this. Good for you for doing this. It just makes me so happy. I'm just so *proud* of you.” I don't know what to say. I admire Sam's speechlessness, too.

“Thanks,” I stammer, and manage an embarrassed, red-cheeked smile.

“Was this for real?” Sam turns towards me. “I mean, talk about inappropriate. If someone lost lots of weight you wouldn’t say something like that to them, like this.”

“I don’t know why people do this,” I answer. “Some say it out loud and others probably think it. I can see it in their stares.”

“Are you okay?” Sam asks.

“Oh yeah. It was bound to happen. It can’t get worse than this today.”

That afternoon I ran into the same colleague again and mustered the courage to challenge her on her what seemed overly exaggerated congratulations. In my mind, I was fully aware that how people interpret my mobility devices and how I feel when using them is a highly personal experience. The social scripts seem to prevail for either wheelchair or crutch use, where the wheelchair represents disability and limitation, and crutches represent health and hope (Linton, 1998; Titchkosky, 2007; Titchkosky & Michalko, 2009). When using my wheelchair people want to know what’s wrong with me and why I have my chair. To ableist observers, they tend to see a wheelchair as only one category. But we wheelchair users see the many different types of wheelchairs, and the different categories of ability that they represent (Linton, 1998). When I walk the questions I am asked change. People show concern and hope that my current ‘sorry state of affairs’ is temporary, and that my “only hope for even a semblance of value is to evoke the “human spirit” and to “overcome disability”, to adapt, to adjust, and to live as normally as possible” (Titchkosky & Michalko, 2009, p. 7). They hope that with time and work I’ll get

stronger and walk better and maybe not even need *those* crutches anymore. Rarely do I get those comments when I use the wheelchair. Comments that are directed to Ti and me usually take on the form of, “I’m sorry that you have to use that” or “I wish for you that you can walk again” or – my absolute favourite – “It must be hard for you to get around”, because what I really want to say to those comments is “If I didn’t have this wheelchair I’d be stuck at home”. For me, my wheelchair will always be an agent of freedom, not confinement.

I tried to explain this concept to the woman who shouted her proud joy when she saw me walking on the 4th floor. I tried to explain to her that I still will use my wheelchair and that I tried walking today to see if I could do it and to see if it helped with my pain at the end of the day. All of my reasoning and explanations seemed to swoosh over her head as if they were caught in a gust of wind. All she said to me before she headed back to her office was, “Well, I don’t care what you say. I think what you have done is inspirational and I’m sticking to that.” Then she patted me on my shoulder and added, “It makes me happy to know that you don’t need your wheelchair anymore.”

Invalidated and upset, I lean back onto the wall. I have to take a moment before I continue walking. What’s the point for me to advocate when people just don’t get it – especially the people who, above others, SHOULD understand?

~

I sat on the couch in our Christmas-decorated living room, looking at the sheepskin house slippers I had just received as a gift. I was happy because my leg braces perfectly fit into the slippers making them into the perfect shoes if I felt like walking a little bit inside the house.

“I’m so happy for you that you have decided to try walking again. I always felt that walking for you is freedom,” a family friend who has known me all my life commented as I studied my slippers.

Freedom. This word has stayed with me for 10 years now, and the feeling that came with it. It was one of those moments when I looked into the eyes of our family friend, and no matter how much I wanted to agree with her, I just couldn't. This word 'freedom' felt like it cut me, like it slashed me, like it was somehow doing me an injustice. It was such a powerful moment of inner reflection as we sat in our cozy living room with the Christmas tree and the ornaments and the fireplace and my sheepskin slippers that I had to stop and acknowledge this feeling.

“Really?” I answered. “Why would you say freedom?”

“Because, it’s something you can do. It makes your life easier. Doesn’t it?”

I hesitate for a moment. Many times I would have simply answered "I guess so," because the issue of walking has always been so important to people in my life, especially with everything I have gone through as a young girl. When I walked, family and friends felt that I was happy; that I was not sick; that I was normal. I could sense down to my bones that walking represented *happiness* to the people around me. Today I know that this happiness means *normality*.

"I don't think that I can call my walking 'freedom'." I said at this precise moment.

“What would you call it then?” she wanted to know. I had no convincing answer for her. No steadfast argument that would sway her or anyone else into my side of the court.

“I would say that walking is something that I can do. But what I really feel is freedom for me is my wheelchair.” I look at her and see that she is struggling to understand.

“But you can do so much more when you walk. You can go into people’s houses. And you say that it feels good to walk.” I nod my head, to signal that I respect her opinion. I also know that I have said this before. It does feel good for me to walk because it helps with my pain.

“But when I am in my wheelchair, I am me.” I explain patiently. “I can do whatever I want to. I feel free with my wheelchair. I’m not limited. I’m actually limited when I walk.” I think back to my university time when my friends used to push me through campus in my wheelchair and I would raise my arms out to the side and feel like I could take off and fly. My friends called me Bluebird back then.

“I don’t know,” she says. “I still feel that walking for you is freedom.”

Looking at my feet, in their sheepskin slippers, I softly say, “I guess I could say that sometimes it can be freedom for me too.”

We move on to another conversation after this one. But I am still lost in thought. Right now I feel that we agreed to disagree. I feel lonely on my side of the court.

When a person sees me walk are they in fact interpreting my walking to mean that I want my disability to go away? Or better said, do people see it as my shoving my wheelchair into a corner and saying “Ha! I don’t need you anymore” (Minaki, 2015)? Of course not. I feel less equal when I walk and I feel more equal in my wheelchair. Why? Because I’m much more independent, and therefore much more me. I can keep up. I feel professional in identity. Even

though I assume a professional identity at work, to the outside eye, I assume stereotypical roles for people in my place of work (French & Swain, 2008). Although I have not storied this within my thesis, I have had many encounters with people who are happy to see me by the elevator and instruct me to continue on to a class/lecture where Professor X is waiting for me. When I say that I'm not the person they're looking for, they appear perplexed as I zoom past them to my destination. I work and study within an environment that tends to assume that "...disabled people are patients and clients rather than people capable of dispensing professional services" (French & Swain, 2008, p. 101).

One time I patiently waited, in Ti, for the elevator to arrive on the ground floor. When the doors opened, four women started to shuffle out and one woman directed an "Oh I'm sorry" at me. Thinking she apologized for using the elevator and not the stairs – this happens a lot – I replied "No problem" and wheeled past her into the elevator. She put her hand on my left shoulder and said "I'm sorry" and then "I know someone like you". As the elevator doors closed behind me, the weight of her comment settled over me. For her I was a pitied wheelchair girl going to the third floor. I, on the other hand, was a PhD student wheeling to my desk to work on my comprehensive examination portfolio.

Perhaps I am so aware of how I present myself that my choice of wheelchair reflects a deliberate empowered decision to model my identity as a wheelchair person? Whereas walking to the average person may appear to allow me to resume life the way it *should be* or to reach a quality of life that I now "can have" (Toombs, 1994, p. 356), I clearly identify this with my wheelchair, rather than with walking. It is in fact the reverse for me and many other disabled

people. So, then in fact it does matter to me how I get around. Because I consciously make choices each day that violate the normative rules of the environment I am in. And I don't even realize at times what my choices may mean, or whether they challenge or even perpetuate those normative rules to the people around me.

I have one final thought about this section on normality and ableism. It is initially the act of being watched and observed that causes me more anxiety than how I get around. My discomfort with being observed and the perception of scrutiny that comes with it is situated within decades of being stared at by medical professionals and citizens. My disability is an immediate signifier of difference to people. It's the first thing people notice, and when people stare at me, I am immediately invalidated as a member of society (Hammell, 2006), immediately reminded of my stigmatized status (Goffman, 1963). Rosemary Garland-Thompson (2009) wrote a fantastic book on staring. She highlights the struggle that starers wrestle with; whether they should look or look away. So complex is this struggle that starers have to weigh their dignity by calculating when their staring is too much or represents just the right amount. The 'staree' (who would be me) has to weigh whether the stare should be met with relish or with dread. What is interesting for me is that outside of the rehabilitation environment I regularly practice what Thompson describes as "staring back" (p. 83) and meeting a stare with relish, something to be engaged with. In the rehabilitation environment, however, I have been conditioned to meet stares as a burden, to feel like a victim who is less than she could be. What makes me a master of social interaction in one environment makes me stigmatized and feel oppressed (judged) in another. A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody



for others an affirmative answer to the unspoken question, “Yes, but in the end, wouldn’t you rather be more like me?” (McRuer, 2006, introduction, section 2, para 6).

~

I cannot escape ableism in my life, and I am not sure if I ever will. I have become aware of how ingrained ableism and its assumptions is and was throughout my upbringing and in the environment around me in my everyday life. I am constantly immersed in ableist discourses that seem normal and remain unchallenged. I do not always have the energy to label ableism when it happens. However, through Disability Studies literature I am finding a way to spot where my experience meet up with ablism and also find a place to critically reflect on the parasitic presence of ablism within my life.

In the next chapter I move on to discuss a more recent development in my understanding of lived disability as someone with spina bifida, and someone who also experiences fluctuations in my membership within the category of the ‘healthy disabled’ due to pain and ageing with a disability (Wendell, 2013). The experience of *impairment effects* factor regularly into my everyday life. I am faced with having to negotiate between my embodied experience of living with an impairment coupled with my need to negotiate daily social disadvantages (issues of social injustice) because of my disability. Within Disability Studies, my embodied experience of pain, limited mobility, and fatigue challenge the social model of disability. My subjective and highly personal experience with my body cannot be addressed by social justice. Thus my life story reinforces, rather than challenges, my disconnect with the strong social model of disability, which I will discuss in the next chapter.

## **CHAPTER 7:**

### **“I Walk, Therefore... I am Less Disabled”**

Our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all. This silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realizing our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments: we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments. Yet our silence about impairment has made many of these things taboo and created a whole new series of constraints on our self-expression.

—Liz Crow, 1996, pp. 209-10

The last time I walked at university full time was when I was a first-year OT student. Sure, I would bring my wheelchair into the building every once in a while, when the weather was very bad, when I was running late, or when I couldn't find a parking spot close to the building. Walking at university today takes me back to that time. How I used to walk into the rehab building's main floor, take the elevator to the 8th floor and then walk to my classroom.

I started the OT program just like every other student: excited to learn to become an OT, fresh out of undergraduate studies. Dedicated to *helping people*. But I had some deeper motivations as well. I was an *insider* within the healthcare system. As I saw my specialists and waited for therapy appointments in the waiting rooms, I was a client. The thought that I was crossing over to the 'other side' occurred to me but didn't seem important. I certainly did not understand that my situatedness within the two worlds could be viewed as political in nature (French & Swain, 2008). People often told me that someone like myself would be important to work at the front lines of healthcare. I was a lifelong patient/client, and now I confidently studied to become a lifelong clinician. Whereas at school I learned to be a clinician, at home I lived as a disabled young woman. At times my days felt like I lived a double life.

Today I understand that I was struggling with my overall disability experience, such as living on my own, studying within the Rehabilitation Sciences, being a common law partner, running a household and the pressures that were placed on me to show the people in my life that I could live a *normal* life *despite* being disabled. I firmly believed in showing that I could overcome my disability and succeed against all odds in this world (Titchkosky & Michalko, 2009). The pressure I placed on myself was intense, gnawing, relentless. The fear of failure

created an indescribable drive to show that I would not fail because I was disabled. However, I lived with a demon in life. My high levels of pain had initiated the process of burn out. I did not feel that my spina bifida was disabling or impairing me. My pain, however, was an impairment that led to disability in my life...and I felt that I could not talk about it to the people around me. I was silently suffering. My pain was wearing me down.

~

I made it through the first year of the occupational therapy program determined in my studies, but shaken in spirit. While my peers talked about the trips they would take over our four-week summer break, I was preparing for specialist consultations. At 26, I had grown weaker and was dealing with high levels of musculoskeletal and neurological pain. My family physician, Dr. Arnold\*, an ally in my life journey, had initiated the referrals to the specialists.

“Pain is not okay,” Dr. Arnold said to me during one of my appointments. “And you do not have to be a hero about living with pain”. He took out his notepad and tore off a piece of paper. Drawing a stick figure he said “This is you, here.” I liked how he always drew things out. “And here you have your tethered spinal cord.” With his ballpoint pen he started to draw a large dot where the lumbar spine of the stick figure could be. Then he drew a large circle around this dot. “This is where you have pain, right?” I nodded. “From what you have told me, you have shooting pain down into your legs and feet.” He drew an arrow from the stick figure person’s lower back down to the feet, “and you have a lot of pain in your spine.” He circled the spine one more time. “And then you have pain and pressure up into your head.” He finished by drawing an arrow from the spine up into the stick figure’s round-shaped head. Then he drew a large circle

around all of the stick figure, its circles and arrows and lay his pen down on the paper, looked at me and said, “In my books this is not okay. We need to figure out what’s going on here.” I started to cry and he handed me a small box of tissues.

“I feel like I’m going in circles. I go from one specialist to another and they always tell me that I’m not their problem. I’m so tired.” I blow my nose and dab at my eyes, mascara has stained my white tissue with black splotches.

At 26 I have come to realize that the adult world I live in does not know what to do with people like me with childhood disabilities. The pediatric rehabilitation centres and hospitals focused on comprehensive clinical care appropriate for people like me. I quickly discovered that the adult healthcare system functioned differently. Few specialists collaborate with each other in comprehensive clinics, rather choosing to see me in their clinics specific to their specialty. I noticed that I was expected to self-manage my care – the involvement of my family seemed less important – and that I was also expected to have a high level of knowledge and thus autonomy with respect to my health (Gorter et al., 2015; Kennedy & Sawyer, 2008). I learned that in the adult system, surgeons were not the medical professionals to follow you; rather they saw you when you had a surgical problem. So where was I supposed to go for ongoing care?

It is easy to get lost in this system, to get shut out, to give up, to stop taking care of yourself. As an adult I was learning about the political nature of disability. I was admired when I did very well, when I did not need any help. The more independent I was, the better I was perceived to be (Gibson et al., 2009). It made me start to not talk about my pain, to not voice my struggling. Rehabilitation specialists were, at the time – and unfortunately still are today – part of

my experience of disablement. The neglect that I experienced as part of the system because I did not fit into their mold of a patient caused a difficult struggle for me in everyday life.

“Rehabilitation is a multifaceted enterprise that involves more than the provision of treatment. For clients, it is a process of learning to live well with impairment in the context of one’s environment” (Hammell, 2006, p. 127). In rehabilitation discourses and theories, ‘living well’ may be aligned with enabling occupation, enhancing quality of life or reducing activity limitations (Wade, 2005). We suggest that these rehabilitation approaches reflect a number of values and assumptions that are rarely made explicit. (Gibson et al., 2009, p. 1451)

Snapping out of my thoughts I hear Dr. Arnold asking me, “Listen. You know what we call this all?” He folded his arms in front of his chest.

“What?” I sobbed.

“We call this ‘passing the buck’. You and I both know that you have some complicated issues. We need to find you someone who can mediate, someone who is willing to be the main consultant, along with me, with the other specialists. People are going to be very concerned about your tethered cord and nerve pain. They are not going to realize that you also have mechanical problems, and that they cause you equal or sometimes even more amounts of pain.”

I nodded and stopped crying. He was right. I couldn’t sit, stand, walk, flex my spine, or stretch without my spine cracking or feeling like it will snap. My sitting tolerance in my wheelchair was 10 minutes at best. This represented a new development in my life.

I have always had neuropathic pain from my tethered spinal cord. But now I seemed to be developing arthritis, in my hips and in my spine. And in a way... I felt like a freak (Overboe, 2009). I always wonder how I look on paper when specialists get a referral like mine? I wonder whether they see “spina bifida” and “tethered cord” and devise a mental picture of what I look like, who I am as a disabled person. And I wonder whether I can’t even get my foot through their door after the door gets slammed in my face with a polite “not appropriate for my practice” statement because specialists already don’t know what to do with the average spina bifida diagnosis and certainly do not know what to do with my nightmarish and freakish medical history. When I hear specialists say consolingly and also jokingly, “I wouldn’t touch your spine with a 10-foot pole”, I feel discriminated against. I feel like I have no chance to make it in this life. I feel like the system does not give a shit about me anymore. Except for Dr. Arnold of course. He does give a shit about me.

“...And we need to start pain management with you.” I got drawn out of my thoughts back into the conversation as Dr. Arnold continued his reasoning. I wanted to say something but he interrupted me. “You are at a fork in the road. You do not have to be gallant here. It’s time that we start talking about medications.”

I was not happy to hear this. Looking at Dr. Arnold I took a breath and honestly said “I hate how being in pain can make me feel evil. It brings out a rage in me, a disappointment that floods me with so many evil and negative emotions that I don’t recognize myself anymore.” I was surprised that Dr. Arnold nodded and told me that he understood.



“I hate that a yellow pill the size of a peppercorn, with an “M” on it can make that go way. I feel so out of control. I hate taking that pill.” Moreover, I was not happy to have to tell my parents that Dr. Arnold and I were talking about this. Medication truly seemed like the last resort for me, and my family.

“There is something I need you to understand, Susan.” Dr. Arnold’s patient voice calmed my emotions. “Pain is like torture to the body. Your body deals with pain by releasing more adrenaline and all of those substances we call good the stuff that help you deal with pain. But with chronic pain, or when the pain doesn’t stop, then your body eventually gets overloaded and it is hard for your heart and your kidneys and everything else that comes with it. Pain is chronic stress. And chronic stress is trouble.”

I pondered about what he just said. I completely understood this explanation.

“We need you to sleep, and we need you to be able to relax a bit. Medication will help with that”.

Even though I understood his reasoning I still wondered how I was going to explain this to my family.

~

Where is a discussion of impairment within Disability Studies? I have done a lot of talking about how Disability Studies needs to inform Rehabilitation Science throughout this thesis. However as I work my way through my adult disability experiences, and as I recognize the social and political tensions inherent in my everyday experiences, I cannot ignore the tensions that concepts such as *impairment* and *body* and *rehabilitation* introduce into my

thinking. And these tensions are not always negative, not always oppressive and damaging. Disability Studies has been critiqued for not being “grounded in an adequate understanding of what I call ‘actually existing disability’, which means comprehending both the diversity of illness and impairment experiences and contexts, and the breadth of everyday life” (Shakespeare, 2014, chapter 1, section 1, para 7). The topic of rehabilitation within Disability Studies as valuable and significant in the lives of disabled people has been neglected, at times blatantly shunned. Scholars challenge the concept of rehabilitation and impairment within Disability Studies and argue that the field may “get dislodged from its radical roots in the emancipatory discourse of the social model and that impairment becomes a key tool in so doing” (Hughes, 2004, p. 67). So debated is the topic of impairment in Disability Studies that a divide has occurred between thinkers. For example, Sally French (2004a) counter-argued Hughes’ point above and described how those of us living disabled lives since childhood find ourselves in situations where denying our impairments is a rational adaptation and key survival skill, yet this denial costs us significantly in life.

For those of us disabled from birth or early childhood, denial of impairment and disability has deeply penetrating and entangled roots; we need support and encouragement to make our needs known, but this will only be achieved within the context of genuine social change (French, 2004a, p. 85).

One may attribute these debates to a growing body of Disability Studies literature that has actively argued that disability is shaped by social forces (Shakespeare, 2014). The simple questions of “What is disability?” and “Which models of disability best explore disability?”

represent valuable and well-explored discussions within Disability Studies (Altman 2001; Bickenbach, 2012). The issue of impairment versus disability has created a deep cleft in conceptualizing disability across the field of Disability Studies. Mike Oliver (as quoted in Thomas, 2004) famously said: “Disability is wholly and exclusively social...disablement has nothing to do with the body” (p. 23). Carol Thomas (2004) explained that for Disability Studies and people within the disability movement to dwell on impairment was “hazardous” because it reinforced the belief that the medical preoccupation with the body took attention away from the central fact that disability is a form of social oppression (p. 23).

Since the early 1970s, scholars dismiss the “medical model”, also sometimes called the “individual model” of illness, which views disability as a pathological condition within the person’s body that can be objectively diagnosed, treated (i.e., fixed), and in some cases cured (Barnes & Mercer, 2010; Bickenbach, Chatterji, Badley, & Üstun, 1999; Linton, 1998; Oliver, 2009; Schultz, Crook, Fraser, & Joy, 2000). Medicalized approaches fail to address the material, social, and cultural determinants of disability. When rehabilitation and medical practices minimize these determinants of disability, interventions become narrow and one-sided interactions with disabled people. The rehabilitation professions were and continue to be considered applied fields of practice, and are critiqued because of their focus on the person first and the environment second (Abberley, 2004; Beresford, 2004; Hammell, 2006; Oliver, 1996; Shakespeare, 2014).

The Union of the Physically Impaired Against Segregation (UPIAS, 1976) first defined the social model as follows:

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.

Disabled people are therefore an oppressed group in society. (p. 14)

Thus the social model emphasizes societal oppression as the source of the experience of disability (Oliver, 1990, 2009), constructs disability as a policy and civil rights issue (Hammell, 2006; Hubbard, 2004; Shakespeare, 2014), and sees the causes of disability as resulting from social structure and how society treats and controls disabled people (Altman, 2001). Scholars repeatedly raise the question of whether we can have a conceptual debate on the legitimacy to “posit a biological, medical or health dimension of disability” (Bickenbach, 2012, section 1, para 4). After all, the social model locates impairments in the physical body and minimizes their role in the disablement process. As Oliver (1996) has stated, “Impairment is, in fact, nothing less than a description of the physical body” (p. 35). The social model, or at least earlier versions of it (Thomas, 2004), is sometimes narrowly interpreted to suggest that medical professionals should play no role in the lives of disabled people. This could perhaps lead to a misinterpretation of the social model, as the model clarifies that for many people, disability is a long-term social state that does not necessarily require medical treatment (Guenther-Mahipaul, 2015). Oliver (1996) has stated,

Many disabled people experience much medical intervention as, at best, inappropriate, and, at worst, oppressive. This should not be seen as a personal attack on individual doctors, or indeed the medical profession, for they, too,

are trapped in a set of social relations with which they are not trained or equipped to deal. (p. 23)

Disability is a complex phenomenon that involves the dynamic interaction between personal and environmental/contextual factors. To medicalize and reduce disability to a bodily impairment creates an obstacle to effectively understand and analyze the complex factors that contribute to disability. The social model<sup>7</sup> as propagated by the disability movements in North America, Britain, and globally resulted in significant changes that promote(d) positive disability identities and decontextualized disability as a human and civil rights issue. Particularly in Britain, this contributed to changes in policy and legislation and the removal of barriers, whether physical or attitudinal/oppressive (Shakespeare, 2014). Nevertheless current Disability Studies scholars have begun to suggest that we need to focus on new, more sophisticated theories that transcend the social model and do not ignore the effects of impairment or the role of medicine and rehabilitation in helping disabled people to thrive (Guenther-Mahipaul, 2015, see also Shakespeare, 2014, Thomas, 2004, Tremain, 2002).

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<sup>7</sup> The social model was propagated by disability rights movements in Britain and globally to shift attention from individuals with mental and physical *problems* to their social inclusion or exclusion. In general, the social model belongs to a group of social approaches (e.g., social constructionism) that pinpoint social oppression as the source of the experience of disablement. In this thesis I focus primarily on the British version of the social model, also called the ‘strong social model’ (Oliver, 1990). Oliver introduced the term ‘social creationist’ to describe the strong social model. The strong social model, Oliver argued, as part of a social creationist orientation, roots disability firmly in material social forces and physical environments, in addition to how different cultures and their social contexts influence (i.e. construct) the experience of disability.

As a novice Disability Studies scholar, I came to appreciate how crucial the strong social model was to the disability movement and how Rehabilitation Science can gain from how Disability Studies as a field conceptually explores disability. In Britain, as its first political strategy, the strong social model identified barrier removal as critical. “If people with impairments are disabled by society, the priority is to dismantle these disabling barriers, in order to promote the inclusion of people with impairments” (Shakespeare, 2014, chapter 2, section 1, para 6). Seeking rehabilitation or strategies for cure was trivial; rather social transformation was argued as key in fighting discrimination against disabled people (Oliver, 1990). A second impact of the social model was the transformation it had on disabled people. Disabled people were able to understand that “they did not need to change; society needed to change” (Shakespeare, 2014, chapter 2, section 1, para 7).

Having lived with my disability my whole life, thinking that society may be the reason I am disabled caused me to feel uncomfortable, insecure, partly ungrateful to the services I had received my whole life. I had been socialized into a system – medical and rehabilitation – that did *not* think this way. As an example of my internalized views on disability, my 20s were about figuring out why I was a problem (Titchkosky, 2007), and what I was going to do to change my problem. The fact that *I am not a problem* has only recently entered my belief system. I had to step away from the idea that my disability was not necessarily something that had to be treated medically (Guenther-Mahipaul, 2015). That being said, throughout this body of work, my lived experiences also give me pause to reflect on why I have been unable to shake my discomfort with the strong social model. My discomfort is shared by other Disability Studies scholars who

have begun to unpack the strong social model and address theoretical gaps within (Crow, 1996; French, 1993, 2004a; Shakespeare, 2014; Thomas, 2004).

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One of my colleagues asked me whether I am going to take on the deeply rooted and at times very persistent theme of ‘pain’ in my life story within this thesis work. Pain as a topic is too large for me to take on. Pain also represents a vulnerable storyline in my life, to which I have yet to let myself open up. I plan to explore it in future work. For the reader who wishes to explore pain further and understand how pain is perceived in society and within medicine I recommend the work by Melanie Thernstrom (2011) *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing, and the Science of Suffering*.

Pain for me has always just ‘been there’. Through a theoretical lens, my lived experience with pain creates a space where some of the theoretical arguments on disability as a social phenomenon fail for me. For many of us who live with disabilities (congenital or acquired) and understand the theoretical arguments of the social model of disability, we face a wall where we don’t have a “place to say that there are parts of disability that are hard” (C. Minaki, personal communication, June 21, 2015). My life with pain offers me the opportunity to highlight an aspect of my life that I find truly disabling. In my early 30s I wrote an article about this titled “Spina Bifida is not my disability, but my pain is...” (Guenther, 2009). The current definition of impairment creates a space for this. Because a definition of impairment allows for a cause (e.g., biological or psychological) that may underpin the pain. However, we need to be careful, because impairment underpinning a disabling experience alone appears as simplistic. There is a

big picture within the experience, within the interactions that we have inside of our bodies, with the people in our lives, and the environments and cultures within which we are embedded. The social model with a social creationist approach alone cannot fill this space. Neither can Rehabilitation Science, if it continues to orient itself to traditional person-first and impairment specific focuses.

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Four weeks of summer holidays and I'm home with my family. I've just turned 26 and have successfully completed the first year of the occupational therapy program. I haven't told my parents how things have been this past year. I talk about school and I talk about my friends, but when it comes to my health I've been fully independent, autonomous, and self-managing for over five years now. I'm burnt out. What troubles me at this moment in time is that I don't seem to have the energy to care anymore. Why go to doctors' appointments? Why do exercises? Why try to take care of myself? It's so much easier to stay at home and just go about my life and school and not worry about the rest of it.

Sitting behind my family house, leaning against the old red brick wall under the maple trees, I cry as I write into my journal. I hear my dad's footsteps approaching on the deck above me but I don't look up, I continue writing in my journal.

"What's up?" he says, looking down to me sitting on the grass. I wipe away my tears.

"I'm tired and I'm writing in my journal".

"Come to the front of the house and talk to us," my dad encourages me. I think about it and say,

"Okay, give me a few minutes".



My dad leaves and walks around the house to the front of the deck. The leaves are rustling with the wind, I can hear cicadas singing. I close my journal, drop my pen into my pant pocket and grab my canes. Slowly I walk through the garden around the house. My parents are sitting on the bench talking to each other. When I approach they grow silent. With every step I feel their silent gaze upon me. I know they can see that I have been crying.

“What’s up?” my dad asks again. I pull up a chair and sit down.

“I have to read you something I just wrote behind the house and you can’t interrupt me.” My dad nods. “You have to listen to me and let me finish all the way without interrupting.” My mom also nods. I open my journal to today’s date, August 18, 2003, and begin to read:

*I’m sitting outside, behind our house, in the setting sun, hidden from everyone. This weekend was so hard on me. I first thought that I didn’t want to be the ‘poor me’ one. You know, the one that everyone feels sorry for. But it always seems to me like I come across that way. So now I just got off a two-hour toilet session, with a BT that would not work, and me crying like a baby. There’s a mirror in the bathroom, one where you can only see the head of your body, but not the rest of it. I look at that head and I think, “Look at how pretty she is. Why is she crying?” If you would only look at that head, you would think this is a normal person, but I can’t look at it that way, because I know the rest of her, her body, and it makes me cry. You would probably interpret this as a statement of someone who hates their body because they don’t like how it looks. They don’t like their appearance. I hate my body because of the challenges it throws at me every day. Every day it’s a new one. My hip, my back, my nerve pain, weakness, my bladder, my bowel, my walking, my cold*

*legs... or so I think it is. But in reality, those things happen to me every day, often together, like torture that I have no control over. Every day I wake up, and I have pain. And every day I tell myself that it is a good day. Because I'm not in hospital... or dead. A family friend said in the car today, that I must be glad that it's the year 2003, because I can live. But what is living? Sure, surgeries allowed me to survive, but for what cause?*

*I wish that I could wake up in the morning and not have to think about "Oh, it's a BT day", or "oh wow, you better stretch so that you can walk to the bathroom". I wish that I could spend an evening out with friends and not have to take Advil. I wish I could be sitting out here, and be crying and writing in this book because I had a fight with my boyfriend or my cat died. But I'm sitting out here because I'm so angry at everything, and how every day robs me of my limits and the life that I will not have. And every day, robs me of that little piece of happiness that I was always led to believe was there for me. The happiness that I believed in so much. I don't know when it left me, the happiness, but I don't remember it. The first things that come to mind are pain, me telling myself that I have to be strong, and that this will pass. How am I supposed to recall happy memories, childhood or adult, if these are the first thoughts that pop up in my mind?*

*So, I found myself on the toilet today, waiting, pleading with my bowels to help me out here because I'm trying so hard to eat well, to drink enough, to take care of myself. And after an hour, all my strength, all my patience, all my energy was gone, and all I could do was cry. Because maybe my bowels would work for me then, because I cried... because I gave in. And I thought about school, and how I would be back at school in two weeks, still*

waking up in the morning and saying to myself, “Oh, it’s a BT day,” or “oh, you better stretch so that you can walk to the bathroom”. And I would do that. And I would go to school, and I would be so happy there because I’m Susan, and I’ve run away from home and my body. I would be learning about people and their illnesses that are far worse than mine. I would be learning about how I can help them live and enjoy their lives. But it’s all a lie, because I know. I know... I KNOW! What it’s really like... And although I can give “I know” as those comforting two words to those people, I will never hear them for myself. And so I keep on getting up every day, hoping that it will be a good one. Smiling, because no matter what world I live in, I am so alone, and the one thing that kept me going for so long, my future, is the one thing that is slowly being taken from me. It’s like a Monet, it makes sense when you look at it from far away, but as you get closer it becomes a big mess and the happy picture disappears. Everyone tells me how normal I am. If I had a nickel for everyone who told me of how successful I can be, of the family I will have, of the life I will lead, I would be rich. I’m almost there I guess, but I feel like I’m living a lie.

I can’t live the life that was written for me, I have to live a life that I can lead, myself. And for some reason it feels very lonely, and I feel like I have to let a lot of people down in order to reach this goal. But if I hurt myself in the process because I’m doing too much and because I don’t want to let people down, then I will be letting me down. One of these persons is my boyfriend. I would give anything to be able to give him the life that I desire to give him, a partner, or wife that has an inspiring career, someone who can create a family with him, someone who he can grow old with. But that would be leading myself into a lie again, because I know that I can’t do all of those things. Not until I start taking care

*of myself, and in order for me to start doing that, I have to let go of a lot of things. But where to start remains the question?*

*Someone once told me that I am this star that lights up a room when she enters. A star on which people make a wish. But like all stars in this universe, I have gone out. And instead of trying to take the last few bouts of energy to light my last existence, I am taking it to light the existence of others. Maybe that's what I have to give up? Maybe that's the first place to start?*

I make it to the last paragraph without crying, but then the tears start to stream down my cheeks. I notice that my mom is also crying. My dad takes a breath and looks at me with very kind eyes.

“I expected this to happen. Everything you have read here is not a surprise for me”. I, in turn, feel surprised by his words.

“Really?”

“Susan, I had no idea.” My mom gets up from the bench and comes over and hugs me. “Why haven't you told us before that this is how you feel?”

“Because I didn't want you to worry about me.” I start to sob again.

“But we are your parents!” She strokes my hair and wipes the tears away from my cheeks. “We want to be there for you. But you have to let us in”.

I feel like this huge weight has lifted from my shoulders. For the first time in a long time I do not feel so alone anymore.

“It’s been hard to watch you in the past year. We can tell that you are trying to hold things together,” my dad adds.

“You hide things very well. You always have,” my mom reflects.

“I’m really struggling,” I say to both of them. “And Dr. Arnold says it’s time to start pain medications.” Instead of showing outrage, both of my parents nod. Their body language signals acceptance and not disappointment.

“You like Dr. Arnold” my mom comments. “He’s been very good for you. We know that.”

“Do you trust him?” my dad asks. I nod. My dad takes a deep breath and furrows his brows. He’s working this out in his mind, I observe. But he hasn’t said ‘no’. I feel listened to.

“What will happen if you don’t go the medication route?” My dad breaks the silence.

“I’m starting to show physical signs of stress. It’s too much, the walking, the pain, my body isn’t doing so well. Dr. Arnold says that medication will help me cope and sleep better. And then I can take care of myself better”. After a brief silence I reluctantly add, “Dr. Reese has suggested that I stop walking. He says that I need to get a power chair because he says that if I keep this up I’m going to hurt my spine and I’m going to hurt my shoulders. And if I hurt my shoulders then I’m in really deep trouble.”

My mom goes back to the bench and sits down beside my dad. “I had no idea what you have been going through. You don’t show it, Susan. If you don’t tell us we have no idea what

you're dealing with. Now that you don't live with us anymore we don't see the health side of you anymore." For the first time in a long time I feel so relieved.

"I just want to be treated like everyone else, an equal, not based on the amazing things I've done or am doing. Maybe Lauren was right? This is all too much for me..."

My dad shakes his head in protest. "I don't think so," he says. "But I am glad that you are problem solving with us. We know you very well. We were the ones who have made decisions for you and about you your whole life. You can come and talk to us 'old' ones." We all laugh as we sit around the garden table. A warm breeze blows around us. The sun has begun to set.

"Basically I just want people to tell me that they can imagine how much I have on my plate, without the comments that come with it, such as 'oh you're so strong' or 'if you take the age of 35 and focus too much on it, you will start believing that you will get sick just like your doctors say you will' or 'don't think about that now' or 'be glad that you can fall back on so many people' or 'look at what you've done, you will still do so much'." I grab for a water glass on the table.

"I can understand this" my mom replies.

"I don't need encouragement or support to keep going right now. I can do that on my own. But I do need encouragement to believe in my limits." I can see an expression of confusion on my mother's face. But she does not interrupt.

"I am not seeing my limitations right now, I am not letting myself see them. And although I could remain optimistic and not let thoughts of a dreadful future after 35 get to me, I may still

end up burnt out and sick by that age. Even if I strongly believe in my abilities to not let my aging body control me”. I am thinking about Lauren’s opinion of me wanting to do graduate studies. As upsetting as her discouragements were at the time I have to wonder whether she had indeed predicted this. Did I do this to myself? Should I have listened to her clinical perspective of me? Should I really not have entered graduate studies?

“It’s like you are flying without a parachute and we are hoping that you are going to land on soft ground” my dad adds. He has a knack for vivid analogies. This one certainly takes me back a step. I notice that my mom again has tears in her eyes.

I carefully think about what I am going to say next.

“I will always live with limits, that is no question. The question is, is it worth it for me to expend energy on trying to hide what’s going on? Just so that I can burn myself out with suggestions from parents, family, and friends that mask the very thing that can save me in the long run?” I look up and address both of my parents sitting on the bench. “Limitations can open doors too”.

~

At 26 I was trying *hard* to leave my body and impairment out of a discussion of my disability experience. If I did not talk about pain, fatigue, weakness, and exhaustion I was doing well. If I talked about these things I had a problem; my body was perceived to be “inferior, blighted or in deficit” (Hughes, 2004, p. 65). I found myself in a great tug of war between overcoming my disability and proving to the people around me that I was amazingly self-sufficient, and immersing myself into truly experiencing my own disabled body for what it *was* (Morris, 1991).

If social model approaches cannot account for the role of impairment, then they will fail to explain the complexities of disabled people's social situation. Moreover, disability rights academics and activists risk creating stories about disability which many disabled people will not recognize as describing their own experience. As disabled feminists have argued, impairment is an important part of the disability experience. (Shakespeare, 2014, chapter 2, section 5, para 11)

I had no comprehensive medical and rehabilitation care. The care that I did receive focused on what to do with my body, and disturbingly, I was discriminated against based on the unique impairment issues that I lived with. I was *too young* to have pain, spina bifida was the reason why I wasn't doing well, thus *this is what your life is*, and if I wasn't going to take care of myself, I was going to create *more problems* for myself.

~

On that September day I walked at school, I thought back to the conversation I had with my parents over 10 years earlier. It was a conversation that changed our relationship with each other. Independence became interdependence, a concept that was not popular within the system, and within my overall social surroundings (Swain, French, & Cameron, 2003). But it worked very well for us; for me. I consult with them now about my health, my appointments, and decisions I face. They are still my decisions, but I now have two experienced and well-versed advisors standing with me. In addition, I was beginning to redefine my notion of disability, to



gain some semblance of control in my life, to develop autonomy and agency with my disability experience, not because of it.

After my final year of occupational therapy studies, I have developed several specific goals in my life. I have naturally, without theoretical thought, separated my specific impairments from my overall disability experience. I need proper pain management and to resolve the mechanical issues that I live with due to aging joints, skeletal misalignment, and imbalanced muscle control. After a few years of trial and error with medications, Dr. Arnold and I came to a sobering conclusion. The mechanical wear and tear in my spine and hips could not be controlled with even the best medications. They made me sick with their side effects. Dr. Arnold stood by his motto, that the treatment should never be worse than the symptoms.

I was 28 years old, when Dr. Arnold and I began to search for a surgeon to assess my left hip. I needed a hip replacement and I struggled to find a surgeon who would give me one. It had been 3 years since I began my pain management journey. I had followed the advice of Dr. Reese. I stopped walking. An OT colleague recommended and prescribed a power wheelchair with dynamic tilt to help with positioning and pain management. But my wheelchair created some tensions for me. Surgeon after surgeon saw my wheelchair and recommended that I limit walking and standing and that then I would “be okay”. As in previous years I was shuffled from neurosurgeon to orthopaedic surgeon, each passing the buck to the other to identify the main issues. I deconditioned within months and my left hip began to lock while I sat in my wheelchair throughout the day and while sleeping at night.

Of the six orthopaedic surgeons I saw, all offered similar expert opinions: “You’re too young”, or “You are not walking so there’s no point in replacing your hip”. I realized that walking served as a golden ticket to surgery. Before each consultation, I had to complete outcome measures and checklists regarding whether I experienced ‘great difficulty’ or ‘no difficulty’ with, for example, carrying grocery bags in either hand from the car into the kitchen, or whether I could climb stairs without using the railing. At one such consultation I thought to myself, “These are ridiculous questions.” I did my grocery shopping using my wheelchair, and I’ve never been able to walk stairs without using the railing. Surgeons told me to use the wheelchair, to not over exert myself, and that, because I was aging with a disability, my limited function was ‘to be expected’.

Life went on for me. I worked as an OT and loved my clinical practice. With time, however, I struggled with sitting in my car and transferring to and from my wheelchair. Living on my own became more difficult and I eventually self-referred myself to a community home care service. My relationship with my partner suffered. I became more and more isolated. My anger with the system grew. I felt angry that no one was willing to help me problem solve my situation. Aside from Dr. Arnold, no one advocated with me. Therapists told me to conserve my energy, physicians queried whether I battled depression, which they automatically linked to my spina bifida rather than the consequences of my pain: “I’m sure it’s normal for people like you to have a hard time coping with what’s going on” a social worker told me one day. From my perspective I was coping quite well with my spina bifida, but I wasn’t coping well with this

system. My optimistic coping turned into an alarming defeat. I again found myself in a pattern of “What does it matter anymore?”

Many of my disabled peers were going through similar journeys that year. We noticed an interesting trend: when you are in your 20s, surgeons who usually see patients in their 60s do not know what to do with us. Those of us with connections learned how to slide under specialists’ doors. We took turns searching out specialists and getting referrals that seemed to take place entirely ‘off the record’. If someone took an interest in our ‘cases’ we were lucky to push forward in the system. This is what happened to a close friend of mine. His brother worked as a surgical nurse with an orthopaedic surgeon specializing in hips and knee replacements. During a typical surgery he said, “Listen, my younger brother with cerebral palsy is sitting on two dislocated hips and he can’t seem to find a surgeon to see him.”

“Is that right?” the surgeon commented. “Arrange for a referral with my secretary.”

A month later I got a frantic message on my answering machine. “Susan, you have to go see this guy,” he rambled, “he thinks like we do about ‘us’.” I wrote down the information and brought it to Dr. Arnold, who immediately referred me. Skeptically I arrived at my consultation a few months later and met Dr. Jost\*. “Well you definitely need your hip replaced, no question about it,” Dr. Jost mumbled as he studied my x-rays.

“And you would do this on someone like me?” I asked incredulously.

“Absolutely,” he explained. “Listen, you use a wheelchair and I know that your main goal is not to walk. So trying to get you back to walking is pointless. But you are an active person. You are

working and you are a productive citizen. There is no point for me to compare you to my other clients,” Dr. Jost concluded. “But I have to admit that many of my colleagues need to be reminded of this when they question hip replacement for wheelchairs users.” He slapped his Fellow on the shoulder and said, “This is why I am teaching my fellows to think outside of the box.”

It had been a long time since I had met a surgeon who did not see me as deficient or broken. And I liked that he said that I was active. I felt active, in my own way.

“When can you come in? I can do it next month”.

This surgery, although tough on my weak, stiff, and de-conditioned body, was a happy success for me, and for Dr. Jost. I started to walk again, and I was able to work toward pain control. At one of the yearly follow-ups, Dr. Jost came and sat on my plinth and shook my hand. He turned to one of his Fellows and said “I have helped people get back to many things after hip replacement: being grandparents, golfers, travellers. But never did I think that my replacing a hip would lead to a PhD student!”

~

Dr. Jost followed the personal and individual dimension of rehabilitation in addition to paying attention to the social dimension of disability as his rehabilitation mandate (Hammell, 2006). He understood what I was doing socially in my life (e.g., working and being a productive citizen, in a common-law relationship, active) and what needed to happen to my body/impairment in order to keep me functioning well within the social dimension of my life. For me this distinction also brings up a discussion that I have not raised yet within this thesis, the

discussion of how impairment within Rehabilitation Science is inherently linked to classification. Specifically I am discussing the *International Classification of Function, Disability, and Health* (ICF) (WHO, 2001). Classification has never been a positive experience in my life. I have spoken about this when introducing Dr. Jost, as many of the other specialists and surgeons I sought referrals to before Dr. Jost seemed to classify my functional abilities into categories within norms that I simply never had, or would not get back.

I have written about the ICF previously (see Guenther-Mahipaul, 2015) in order to lay the critiques by Disability Studies scholars of the classification on the table. There has been quite a debate about the usefulness of the ICF, and the framework's potential to cause more harm than do good for understanding the complexity of disability as a concept (Bickenbach, 2012; Bickenbach et al., 1999; Hurst, 2003; Imrie, 2004; Shakespeare, 2014). In fact, Disability Studies scholars either ignore or dismiss the ICF, arguing that it is aligned with medical model thinking (Bickenbach, 2012). However, even though the framework does come with flaws, there is also some merit to the ICF, even from a Disability Studies lens. Although this discussion is too extensive for the scope of this thesis, I wish to introduce some of the critiques and perhaps, as Jerome Bickenbach (2012) challenged, to highlight the misunderstandings and flaws attributed to the ICF. Overall, Disability Studies scholars used the ICF as a subject on which the "conceptual knives of the disability movement were sharpened" (Williams, 2001, p. 134).

The ICF attempts to embody a conceptualization of disability that is grounded in human functioning. Grech (2009) argued

...with the ambitious aim of becoming a unified universal framework for defining and quantifying disability in a culturally neutral way, the ICF attempts to bridge the medical and social models by providing a biopsychosocial model, motivated by the effort 'to achieve a synthesis' and 'provide a coherent view of different perspectives of health from a biological, individual and social perspective (WHO, 2001, p. 20). (as cited in Goodley, 2011, p. 19)

The ICF defines body functions and structures (impairments), activity limitations and participation restrictions, and contextual factors including environmental and personal factors (WHO, 2001). The framework is meant to emphasize health of all people, not disability, and within the Rehabilitation Sciences, researchers use the ICF to explore participation of persons and how they interact with their environments (Bickenbach et al., 1999; Desrosiers, 2005; Levasseur, Desrosiers, & Tribble, 2007).

The WHO began to develop the ICF in order to classify the outcomes of disease. One of the main critiques of the framework is the WHO's goal to make it a unique nomenclature not only to describe but also to classify body functions, activities and participation and environmental factors (Bickenbach, 2012). The end result has been a misinterpretation that the ICF can measure health and disease outcomes (Hurst, 2003; Levasseur et al., 2007), which it was not designed to do. In fact,

rehabilitation professionals have either complained bitterly (and justifiably) about the scant justification for the WHO scaling, or have resorted to exotic

statistical techniques, such as Rasch Analysis, to generate reliable measurement scaling from data form repeated clinical use of the WHO scale. The jury is still out on whether all of this will resolve into usable metrics. (Bickenbach, 2012, Section 5, para 3)

A strength of the ICF is its recognition of disability as a complex phenomenon that requires dynamic analyses and interventions that span across and link medical and sociopolitical issues. Another important aspect of the ICF framework is its position that disability is not a phenomenon that belongs to a minority group but rather one that affects society as a whole (Shakespeare, 2014). The ICF has created some important shifts in disability healthcare and research, however a Disability Studies lens raises some key limitations that call into question the ICF's promise of change (Hammell, 2006).

The ICF fails to distinguish between the *personal* and the *social* within the classification system. It also cannot distinguish between *activities* and *participation* since although the framework sees both as different, in practice those two categories do not appear to be different (Bickenbach, 2012). The WHO (2001) expected that continued use of the ICF would lead to empirical research that would clarify the “operationalization of the notions of activities and participation” (p. 237), yet more than a decade later, this has not happened. Moreover, the ICF cannot describe the impact and the effects of social exclusion (Üstun, Chatterji, Bickenbach, Kostanjsek, Schneider, 2003). What do Disability Studies scholars mean by this? In practice, distinguishing between the personal and social dimensions appears to make little difference. However, with respect to data collection, conceptual confusions can negatively impact policies

and disabled persons. Researchers can inadvertently use the ICF as a detailed taxonomy to structure data collection (Barnes & Mercer, 2010) with the end result of classifying function. To classify function, means to unintentionally classify disability (Fougeyrollas et al., 1998; Hammell, 2006). Disabled people are put into situations where they are identified, labeled, and thus classified based on their bodily or functional differences in order to seek or be allocated health and community services (Hurst, 2003). Disability Studies, as such, has important contributions to make with respect to the conceptual confusions remaining in the ICF.

We understand that this is a political decision by the WHO that is designed to satisfy the social model. However, it is a cosmetic choice, as we end up with taxonomies that allow each dominant group to maintain its ideological position: An individual's disability is viewed in terms of impairments of body functions, structures, and activity restrictions of the person as a whole. (Fougeyrollas & Beauregard, 2001, p. 185)

Thus, the ICF perpetuates a tension between social and individual model accounts instead of offering an alternative understanding to them (Barnes & Mercer, 2010). There is no simple solution, no answer to understanding the process of disablement within our society. Somehow, the disabled person seems to be responsible for social consequences and how they choose or do not choose to participate in everyday life (Fougeyrollas & Beauregard, 2001). I certainly struggled greatly in my mid-twenties with the overall system. I needed to find the appropriate support and healthcare services, but I was also struggling with my identity as a *disabled woman*. Fougeyrollas and Beauregard (2001) criticized the ICF for its potential interpretation of person-first focus:



One of the most harmful and violent consequences of this (person-first focus) process occurs when the individual who is different adopts this label and bases his or her identity on all of the disabilities and oppression situations attributed to him or her. (p. 187)

These types of critiques have resulted in my carefully weighing all of the arguments about how *disability* and *impairment* are perceived within the Rehabilitation Sciences and Disability Studies scholarships. And I am coming to understand that Disability Studies is in need of opening communication about impairment *and* disability. Recent research that tested the ICF with impairments such as hip and knee arthritis found that impairment *does* contribute to participation restrictions and that these restrictions can be reduced with joint replacement (Davis et al., 2012). I have chosen to raise the issue of impairment because I believe that both Rehabilitation Science and Disability Studies can inform each other on this issue. I am not denying that disability is caused by society (Oliver, 1990); however I also cannot agree with Oliver and Barnes (2012) when they argue that impairment "...is not the cause of disabled people's economic and social disadvantage" (p. 22). And my contributing to a theoretical discussion on impairment does not mean that I am a steadfast supporter of the ICF. I understand the many theoretical arguments of how focusing on impairment can be perceived as a threat to Disability Studies scholarship. For example, Hughes (2004) criticized Disability Studies for shifting too much towards restoring the credibility of Rehabilitation Science. Hughes questioned whether Disability Studies owes its "very existence to successive reformulations" of the ICF, and

that it has moved away from its "radical roots in the emancipatory discourse of the social model and that impairment becomes a key tool in doing so" (p. 67).

I know from my life experience that removing barriers does not remove the problematic influence of impairment in my life (Shakespeare, 2014). And it is my struggle with the social aspect of disability and the embodied experience of impairment that caused me anxiety on September 16, 2014 - the day I chose to walk at school. The day that my reflections throughout this thesis began to take shape. The orientation and type of thinking about (categorizing) disability, function, and impairment in my adult life surface often, in my personal but also social and medical contexts. As Overboe (2009) described:

Yet sometimes disabled people do not fit neatly into these categories. For example, initially I was judged to be abnormal in comparison to the able-bodied population (Foucault, 1980). In some ways I could accept this designation because I was classified (albeit negatively) as having cerebral palsy which gave me a sense of "identity" (albeit devalued) and "place" (albeit marginal). However, after an incident in my life I began questioning the classification of people. While undergoing a physical examination the head orthopaedic surgeon told the observing medical students that I failed to reach the recovery levels expected of cerebral palsy patients. I was shattered because not only was I not "normal" but now I was also judged to be a "freak" among people who experience cerebral palsy.

(pp. 83-84)

I identify with Overboe's statement because the multitude of challenges I face due to disability and/or impairment are at times not understood, or shrugged off, dismissed by multiple perspectives on *problems* like me. Perhaps this is precisely why Disability Studies as a field could offer so much to further developments of the ICF. In my opinion, Bickenbach (2012) best summarized the need for Disability Studies in further development of the ICF:

...the ICF cries out for participation by the widest and most inclusive range of stakeholders, including, of course, those in disability studies. There is little doubt that the conceptual confusions remaining in the ICF could profit from disability studies scholars, if only they would turn their talent to this enterprise. (Section 5, para 12)

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The elevator slows to a halt and the doors open with a 'ding'. I shift my weight forward and begin to step out onto the carpeted fourth floor. I feel numb, hot, tired, and anxious. Now I can't turn back. I have to walk straight ahead. I can see room 422 right in front of me. I think about what I am going to tell James about this day. I know he's going to ask me at my next appointment.

When I saw James last, he asked me, "Is there anything else you want to talk about today?" as he finished typing up his progress notes on the computer.

"Well," I began, "Not really. I know what to do with my exercises. The big question is how I'll do walking at school", I said as I sat on the edge of the plinth, with one crutch in either hand, staring at my shoes on the blue-carpeted floor.

“You can absolutely do this. And you’ll see a big change in your strength and range of motion over time. You’re at this point now where you can push a bit more.” Quickly he adds, “With structure, of course, because you don’t want to overdo it”. I think to myself, he’s really gotten to know me. I’m the type of person who does not set limits for herself. I push myself hard, too much, and too fast in life and especially with my physiotherapy goals. If James says 5 to 10 repetitions as tolerated, I tend to ignore the *as tolerated* part of his instructions and narrow in on the 10 repetitions. My family will remind me that I tend to “overdo it” and my friends as long as I can remember have labeled me an overachiever, a “supercrip”. The supercrip model is worth mentioning here as I have alluded to, but not specifically labeled the supercrip mentality before: First, in my interaction with Jenn, my physiotherapist who recommended that I quit PT for a while to live the life of a regular teenager. And then again when I initiate a meaningful talk with my parents that I need their help to set limits in my life to help me negotiate my life as a student of occupational therapy.

The supercrip mentality is one I had to let go of, for the sake of recognizing that I am not a problem in society, and that my life is not about overcoming my impairment and thus also my disabled status. When I began my rehabilitation protocol with James after my surgery, Derick often found me at the end of his work days drenched in sweat and in tears because I had worked myself past my capacity. I brought this up with James, and asked him for structure because the concept of ‘as tolerated’ has never been a part of my mindset in the past. In a way, this mindset did not seem appropriate if I was going to live a *normal* life. This has been a byproduct of decades of my attempting to achieve what the supercrip model represents as “...unexpected

accomplishments or live a normal life just like people with no disabilities” (Zhang & Haller, 2013, p. 321). With time James got to know about my history, my childhood experiences with surgeons and therapists and my driven nature to succeed in taking care of my body as best as I could.

Compared to the other available disability models, the supercrip model would appear to be empowering. However, the supercrip model can have oppressive consequences that have been shown especially within media portrayal of high performance disabled athletes (Zhang & Haller, 2013). With respect to how I approach rehabilitation services and interact with my rehabilitation providers, a supercrip mentality caused me to set unattainable goals for myself. I told myself (and this was reinforced by the people around me) that walking was important, and that I should walk as normally as possible by using canes instead of crutches, and to try to walk without leg braces if possible. Again, this experience represents an example of how normalcy as a discourse represents a profound theme throughout my life and how *ignoring my impairment* was of high importance. Jenn often tried to reason with me: “Canes are going to be harder on your wrists and shoulders,” she would explain. But I was stubborn. I built my self-identity on “If I can do it, then I’ll do it”.

James confessed with time that he had never needed to communicate structure to a client. He’s never had to specifically tell a client to not walk more than five minutes at a time or to not give a range of exercise repetitions but a specific number. Over a period of six months he successfully reframed my understanding of rehabilitation specific to my body and hence my impairments. I began to appreciate my body’s way of moving and working with the limited joint

ranges I have and the codependency between muscle strength and muscle stretch, a concept I had never had explained before by a physiotherapist. My decision to work with a physiotherapist like James is an example of my seeking out an expert. Consulting with an expert in services for my health and well-being in turn makes me an expert (C. Minaki, personal communication, February 15, 2015).

When I choose to work with a professional like James, I am giving James consent to get to know me within our therapeutic relationship; to get to know who I am in life, and how I live with my disability, my body, my impairment. I know and have met therapists with power who "...wield that power by imposing inferiority and invalidating labels on those with less power" (Kallen, 2004, p. 34). For me going to a physiotherapist is not just about being taught exercises, it's about being able to "get on with my life" (Hammell, 2006, p. 124). I continually strive to gain some continuity between who I am now, and who I was before. The simple act of aging with a lifelong disability challenges this liminal (transitional) space every day. For me, managing the liminal spaces I exist within means that I seek the expertise of a rehabilitation professional for the sole purpose of getting out of the transitional states that I find myself negotiating in body and life.

What gives James the right to provide a professional service to do with my body? I am an occupational therapist myself, could I not figure out what to do with my impairment needs? This is a question one of my Disability Studies mentors asked me recently, and I reflected on the extreme spectrum of perspectives that can come out of the contested nature between Disability Studies and Rehabilitation Science approaches to disability. Contrary to the beliefs of the harsh

critiques that have arisen over the past decades Disability Studies is not anti-rehabilitation. Disability Studies is, in fact, against the rehabilitation practices that prevail in today's healthcare system. Disability Studies, overall, is against how rehabilitation is done, and how the larger society views the field and the purpose of the field. Occupational therapists and physiotherapists are characterized by professional traits such as trust, respect, knowledge and a belief that the client-therapist relationship will benefit the client (French & Swain, 2008). However, as a person experienced with the client-therapist relationship, from both a client and a therapist viewpoint, I know that "there is often a mismatch between the ideas and objectives of professionals and those of disabled people that has led many disabled people to regard professionals with suspicion" (French & Swain, p. 132). But as I said before, to focus solely on how disability is socially constructed and is thus a political discussion takes away an important experience of healthy disabled women like me who live with impaired bodies through pain, fatigue, and weakness (Wendell, 2013).

The discussion of the body is extensive within disability studies and feminist theory (see Garland-Thomson, 2013, Tremain, 2002 among others). All I want to reiterate here is that we need to open a discussion to both, that we need to talk about disability and impairment as both social and embodied phenomena (Marks, 1999b). We also need to understand that focusing on the body, and the embodied phenomena, over the social approaches and how society constructs disability can result in marginalization, power, and favouring normalizing practices (Hammell, 2006; Linton, 1998; Marks, 1999a; Titchkosky, 2009).

Like Jenn, James demonstrates an awareness that an important therapeutic goal is to assist me in how I redefine my changed self, more specifically, how I find and reconnect with me. The *lived* body over the *physical* body holds the most importance for me. James admits that he has never worked with a person who has lived with a long-term (congenital) disability like mine, and who also comes with professional training within Rehabilitation Science. Over the year and a half that James and I have worked together, he has witnessed firsthand the intricate changes I grapple with in terms of my disabled identity, and the shifts that were thrust onto me as I needed a partner to help me adjust to a ‘new me’ after major reconstructive surgery. This meant trusting James with my body, and seeking his knowledge about my body in order to help me negotiate my impairment; not to overcome my body, but to reclaim it (Rich, 1986; Wendell, 2013). James also has learned that my goal is to live healthy while experiencing chronic, life-long impairment (Kimpson, 2000).

At my appointment I try to explain to James my anxiety about walking.

“It’s like when I’m walking through that building I feel like every person in there is going to do some sort of a gait analysis on me,” I reveal to James. “I can’t tell you how many times people will say to me that they thought I have a spinal cord injury because I look like I ‘have one’.” James knows that I am an occupational therapist and that I study and teach within a medical/rehabilitation science building. Each day I am surrounded by nursing students, medical imaging technologists, personal support workers, doctors in training, students of occupational and physical therapy and assistants, child life development specialists, pharmacists, etc. The environment within which I work and study is all about disability, chronic illness, and health



conditions that require remediation and health services. Although I call my program's building my place of work, I often feel that I don't fit into this environment. I get this sense that people in my own building of work and study see me as a client or patient, a "community faculty" who comes in to assist in the education of students to learn how to manage and help someone like me. I run my hands through my hair and sigh "I know what I'm saying is silly".

James laughed and leaned back in his desk chair. "But wouldn't you rather want it to be those types of students than people at the mall who may not really understand why you walk with crutches?" I paused to think about James' response. I want to ask him: Can any medical professional say that they truly understand me? Do professionals have the right to stare?

Staring represents an intimate experience for me, especially when I seek the advice of a rehabilitation specialist. Of course, as professionals we do not label our assessments and observations as 'staring'. But how professionals label their actions and how these actions feel to me as a client contrast significantly. I have talked about this contrast in earlier stories within this thesis. When I walk, and people stare, it feels like an objectification of me, although the average person staring at me does not bother me, and I can brush the stares off. Having a rehabilitation professional assess me – observe (stare at) how I walk – makes me highly self-aware. I feel as though the rehabilitation professional has Superman-like powers. With a tilted glance they can x-ray my body and peel back the layers to reveal the muscles, ligaments, and joints within and see my most intimate workings. I wonder if therapists ever think about the invasive practice of observing and interpreting a person's movements? To be able to label a person in our minds or on a report as belonging in a certain category of disability, to then accept this label and contently

move on. We do this with many people: we wonder whether a person is pregnant, or whether they are married, etc. But the analysis of the disabled person by rehabilitation professionals has always seemed invasive to me.

Instead I say “Well”; again I look at my crutches in either hand and my shoes on the carpeted floor, “Isn’t it different though? PT and OT students are going to see me through a physical lens. They try to figure out what muscles are or are not working and how that could be changed. Or worse, they might even try to figure out what they would recommend to someone like me. I feel like someone at the mall wouldn’t really put that much thought into my walking even if they gawk at me the whole time.” James shakes his head and then nods in agreement. I can see that he is grasping for words, seeking a rebuttal to my feelings and anxiety.

“Come on, James,” I continue, “You know I’m right. We all do this. We see someone walking and we have a mental checklist as to why they have a unique gait pattern, or what kind of disability they might have”. We both laugh, as trained professionals not too far removed from those rehab school days. “Susan, either way people will look at you, but I don’t think it’s as severe as you feel it is”. I know that what James says is right. Part of me feels that I may be putting too much thought into my anxiety. But I also grow curious of my inner voice, about the feelings that wash anxiety, dread, and nervousness all over me. I have spent years shoving my voice under the carpet. I have spent years comforting my thoughts with statements like “It is what it is”. It’s interesting to me that I am not doing this here, today.

I grab my bag and jacket, get up from the plinth, and smile at James.

“Sometimes I wish that it wouldn’t matter to people how I get around”.

~

“I wish you could change that last sentence” Christina comments after she reads my narrative.

“Why?” I answer. “That’s how I feel.”

“But it doesn’t fit with Disability Studies principles” she adds.

“I think it does.” I reply. Then I lean back in my chair and reflect on it. Why did I write it like that? Is this perhaps a reflection of how I felt in previous years? Did I write this last sentence without thinking it through?

“It’s how I feel,” I finally reflect. “I don’t want to change it because I must have written it for a reason.”

Christina smiles at me through my computer display. Through video chat we toss ideas back and forth. At the end I conclude, “If I change it, I can’t analyze it anymore.”

“That’s true”, she comments as we agree to disagree.

We both talk about how hard it is to find literature that discusses the experience of congenital disability. The experience of acquired disability, although at times comparable, does not parallel the experiences of those of us whose disabled/impaired bodies have always in fact been our ‘normal’. Society strives for normal in everything we do. I have found that when I wheel with Ti, I shake up normal, and shut the door on the “dominant standards and values of ableist societies that might not be in the best interest” of people like me (Hammell, 2006, p. 24). What do I mean by this? In some ways, people see a wheelchair as a device that confines people,

a thing into which people are stuck. In the rehabilitation environment I feel that my ability to walk signals my body as a project (Hammell). When I walk in the rehabilitation building I subconsciously feel the role of Rehabilitation Science as a political practice. I open the door to the social norms that drive this enterprise. It is when I feel the most oppressed and thus the most disempowered. I am highly aware that my walking fits into the idea that I am trying to eliminate the characteristics and traits that threaten what society holds dear. My walking and deliberately leaving my wheelchair in the van signals to observers that I am trying to eliminate my disability.

Perhaps I take on two roles within the rehabilitation building. For some, I reinforce the dominant belief of 'normals' that I am to be pitied in life. If I challenge those beliefs, I appear to be in denial; I appear to have a false consciousness (Hammell, 2006). In a sense this happened to me when I ran into my work colleague on the fourth floor, and also happened when I talked with my family friend about walking and freedom. I find it highly frustrating when people see themselves as more enlightened in their understanding of what my situation should be. Very often healthcare providers assume this enlightened understanding as normal. At times my mere presence within the rehabilitation building, my place of study and work, challenges this enlightened worldview. Thus, in my adult life I carefully choose what types of rehabilitation professionals I would prefer to give my business, as a healthcare consumer but also as a scholar who understands the underlying theoretical issues on disability and impairment.

I know that most rehabilitation professionals know that a wheelchair can be mobilizing and empowering for a person. This is not a new concept. But the feeling that goes with using a wheelchair (versus walking) seems to be less appreciated. Walking still holds more value in

society than a wheelchair does. Walking remains a golden ticket to status in society for patients and therapists. In my case, my Stix – compared to Ti – represent a seemingly black and white extreme along a spectrum I will call here ‘getting around in life’. And people feel the need to pass beyond my private boundaries to encourage me toward a better one rather than a worse other. I am very aware of this each time I take my Stix rather than Ti into the rehabilitation building.

As I have thought this through, I say to Christina that it clearly does matter to me how I get around in my life.

“I’m glad that you see the other side now” Christina comments.

“Ugh, this can all get quite complicated, can’t it?” I sigh.

“You’re getting people to think at least, Susan. Let’s hope people talk about this some more.”

~

I reach 422 and take a deep breath. I glance at the wall clock and notice that I am 15 minutes late to the meeting. “Doesn’t matter,” I comfort myself. I open the door and step inside.

The coordinator looks up and smiles and says, “You made it!”

“I made it” I reply, out of breath. “Although I forgot to factor in that my walking through this building takes a bit longer than when I use the wheelchair”.

“I guess it would, wouldn’t it?” a colleague comments. I smile her way and sit down on an empty chair next to the coordinator.

“Good on you for taking that step,” another colleague says.

I smile at the people in the room and take a sip of water.

“Today I decided to walk to work. That’s all.”

**CHAPTER 8:**  
**“I Walk, Therefore I (Simply) am”**

...living a real life has meant resisting [the] formulaic narratives.

Instead of letting the world turn me into a disability object, I have insisted on being a subject in the grammatical sense: not the passive “me” who is acted upon, but the active “I” who does things.

—Harriet McBryde Johnson, 2005, p. 3



Before I began writing my narrative, I felt the most vulnerable. Thus, I decided to meet with my long time mentor in Disability Studies and the doctoral program, Alison\*.

“It is natural for you to feel exposed.” Alison comments on my vulnerability. “You need to theorize the part of your knowledge where you bump up against disability. The point where you bump up against disability is the part where you bump up against the ‘other’ perspective”.

“I feel that I am grappling with the rehabilitation world,” I admit to her. “I somehow feel that it doesn’t fit for me. And then other times I feel that I do in my own unique way belong.”

“Your choice to use walking as a theme for your writing is unique, Susan,” Alison reflects. “In a way the rehabilitation building is a place of remediation for you. It will help you explore what parts of your life can help or have helped you with your conversion to Disability Studies”.

I think about what my greatest worry represents. I worry about the points in this process where I try to reconcile the experiences between my life within the Rehabilitation Sciences and my life linked to Disability Studies.

“Do you identify as a disabled person?” Alison abruptly asks.

“Yes.” I am struck by my quick answer to Alison’s question. In this moment I feel empowered by theory and knowledge.

“Your experience, your identity is very important,” Alison concludes. “Often experience such as you have is not validated as real knowledge within our world of Rehabilitation Science.

Disability Studies is built on a large culture in the embodied arts. It is about how disabled people move in the world. You belong to this group now. Your life experience is important knowledge”.

## Overall Conclusions

### Why Embark on this Journey?

I walk, therefore I (simply) am. How do I conclude this body of work when I feel that I am just beginning to grasp it? When I feel that after writing this autoethnography I understand for the first time where and why I have something to offer to the discussion on *disability*? At this point within my process it is perhaps time to conclude by exploring where I stood in the past, and where I find myself now. In my introduction I spoke about the red wooden door in my life (i.e. the ‘other’ view of disability) and its role in my having to face scholarly questions about myself as a clinician, and a researcher, and a disabled woman. I do not have neatly unpacked answers to these questions: *How do I view disability? Do I identify as disabled? What does disability mean to me, as a disabled woman and a disabled scholar?* These questions, raised for me the importance of discussing disability and rehabilitation from another side – from opposing world views. I have taken the power and courage to dare to pass through to the other side of the red wooden door.

Just because I have lived with my disability my whole life does not mean that I came into the Rehabilitation Sciences knowing how to share special insights about disability with other people. I certainly had insights to share, and knowledge for others to consider, but I lacked the methodological tools to research and educate others on my knowledge. As I learned about autoethnography, I recognized that this methodology offered me the means I required to bring a scholarly discussion on disability to the forefront. Thus, as a scholar, I am now in an interesting place. I am uniquely situated to disrupt thinking on disability in evocative ways. Just as women

were in feminist studies decades ago, or ethnic groups in minority studies, as a disabled woman and clinician I hold a different position among my academic peers within the rehabilitation sciences. At times this is a lonely position on which I have only recently reflected. I know colleagues who have developed or acquired a disability later in life and thus work as disabled rehabilitation professionals. But I have not met many other colleagues who like me are *lifers* when it comes to our disabilities and impairments. Autoethnography, as part of my thesis journey, grounds my knowledge on disability within a scholarly process of inquiry.

What this work has illuminated for me over everything else is the fact that I lacked a foundation of disability theory within my occupational therapy studies. This lack in foundation, coupled with the normative trajectory my life was on, created a fear within myself with respect to theory and how clinicians and researchers used theories to support clinician reasoning and research. I felt like my classmates and I were tourists in a strange city. I often felt like a native who knew the city and who would help tourists find places to go with the help of their maps (theories). Although I knew the city without maps, their maps helped me understand how my peers planned to explore the city. Within our study groups we followed a rubric to help us outline our assumptions and explore the theoretical underpinnings that would then guide our assessment and intervention processes.

My disconnect from theory, and my natural gravitation – my subjective (internal) way of knowing – towards getting at the answers within action plans (objective), created a deep cleft of insecurity. I could not grasp why, for me, the theories often felt one-sided, incomplete, static, limiting. I spent much time asking peers to explain how *they* understood the theories, so that I could somehow fit myself into that line of thinking. Today I understand that I was trying to

normalize my experience, to *overcome* my disability (physical and culturally) within the Rehabilitation Sciences: this is a concept Disability Studies labels “normative violence” (Titchkosky, 2007, p. 177). If I learned how to think like my peers, then I solved the problem of my disability within my field. If I overcame my insecurities with theory, and my feelings of not belonging, then I had assimilated into the unquestioned normative demand of what disability ought to be. As an OT student it never occurred to me that as students we could venture out of the world of Rehabilitation Science to explore the theoretical foundations in literature that pertained to both rehabilitation and disability.

When I returned to pursue my doctoral degree, I was introduced to Disability Studies. Disability Studies was mentioned as a field among others that conceptually had something to offer to the study of disability issues. We did not need to include Disability Studies within our coursework and assignments. However, I felt intensely connected to the writers and theorists within this field. The writers dramatically challenged my definition of disability and my identity as a disabled woman. All of a sudden I found myself connecting to an academic discipline that spoke of disability in a socio-political way, and also a discipline highly critical of the rehabilitation professions and medicine within which I was housed. I did not know where to organize, along my academic journey, the tensions I felt within myself regarding perspectives on disability and rehabilitation, how these tensions came alive in the works of this influential field. However, I felt permitted to explore these tensions, even though I still cautiously focused on assimilating myself into the Rehabilitation Sciences environment – to insert myself into the business of disability as usual.

As a clinician I felt loyal to Rehabilitation Science. More importantly, as this thesis work illustrates, I live as a disabled woman who has regularly required rehabilitation services throughout her life, and thus I actively seek rehabilitation services today. My very life experience and lifestyle clash with the critiques of the Disability Studies writers. As a client, I have the *power* to choose with whom I work, and finding the right fit with therapists and medical providers is something I have prioritized in my adult life. I was powerless as a child and young adult, but I am no longer powerless. Yet I live in a system that does not respect this *choice* with ease.

Thus, I struggle to summarize this body of work, as each reader will derive different meanings from my story and the theoretical tensions embedded within it. My experience of living with spina bifida over the past 37 years and being educated as a rehabilitation professional represents a powerful narrative in my life – personal, social, cultural, and political. I began my doctoral journey by trying not to bring my personal connection to disability theory out into the open. I could not do it. Meeting other disability theorists with disabilities similar to my own forced me to face the reality that my efforts at separating disability experience from knowledge meant that I was oppressive toward myself. By not passing through the red wooden door, I was caged in my life and in identity. This body of work represents the great risk that I took during a time when I continuously tried to shut out the *personal* and instead opt for the *scholarly*. Narrating my experience of disability and rehabilitation in order to offer the reader and myself useful knowledge assumes the form of a highly personal but also hopefully scholarly work-in-progress that has been selected with cautious attention by me as a marginalized narrator. Yet, in a sense, my work only assumes a partial form of me as a person.

As I have passed through the red wooden door, I have left it open for others to follow – for others to join me in my goal to illuminate the theoretical depths of social relations to do with interdependence (Chapter 3), power and powerlessness (Chapter 4), client-centred practice (Chapter 5), and ableism (Chapter 6). More importantly, my work illustrates how these concepts bump up against the ever pervasive demand of normality within society, perpetuating the stereotypical assumptions of *disability as usual* without being challenged, critiqued, or simply reflected upon. A critical reflection on these concepts steeped in society's normative demands opens a possibility (for me and the reader) to explore the political tensions in conceptualizing disability and developing discourses on disability and impairment between two fields that sadly often do not see eye-to-eye. This body of work, therefore, is a result of my identity as *disabled*. I have identified as belonging in the disabled world, culture, and way of thought about disability. This identity has offered me a unique opportunity to disrupt how disability is viewed within my profession and academic field – the Rehabilitation Sciences – and open possibilities to research, teaching, and social and political action regarding how this field should approach disability and rehabilitation.

### **Contributions to Understanding Disability and Rehabilitation**

Many times throughout my process of autoethnography I felt vulnerable. I still feel vulnerable now, even though I am drawing this process to completion. I pause to ask myself whether this work is *worthwhile*? I was afraid: afraid to speak up about perspectives and attitudes on disability, lost in a perpetual cycle where those of us born with our disabilities do not speak up, do not challenge, do not complain. I did not want to be a *shit disturber*. I did not want to be

viewed as ungrateful. So ingrained is this way of thinking that I was surprised, in writing my own story, how much the normalized, medicalized thinking about my disability and my body had seeped into my language, penetrated my internalized self-concept of who I am as a person.

I have attempted to offer a unique contribution to Rehabilitation Science knowledge, but also to the field of Disability Studies. I have experienced a transformation into a disabled theorist, within a field where some recognize the need to draw disability theory into rehabilitation thinking. This transformation is powerful yet also one I am required to meet with respect. My story within this thesis explores, in an evocative way, my relationship as a disabled child and woman with the Rehabilitation Sciences – in life and in academia. The struggle of normality within my profession drives certain ways of theoretical thinking (French & Swain, 2008; Hammell, 2006), where those ways become dominant over others. The normative discourses with which I struggled through my narrative are pervasive elements in my life trajectory. I respect this today, but I do not accept it.

Disabled scholars, whether we are writers, researchers, advocates or educators, are immersed within an atmosphere where it is expected that we step outside of our disability experiences. These expectations remind us that true qualification (in the opinion of a *normal* society) comes from being able to write, research, and educate about a *normal* life (Minaki, 2011). Disability Studies supports me with holding my disability close, not at a distance. Holding my disability close will not disqualify me as a clinician and scholar. I am not simply telling my story. I am shaking up the normalizing tendency to view someone like me, with a story of

disability, as unfortunate, tragic, and broken. Rehabilitation Science needs work that disrupts normalizing thinking in order to lay a foundation for research, education, and policy.

Autoethnography, as a methodology, offers me a unique way to explore the ‘other’ side, the side I have shied away from for the majority of my life. I can reflect in a scholarly way on the experiences I have had in life, and the interactions I have had with the people in that life. My experiences challenge and also encourage me to venture beyond the normal, the typical, the traditional. My experiences have created an opportunity for me to work with the literature, to challenge the literature beyond theory. I have reflected for half of my doctoral studies on the Disability Studies literature, to understand that themes like power, ableism, and independence are (or certainly can be) oppressive dimensions in the lives of disabled people. I have shied away from theoretical arguments surrounding client-centred practice, my embodied experiences of these themes relating so intimately to disability and rehabilitation theory. How could I not read this literature with a lived connection to my own experiences within these – to me – very *real* themes?

My life story also allowed me a separate connection to Rehabilitation Science that some Disability Scholars (and thus also disabled people) do not have. In this sense, this body of work reveals (at times explicitly) the intricate complexities of disability and rehabilitation – in my life, and possibly the lives of others with similar experiences. A conundrum for me, perhaps, occurs with respect to how I *appear* outwardly, as a disabled woman, versus what I have lived through. I am a white female who grew up (albeit disabled) in a middle-class family, and am still economically privileged over other disabled people. I am married, I drive, I own a house, and I



am relatively healthy (albeit disabled). My outward appearance, as a woman with spina bifida, situates me differently than a woman with the same social status who may live with for example, cerebral palsy. As the disability hierarchy suggests, a woman with cerebral palsy may *look* more disabled than I. But this is deceiving, as this woman may not have had as many surgeries as I have had, and may not live with severe chronic pain. For this reason, my lived experience gives me an opportunity to work on activism within the Rehabilitation Science community, as a disabled clinician and researcher. My life experiences encourage me to translate knowledge for the field of Rehabilitation Sciences in addition to remaining committed, as many Disability Studies scholars are, to prioritize the overall rights of disabled people in society. I understand that my “I”, my self, is uniquely narrated, unique to me and the relationships I share with the others in my life.

I am confident today that my lived experience with my most recent leg surgery and recovery were the catalysts to disrupt the literature, to disrupt practices, to disrupt theory. Just as I was surprised through this body of work that so many of the normalizing themes of ableism, disablism, independence versus function, power and powerlessness emerged throughout my story, I was surprised how my story links Disability Studies with Rehabilitation Science. My story illustrates the necessary relationship between disability and impairment experiences – a relationship that I cannot ignore any more. In this moment, my thesis work forces me to take a side. Creating knowledge about my disabled body and impairment experiences, in the midst of socio-political issues of normalcy, power, ableism, institutionalization and independence, greatly shapes my subjectivity – how people view me, and how I may internalize those views.

I cannot wrap up this research by providing an answer to all of the questions and reflections that I have revealed within this work. I set out to explore a journey that would reveal to myself – and the reader – how I have come to reconcile disability and rehabilitation as interactive concepts. I have created knowledge that reflects more my process of *becoming* a disabled researcher rather than *being* one. The discourses I raise within this research matter not only to me and my disability experiences, but matter also to the socio-cultural responses to my experiences. As a result, this type of work has empowered me and has opened communication broadly about issues of social justice.

I have attempted to open up this narration to readers (whether they read from within the Rehabilitation Sciences or beyond) to disrupt their notions on disability and rehabilitation, and to support their reflections and questions that they themselves may bring on this topic. I am also answering the call from within Disability Studies to bring disability theory to the forefront of the discussion *within* the Rehabilitation Sciences. There is no single best way to do this. In recent decades, partnerships in the research process have become mainstreamed, across many disciplines, including Rehabilitation Sciences. Proponents of disability research warn that establishing such research partnerships is not enough (Thomas, 2002). Such partnerships risk perspectives and research approaches based on social model thinking, which I explored in Chapter 7 as an outdated ideology that some Disability Studies scholars argue is in need of revision. I have answered the call of disability theorists to “write [myself] into the analysis” (Barnes, 2004a, p. 32), and to identify the relationship between the subjective experience and the objective action required in the outside world. I have also produced a body of work that intentionally draws out themes of normality and thinking of ‘disability as usual’. I

recognize that at this point of my process, I have challenged my own internalized stereotypes and assumptions of disability in my life. Thus, as a researcher or scholar interested in a disability research partnership, I bring an understanding about normative research processes on disability. I openly resist the normative violence in my life and within my academic environment. This is perhaps the greatest contribution of my work to both fields.

### **Implications for Future Research**

Throughout the research process, my choice of autoethnography as a methodology had a significant and unexpected impact on the transformation of my parents as I explored disability and rehabilitation. I had to learn to sit with the ‘relational’ silences in my story, those silences that forced me to take a step back and recognize that my story occurred in relationship to others, even when there were silences. As a reflexive narrator, I decided to intentionally bring in other silenced voices – like those of my parents – to help me recover a more social, external voice.

Several times throughout my interactions with my parents (whether they read my narrative or discussed it with me), I found myself reflecting on the different ways each of my parents inserted themselves into my story. My father, a logical thinker and problem solver, an engineer by training, represented the normalizing narrative in my life. I have teased out some of these themes of normality throughout my analysis, recognizing my father’s role in helping me find balance between health, function, and disability. My father was particularly impacted by my cultural exploration of people’s actions, my situatedness within those interactions, and the themes of power and independence and the resulting impact of us as a family unit. Not only did he remember every surgeon’s name and their surgical fellows and residents, he spent days on the

computer searching them out, exploring where they ended up and what perhaps they are doing now in their careers. This is when he stumbled across the quote I have used to open *Chapter 4: I walk, therefore I am oppressed*. This experience was the first time I have seen my father question medical advice, and to voice the powerlessness he felt during that time. His transformation created the drive my mother needed to read my narrative, as my mother had initially shied away from *our* past. My mother was reminded of the social roles she assumed as a parent with a disabled daughter who fluctuated at times in extremes between healthy and unhealthy disabled labels. She was immediately taken back into a time of helplessness, judgment, and abandonment by the medical system. She feared that I, as her daughter, might in fact blame her in my adult life for decisions that my parents made for me. This research was hard work for the three of us. It was emotional, raw, and intimate.

During this time I was plagued by a worrisome thought: suppose that my parents were to participate in a research study exploring their experiences of raising a child with spina bifida. Could a researcher or scholar undertaking the interviews and analysis possibly interpret their stories through a perpetuated lens of normative violence? I did not expect that the transformation I had with respect to assumptions of normality within my life, might be critical to a parallel transformation for my parents. So profound was the reflection of my parents with respect to how they embodied their participation within my autoethnography that they dared to ask questions that they would not have asked before.

“Do you think that these disability theorists would have told us that we raised you wrong?” my father asked me one evening at the dinner table. This single question created an

interesting conversation with respect to what is *normal* – what was normal for us as a family, and what was normal for the medical specialists who were tasked with providing advice and care throughout my life? More importantly, what was normal to the very medical professionals whom my parents trusted as experts? In the end, this research process created for us an environment where we could safely wrestle with the assumptions to do with normality and disability as usual – for us to let those assumptions go. During this process, my parents needed me to give them permission to reflect on their experiences. But more importantly, both of my parents needed me to show them how to voice their experiences within the oppressive system in which they raised me. To give them a language to communicate through the normal, to me, has significant implications for research and practice within the field of Rehabilitation Science.

### **Implications for Education**

With respect to the educational setting, autoethnography offers potential not only to researchers similar to myself (those who live with diverse cultural knowledge), but also for a group to explore the cultural tendencies and orientations towards particular problem scenarios. For me, the greatest implication of a Disability Studies perspective has been to disrupt the medicalization of disability within my teaching. I have discussed throughout this body of work how ingrained this way of thinking is in rehabilitation practices. A significant challenge for me has been to find a way to break my silence and to disrupt the normalizing discourses that we reach for in our theoretical toolboxes in teaching. This does not only apply to me because I have unique lived experiences. The ability to disrupt normalizing discourses is available to any clinician and educator interested in disrupting traditional medical perspectives.

The difficulties inherent in educators challenging medicalized thinking lies in the fact that the language used within Medicine and Rehabilitation Science focuses very much on medical problem solving rather than the broader social and cultural spheres within which disabled people are embedded. This has been a particular interest for me as I have come to appreciate the critiques that disability theorists have about rehabilitation practices and the overall assumptions by rehabilitation professionals about the disability experience (Mahipaul, 2015). Below I highlight an example of how I helped occupational therapy students challenge medicalized thinking within a problem based learning scenario at McMaster University.

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The second year occupational therapy students decided to begin their problem-based learning term with a case scenario featuring a young woman, Chloe Atkins (2010), with symptoms of myasthenia gravis (undiagnosed) but having been diagnosed and hence labeled with conversion disorder. For the reader who knows little about conversion disorder, patients diagnosed with this disorder often exhibit debilitating neurological symptoms, without have an underlying neurological impairment. Thus they often require psychological treatment and intervention in addition to neurological rehabilitation (Atkins, 2010). At that time, having delved into the Disability Studies literature, coupled with my lived experience with medical specialists and rehabilitation professionals, I found myself uncomfortable in how the students endeavoured to set their problem-based learning objectives for the scenario.

“I think we should look at what myasthenia gravis is” one student commented. Then another student added, “And maybe we should look at energy conservation and education.” The

six students around the table nodded as they wrote their lists of learning goals and assumptions. Another student asked, “Should we look at conversion disorder? I have never heard about it and I would be curious to read up about the psychological needs of a patient with that”. Again everyone nodded and wrote into their notebooks. They all looked at each other again and then the student to my right said, “Cool, okay, we know where to begin now”.

I looked at the students sitting around the large table. I marvelled at their growth – they were almost entry-level clinicians – and they required little guidance from me at this stage in their training. But I could feel my heart beat hard in my chest as I grappled with myself internally. “Susan, you have to say something here,” I thought to myself. “This seems very one-sided to you and you know it.” “Say something, NOW!” I screamed at myself, knowing that the moment of opportunity would be lost within seconds.

“I feel like I need to interject here.” I began to speak. 6 pairs of eyes looked up at me. “What else can you gather from the scenario that you haven’t listed as an assumption or learning goal?” Silence. The students hovered over the pages trying to scan for an answer to my question. I patiently waited.

“We could look at how her partner experiences her illness?” One of the students breaks the silence. “Her partner is an OT, right?”

“Sure, you could do that” I agreed. “But what else are you assuming if you chose to follow the initial learning goal list you have just outlined?” I continued to push them, more confident in my reasoning now. Again there was silence. After a few moments I decided to give them the answer.

“You are assuming that she indeed has conversion disorder. You are labeling her as a difficult patient without giving her the benefit of the doubt. You essentially have taken her power as a client away before you have even met her. You are taking the evidence of what your colleagues have said about ‘her’ and not giving her a chance to advocate for herself.”

One of the students leaned back in his chair and commented. “Honestly I don’t know what I would do. But you’re right, we are assuming things before knowing all sides.”

“You are medicalizing her case without paying attention to her experience of her condition within the medical system. How do you think she feels having no one believe her? She is essentially medically ‘charged’ with making up her condition. What does this mean to you?”

The group eagerly looked at me again. Silence told me that they wanted to hear more of my reasoning.

“Would you say something to your colleagues?” I asked them. “If you felt even a sliver of doubt in her diagnosis, would you say something to a colleague who believes that she is ‘faking it’?” I felt passion rising within me. I was invested in this topic because I personally understood the interactions this client lived through with her medical professionals.

“Is this case about advocacy?” one of the students asked.

“I don’t think that these kinds of situations happen that often,” another student added. I found myself shifting in my seat.

“I have to disagree with you on this point,” I began to explain. “Clients experience being misunderstood and mislabeled by their healthcare providers every day.” I took a deep breath.



And suddenly, in my determination to paint a picture of the client experience, I found myself sharing a few of the difficult experiences I have shared within this thesis.

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Researchers and educators within the Rehabilitation Sciences must understand that we are embedded in a culture and environment that perpetuate disability as deviance, and as a medical problem that requires remediation. As rehabilitation professionals, we do valuable work every day. However, we must critically reflect on the services we provide, and more importantly critique the assumptions we make about clients and disabled people in general (Guenther-Mahipaul, 2015). This process was meant to make knowledge (i.e., Disability Studies literature) more accessible for a Rehabilitation Science audience. I understand that in many ways, the rehabilitation world exists in parallel to Disability Studies, where few Rehabilitation Science professionals engage with this vital literature. Rehabilitation Science as a field can take on important roles in breaking down barriers, supporting advocacy, and recognizing disability as a social justice issue.

As educators, we can assist students to frame disability as a social justice issue through a Disability Studies lens. Students need opportunities to understand the history of disability in the healthcare system, and to appreciate the goals of the disability rights movements across the globe. In addition, Rehabilitation Science, as a field, needs to acknowledge the struggles that disabled people face in their lives. We have seen important political and legislative improvements with respect to disability rights, however these improvements are ongoing and in need of support, further development, and growth. An important place to start is to have students

reflect on the language and discourses that continue to be underpinned by a biomedical definition of disability (e.g. Linton, 1998; Ross, 2013). I do support the revision of the social model (see Chapter 7). That being said, what the social model gifted us is a definition of disability that helps students break down discourses on disability that focus on the ‘us/them’ dichotomy, critically consider the use of ‘person-first’ language, and consider the impact of disablement in clients’ lives. With such an orientation towards learning, we can avoid the pitfalls of medicalized thinking within Rehabilitation Science education.

### **A Path Forward**

How am I, as a rehabilitation science scholar and educator, going to add to a foundation of disability theory? How can I mitigate the tensions between disability and rehabilitation, and between two important fields such as Rehabilitation Science and Disability Studies? Autoethnography holds promise for researchers interested in contesting authority, representation, voice, and method in order to move fields forward in how they connect social sciences with literature (Ellis, 2004). I chose to situate myself within post-structural thinking throughout this research process for the very reason that I wanted the reader to derive meaning and truth from my perspective, based on how the reader chooses to interact with my story. It was important for me to have the reader participate inter-subjectively, to insert some of their own life experiences into my story so that they might make my story theirs, and thus understand the broad theoretical issues represented within (no matter within which academic discipline they are situated).

The simple act of the reader and me presenting to each other throughout this body of work represents a method of dissemination: to create and move knowledge forward within

academia and beyond. Autoethnography has offered me a way to tell my life story and challenge the stereotypical and perpetuated societal ideas about disability that I am surrounded with in my everyday life. To challenge *disability as usual* is why I chose to immerse myself within this work at the doctoral level and not just write an autobiography that readers may interpret through the entrenched lenses of normality. As Harriet McBryde Johnson explained,

Of course I worry...As much as I resist, those dominant narrative templates may be imposed from without. All readers come with their own perspectives; inevitably, some will read through the filters of social expectations. In this medium, I can't adjust the tale as I go along, based on individual reactions. I must fix it once, knowing the conversations will move on without me. (Johnson, 2005, p. 5)

I intend to revise this thesis work into a publishable book to reach Rehabilitation Science readers, but also to contribute to existing autoethnographic works published by Disability Studies writers. Much of Disability Studies literature exists in the form of books and chapters within edited books, whereas, dissemination and knowledge translation within the Rehabilitation Sciences occurs primarily in academic journals. I will revise parts of my thesis into shorter manuscripts suitable for academic publication within the Rehabilitation Sciences. I also plan to write one or more manuscripts detailing autoethnography as a methodology to add to body of works in qualitative inquiry that explore narrative research in both Rehabilitation Science and Disability Studies. I am interested in developing teaching materials, lectures, and workshops on

autoethnography for Rehabilitation Science researchers, in order to introduce reflection by researchers on cultural practices and discourses on disability and rehabilitation.

Finally, I intend to become more involved within Disability Studies organizations and associations to contribute to community advocacy and social justice agendas. Many Disability Studies scholars critique academia for failing to respect and acknowledge the reality of disabled people in our society and thus challenge scholars to step outside of academia into the social (real) world. There are many champions in Disability Studies across Canada and I intend to reach out to them to share my work and to seek advice on how to build on this work for further contributions in the area of disability and rehabilitation knowledge. I am interested to explore avenues for partnership initiatives between Disability Studies and Rehabilitation Science stakeholders, where champions can contribute knowledge on research practices that attempt to merge lived expertise with academia.

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I see myself differently at this point than I did when I began this research. My autoethnography provided me an opportunity to creatively re-discover myself through an empowering research process, and to realize how I am also situated within a socio-cultural journey. This journey has not come to completion here; rather, it has begun. My analysis challenged my story, fluidly drew more experiences in and out, to transform my understanding of myself and the experiences I have had. This is a level of consciousness that I would not have reached were I not to have included my personal experiences. The value, and meaning, that I

have discovered with respect to narrating and '*re-searching*' my experiences with disability and rehabilitation were empowering. And thus I have to conclude that they were worthwhile.

There are aspects of foundational theoretical works within Disability Studies that I have not explored within this thesis. These foundational concepts represent a path forward for me. For example, the impact of social justice in my life has to be narrated parallel to rehabilitation experiences. Rehabilitation, as a whole, perhaps represents a small space under an umbrella of social justice, that draws into it many more interactions with people and family and colleagues that I could not include within this body of work. As part of the highly theoretical explorations of Disability Studies I also need to delve deeper into an exploration of the body, and feminist theory with respect to disability. This will represent a risk that I accept as I attempt to explore and accept critique from within Disability Studies to discuss impairment and the body in relation to disability and rehabilitation.

For the purpose of this thesis, each of my chapters creates an entry point to disrupt disability and rehabilitation from which I could venture into deeper theoretical analysis. In fact, I intend to continue my exploration in these areas, specifically within the wider social discourses to do with the congenital versus acquired disability experience, and social and political impacts of disability hierarchies within which many of us are slotted. Autoethnography lends itself well to exploring topic areas that are entrenched in tradition, power, and ideology (Ellis et al., 2011).

Autoethnography is not for every researcher. Experienced researchers warn that autoethnography does not mean easier research – an easy way out of the labour-intensive traditional qualitative research approaches that include literature reviews, identifying research

questions, data collection, and analysis. I at first heeded their warnings, understanding that graduate students can falsely assume that if they have a story to tell, they can easily write about this story for scholarly merit. Did I have a meaningful story and epiphanies? Was I able to look outside of my experience and reflect on how others interacted with me? Did this work mean something only to me? Or did I feel that my story belonged as part of the larger community within which I live? I trusted the works that have come before mine. Autoethnographic work provides fertile ground for individual and community (social) transformation. For me, this work was not about telling a story of *what people did to me*, rather, I was “telling on myself in the context of culture” (Alexander, 2011, p. 551). Thus, I see potential for using autoethnography within the Rehabilitation Sciences as a research methodology that can bring a group of people together to illuminate the political happenings of society and culture.

Within practice, autoethnography shows promise in connecting practitioners’ personal experience with practice context (Bright et al., 2012). I see potential for research participants to come together and narrate their experiences rather than answer questions, and for researchers themselves to connect their experiences as part of this process. I see opportunities for research teams to reflect on and analyze underlying assumptions with respect to disability, normalizing violence, and partnership practices. I anticipate that Disability Studies scholars can collaborate on how, effectively, to narrate theoretically complex concepts, steeped in lived disability experience, in accessible ways to wider audiences.

Finally, as a disabled woman, and one who grew up lonely and alone within her disability experience, I see potential of autoethnography to reach disabled children and adolescents who

may not know how to talk about themselves and who yearn for a language and discourse *about* them, *for* them. I see great power in autoethnography for this purpose, in research, in teaching, in people's own private environments and within greater society.

### **A Final Thought**

I gravitated towards autoethnography because I felt it important to explore how I could create knowledge based on my disability experience and my embodied experience of activism and knowledge. I have been rooted within my disability community as an advocate and public speaker. This thesis represents my first attempt, in writing, to create resistance to the dominant socio-cultural forces I live within/among and to disrupt the normalizing discourses within Rehabilitation Science. But it is also a way for me to disrupt critiques on rehabilitation practices within Disability Studies. Although I advocate for a shift in perspectives, I realize that it is not that simple for the rehabilitation professions to change the core underlying theories and philosophies that underpin our practice models and research. In fact, I know that this shift is already in motion. To consider bodily impairment and social limitation by combining “the best work from both fields holds tremendous promise in supporting disabled people” (Mahipaul, 2015, p. 204).

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In autoethnography, it is the reader who assesses and determines the quality of work (Ellis et al., 2011). At the end of this process I do wonder whether I have met the standards required for doctoral work, especially the level of critically interpretative work I have chosen to

complete. I draw from the work of Judith Meloy (1994) in order to offer the reader six abridged criteria or suggestions from which to judge the quality of this body of work.

- Verité: Does the work ring true? Is it consistent with current and accepted knowledge in the field, and if not, does it explore why? Is it intellectually honest and authentic? Does this work disrupt and perhaps unsettle taken-for-granted notions (e.g., of disability and rehabilitation)? Are power differentials underlying to the experience of disability explored?
- Integrity: Is this work structurally sound? Did the researcher appropriately lay out and design the research process?
- Rigour: Is there sufficient depth to the reasoning within this work? Does this work transcend fixed forms of subjectivity?
- Utility: How relevant is this work? Does it contribute to the fields from which it emerges? Does it open new research directions or avenues for action?
- Vitality: Is this work important, and meaningful? Does it show the reader a sense of vibrancy, dependency, excitement of discovery? Does the researcher write with an appropriate voice? Is the reader left with powerful metaphors and imagery?
- Aesthetics: Does this work offer the reader insights? Is it enriching, perhaps pleasing to anticipate and experience? Does it touch readers' spirits in any way?  
(Meloy, 1994, pp. 44-45)

I leave the reader with these questions, not to summarize the quality and merit of this work, but in order to stimulate and open a conversation on the possibilities this research enables.

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I am on the other side of the red wooden door and there is a new world for me. This is where I am *now*. I have found a different way of thinking. I am experiencing embodied ways of



knowing. I belong and am situated as part of a whole made up of multiple and connected voices. My analysis of this work required a transformative consciousness – a consciousness that demanded that I meaningfully reflect on my experiences and find value in my voice. As I have crossed the threshold of the red wooden door I hope that I have opened the world of the other side to the reader. If so, this will have made my research and narrating my experience worthwhile.

~

“As I was walking today, in the rehabilitation building, I realized that I *am* a Disability Studies scholar.”

—Susan Mahipaul (Sept. 16, 2014)

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Inspiring Innovation and Discovery

## APPENDIX A

### LETTER OF INFORMATION/CONSENT FOR POTENTIALLY IDENTIFIABLE PARTICIPANTS

#### **“I walk, therefore I am...”: Multiple reflections on disability and rehabilitation**

##### **Principal Investigator:**

Susan Guenther-Mahipaul  
School of Rehabilitation Science, Faculty of Health Sciences  
McMaster University,  
Hamilton, Ontario, Canada

##### **Doctoral Supervisor:**

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##### **Purpose of my study**

The purpose of my research is to explore my life story as a woman living with spina bifida and who also works as an occupational therapist. I wish to better understand how my profession understands a social and cultural phenomenon like disability. I am conducting this research as a requirement for the completion of my PhD in Rehabilitation Science.

##### **Procedures involved in my research**

Because I am telling my life story, you can imagine that people in my life also appear in that story, including you. My intent is not to tell my whole life story and details of our relationship, but to focus on specific encounters that I have had, and possibly you have had along with me, with the health care system, doctors, and rehabilitation professionals about my disability. I want to tell those stories so that my experiences can help readers understand key themes of what it is like to live with a disability and the impact that rehabilitation services (e.g., positive and negative) can have on this experience.

I want to be sure that you are comfortable with how I describe our relationship and interactions. Therefore I will provide you (by email) a draft of the sections of my story in which you appear. I want to give you an opportunity to respond to these story sections, whether you liked or did not like reading them. But if you are uncertain of how I talk about you or wish to talk about what I

have written, then we can meet to talk about your comments and questions. I will then revise my story based on our discussion. If you are not comfortable with anything that I write in my draft, then I will not include it in my research.

### **Potential harms, risks, or discomforts**

It is not likely that there will be any harm or discomfort that results from you appearing in my story and research. However, I do write at times about stories that deal with emotional issues and topics that involve stigma and discrimination. I will check in with you regarding how and to what extent you are implicated in my stories before finalizing all drafts. If, for any reason at this point, you are not comfortable appearing in my stories, then you can withdraw your participation (as detailed below).

### **Potential benefits**

Some potential benefits of this study could include enabling rehabilitation and medicine professionals to better understand the disability experience. Family members of children with spina bifida and other congenital birth defects may learn more about the lived disability experience over time. This study could also benefit with respect to how medical professionals are trained, and how policy and research are developed and conducted.

### **Confidentiality**

As much as possible, your identity will be concealed. However, since our personal histories and experiences overlap significantly, others might be able to identify you through some of my story's details or through your relationship to me.

I will keep all information that involves you in a locked cabinet where only I have access to it. Information stored on my home computer will be protected by encryption. Once my study has been completed, the information in which you are implicated will be securely stored and destroyed with the remainder of the data, after 5 years.

### **Participation and withdrawal**

Your participation in this study is voluntary. You will be able to withdraw without question or consequence, at any time until May 11, 2015 at which time I must begin finalizing my thesis for submission. After May 11th I will not be able to withdraw the stories that you appear in or the data you provided regarding the stories. I will expect that you notify me verbally, as soon as possible, whether you would like to withdraw from my research, or whether you agree to be included as described in this letter.

### **Information about the study results**

My study will be completed by the end of September 2015. If you would like to receive a brief summary of the results or notifications of any outcomes of this research, please let me know (below) where you would like it to be sent.

**Questions about the Study**

If you want to talk with me at any time about the stories and your participation, please contact me at: [mahipaul@mcmaster.ca](mailto:mahipaul@mcmaster.ca)

This study has been reviewed by the Hamilton Integrated Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

HiREB Coordinator  
Tel: (905)525-9140 ext. 42013  
Email: [mazzedeb@hhsc.ca](mailto:mazzedeb@hhsc.ca)

**Consent:**

- I have read the information presented in the preceding information letter about the research being conducted by Susan Guenther-Mahipaul, PhD candidate at McMaster University.
- I have had the opportunity to ask questions about my possible participation in this study, including the risks and benefits, and to receive additional details if requested.
- I understand that if I agree to participate in this study, I can withdraw my participation partially or fully, without consequence, at any time until approximately May 11, 2015.
- I have been given a copy of this form.
- I fully agree to participate in this study.

Signature: \_\_\_\_\_

Name of Participant (printed): \_\_\_\_\_

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

Name and signature of witness: \_\_\_\_\_

In addition to participating in this study, would you like to receive a summary of the findings and/or notifications about any outcomes of the research such as publications or presentations?

Study results: Yes or No (**circle one**)  
Notifications about outcomes: Yes or No (**circle one**)

If yes, please send to this email/ mailing address:  
\_\_\_\_\_  
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## APPENDIX B

Inspiring Innovation and Discovery

### RECRUITMENT SCRIPT FOR POTENTIALLY IDENTIFIABLE PARTICIPANTS

#### **“I walk, therefore I am...”: Multiple reflections on disability and rehabilitation**

**Principal Investigator:**

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**Main points to cover when recruiting/connecting with all participants in my life story:**

1. I am conducting a research project that looks at how I, as a disabled woman and occupational therapist, have come to understand disability within our society, culture, and within my own profession.
  - a. I am conducting this research as a requirement for the completion of my PhD in the Rehabilitation Sciences.
2. I have selected you as a potential participant because you are an important figure in my life story.
3. Your participation in this research would involve
  - a. reviewing draft sections of my thesis in which you appear
  - b. meeting to sign consents and/or discuss how you appear in my story
4. Your confidentiality will be completely protected
5. I do not expect that you will participate in my thesis work. I can complete my thesis work even if you chose not to participate.
6. If you decide that you do not want to participate or are uncomfortable with what my thesis work is about, our relationship/friendship will not be affected in any way.
7. I'm wondering if you are interested in participating. Please take some time to think about it and let me know if you have questions and or concerns.