

Narrative Inquiry into the Lived Experiences of the Diverse Meanings of Disability

by

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Abstract

“To *experience an experience* is to do research into an experience” (Clandinin & Connelly, 2000, p. 50). I intended to study my own lived experiences of understanding the diverse meanings of disability and ability as they were lived by exploring their temporality (i.e., the timeframes—past, present, or future—in which they occurred), their sociality (i.e., the ways in which they intersected with socio-cultural influences), and their place (i.e., the physical and topological locations where they took place). Furthermore, by attending critically to my own lived, told, retold, and relived stories of these experiences, I sought to understand how my own disability constructions were constituted, shaped, expressed, and enacted within and against grand narratives (e.g., cultural historical traditions and assumptions about disability and ability; common ways of thinking about them in certain societies; theories, paradigms, and ideologies related to adapted physical activity). Finally, by composing interesting, thought provoking, and evocative stories and reflections, I hoped to inspire the readers of my dissertation to reflect on and think critically about their own disability construction and practices.

In order to achieve these objectives, I made use of narratives, the storied representations of my lived experiences. These formed the basis, and the subject, of my journey. Clandinin and Connelly (2000) provided the conceptual framework for this narrative inquiry: *puzzling* in a metaphorical *three-dimensional narrative inquiry space*. Like a person putting together pieces of a puzzle, I searched and re-searched for ways to connect fragments of my experience by composing *field texts* (i.e., annals and chronicles, autobiographical stories, family stories, field notes, and daily journals), and I brought these pieces together by interweaving each field text in relation to the others, while responding to questions such as: how my own disability construction

was experienced in relation to particular times, places, and social contexts, and how studying these experiences would be socially meaningful and significant (Clandinin & Connelly, 2000).

As a result, I presented analytic insights of my journey as a series of stories and subsequent reflections. In *Chapter 1: My Narrative Beginnings*, I presented a set of contextual stories about, and reflections on, my experiences of coming to my dissertation research. In *Chapter 2: Narrative Inquiry as Methodology*, I described my pragmatic perspective as a narrative inquirer and the framework of my narrative inquiry. I also presented a story of my own narrative turn in this chapter. In *Chapter 3 Methods*, I provided methods of this inquiry, including the processes of composing field texts, moving from field texts to a research text, and composing a research text. In *Chapter 4: My Own Disability Construction*, I presented the ways in which I came to understand the meanings of disability within and against grand narratives. I highlighted the complexity, temporality, and continuity of my disability construction in particular times and places, and in particular personal and social contexts. In *Chapter 5: Reliving My Own Disability Construction*, I presented the potential implications of my own assumptions about disability and ability for my past, present, and future adapted physical activity practice. I also illustrated the importance of being attentive to reflexivity, “counter” stories, and social responsibilities as ways of opening up ethically framed future possibilities for disability construction and adapted physical activity practice. Finally, I presented the personal, practical, and social meanings of this dissertation journey and my aspirations for my future living and reliving as a reflexive, relational, and transformative narrative inquirer in the field of adapted physical activity in *Chapter 6: Ending Tentatively with New Beginnings*.

The potential contributions of this journey may be: increased awareness and acceptance of lived experiences as valuable sources and sites of understanding disability; recognition of the

self as an integral aspect of disability knowledge generation; acknowledgment of the socially interactive and relational nature of disability knowledge generation; appreciation of the importance of reflexivity to understanding disability and its implications for adapted physical activity practice; enhanced visibility of diverse perspectives in the construction of disability and adapted physical activity practice; and recognition of narrative knowing as a way of understanding disability.

Dedication

To In Hae, Paul, and Reina Soul;

to my parents; and

to all my family.

I am not alone.

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Chapter 1: My Narrative Beginnings

I am a PhD student in the field of adapted physical activity (APA), a cross-disciplinary field of study aimed at the advancement of scientific and applied knowledge related to disability, sport, and physical activity (Hutzler & Sherrill, 2007; Reid, 2003; Reid & Stanish, 2003). I was born and raised in Korea, but I currently live in Canada with my wife and two children while I pursue my PhD program at the University of Alberta.

Let me open with my *narrative beginnings* (Clandinin & Connelly, 2000), a set of contextual stories about, and reflections on, my experiences of coming to my dissertation research. They recount how I entered the field, and how my research interests and assumptions have been shaped and transformed.

My Story, Part 1: Entering the Field of APA

It is hard to imagine my life without soccer. Soccer was part of my everyday life during my childhood and youth. I was the sort of kid who wore soccer shoes everywhere, even in shopping malls and churches. I went outside every single day, rain or shine, to play soccer with my pals until the sun had completely set. Once at home, I watched soccer games or highlights until my mom told me to go to bed. Then, I went to bed with my favorite soccer ball instead of a teddy bear.

I am still playing soccer at the recreational level with my local neighborhood team twice a week. In addition, I now dream about my son becoming a professional soccer player for the world's best soccer team, Manchester United. My son is only 4 years old; yet this is my hope for him. Yes, I am that crazy about soccer!

At the age of 18, I applied to the Sport and Leisure Studies department at Yonsei

University in Korea. I imagined myself becoming a famous professional soccer coach or an owner of the world's best centre for training young soccer players. During my undergraduate program, my soccer life continued. I ran a small children's soccer club, and I was captain of my department's intramural team.

During one of my intramural team practices, I sustained a severe ankle injury. My ankle was not broken, but 75% of my ankle ligaments were torn. My intramural soccer was brought to an abrupt end. I had to undergo surgical operations and four weeks of hospital treatments. I tried my best in my rehabilitation programs to recover from my ankle injury and to get back to my healthy and "normal" life. I followed my rehabilitation doctor's instructions to the letter, because I trusted that his knowledge would cure my injury as soon as possible, and I would be able to return to play.

During the third week of my hospitalization, my routine became monotonous, and I started to feel bored. I asked for permission from my doctor to go outside the hospital in a wheelchair; and the doctor allowed me to do so. I felt exhilarated escaping from my tedious hospital routine. Changing my patient gown to my Nike training pants and T-shirts, I wheeled outside of the hospital. I inhaled the fresh air, closing my eyes, enjoying the sunlight, and stretching my arms.

At one point, I noticed a huge gym at the corner of the hospital. I, the active and kinesthetic lad in a wheelchair, became very curious about what was going on there. I wheeled rapidly to the main entrance, but there were stairs blocking my access. I was quite annoyed. I decided to try the left side of the building, hoping to find wheelchair

access, but there were only stairs. It was very frustrating. Sweating a lot, I wheeled to the backside of the building. I intended to turn at the corner of the building, but there was a 1.5 foot rise completely blocking my way. There was not even a 3 foot gap for me to sneak through. I became very angry.

Wheeling back to the main entrance, I thought about whether I should try the right side of the building or give up and go back to my ward. However, my struggles finding an accessible entrance got my competitive spirit up. Giving up was not an option. I wheeled with all of my strength as there was a slope, but I did not care. I kept on going. I finally saw an accessible ramp attached to the right side entrance. Out of breath, I sat in front of the door. I slowly pushed on the door.

"Oh no!" I cried.

It was locked. I could hardly restrain my anger. I wanted to yell at someone for discriminating against people with impairments by not providing wheelchair access to all the gym entrances, or posting sign explaining where the accessible entrance was. I was especially upset that the only accessible door was locked during business hours. I concluded that the gym operated under a discriminatory policy aimed at keeping people with impairments out of the building.

I wheeled back to the main entrance for the third time. I arrived at the entrance huffing and puffing, my face red. I sat there glaring at the stairs. A person approached.

"Excuse me. . . . May I help you?" she asked me carefully.

I took a few deep breaths, not wanting to direct my anger at her. I explained my

situation and politely asked her to go up the stairs and get a staff member to come down to talk with me. To my great relief, she was sympathetic to my situation and went inside.

A few moments later, a staff member from the gym came outside. I thanked the stranger for her assistance, and she continued on her way.

I turned to the staff member.

"Why is the door on the right side of the building by the accessible ramp locked?" I asked. "I was not able to get in." I did not yell at him as I would have liked to do, but I had a frown on my face.

He did not reply, but he seemed obviously irritated. I became infuriated with his dismissive attitude. After a few seconds of silence, I asked again with an accent on each word, "Why. . .is. . .that. . .locked?"

"Because no one is using it! Everyone is using the front and the back door right by the parking lots," he answered with an annoyed look.

"What about me? I was going to use the door."

"What are you going to do inside?" he asked me instead of answering my question.

"I just wanted to have a look."

With a derisive smile on his face, he said, "Have a look for what? Are you thinking of becoming a member or something? I don't think you can do anything with your wheelchair in the gym. I think that is why we don't have any patient members who use wheelchairs or anything like that. This is a 'fitness' centre."

"How come you think I cannot do anything in this gym?" I did not intend to become a member, but I really did not like that he was assuming my injury prevented me from exercising there.

Several passersby were gathering around us. The staff member did not seem to want to maintain the argument with people watching. He blurted out again, "Listen, man, you would do better to find a gym for the disabled, if there is any. I am not going to open the accessible door for you. You know what? You can join us if you can walk up to the stairs." Then he went back inside.

I just sat there breathing deeply. I covered my face with my hands. Then I heard exclamations from the people surrounding me. "Tsk tsk. . . ." "Oh my gosh. . . ." "Hmmm. . . ." I looked around, slowly and hesitatingly. Their eyes showed me that they felt sorry for me; they pitied me.

"Excuse me!" I wheeled very quickly to get away from the situation as soon as possible.

I went back to my ward, lay on my hospital bed and covered my head with a blanket without even changing my clothes. I felt burning tears covering my face. In my ward that night, I fought to make sense of what had happened to me. My heart was saddened. I had never before experienced being physically denied any sort of access because of who I was. Also, I had never before experienced that much emotional frustration and embarrassment in front of strangers. I just could not believe what had happened to me.

For the remaining period of my hospitalization, I kept asking myself, "Is this what people with impairments go through every day of their lives? Being refused. . .denied. . .excluded. . .ridiculed. . .humiliated. . .embarrassed. . . . Oh God. . .how pitiable they are. . . . Being a person with an impairment must be an absolute tragedy!"

After that, I stayed inside the hospital. I assumed that I would face another awful situation, because I "looked" disabled. I was afraid of exposing myself to the harshness of this discrimination. I never ever wanted to feel that way again. Instead, I used my hospital time to think deeply about how I would prevent these unacceptable experiences of exclusion of people with impairments, and how I would change discriminatory assumptions about them.

It was during my hospitalization that I became interested in an adapted physical activity (APA) academic career at a post-secondary institution. I imagined that if I could teach ten pre-service professionals to challenge discriminatory assumptions about people with impairments, it would be ten times better than merely being only one professional myself. I also envisioned pursuing research activities aimed at promoting social change for people with impairments. As a result, I applied to the APA graduate program at Yonsei University. I thus entered the field of APA.

Reflection: My own disability construction. Reflecting upon these events, I recognized that my negative experiences contributed to my own perceptions of disability. Having been denied the access to the gym, I took for granted that people with impairments were vulnerable, oppressed, and marginalized (Charlton, 1998; Jaeger & Bowman, 2005; Oliver, 1990). Based on my experience of being pitied by the people surrounding me, I assumed that disability must be an

embarrassing and tragic condition in an individual's life (Clapton, 2003). In addition, having looked disabled due to my wheelchair use, I began perceiving disability as something to be avoided or hidden away (Jaeger & Bowman, 2005; Oliver, 1990, 2009; Shakespeare, 2006, 2007; Smith, 2009; Titchkosky, 2003).

My understandings of disability were thus strongly influenced by the so-called *medical model of disability*, which perceives disability as an individual problem, restriction, or lack of ability due to a defect in or failure of one's body (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). From the medical perspective, disability is amenable to medical diagnosis and therapeutic treatment designed to achieve normalization (e.g., regaining my ability to walk through medical rehabilitation) (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). My ankle injury presented me with a mobility impairment, albeit temporarily: I was unable to walk.

People's *attitudes* also dramatically shaped my experience. The staff member's discriminatory attitude was problematic (Reel & Bucciare, 2010; Titchkosky, 2011). Due to my wheelchair use, he labeled me as "disabled" based on his perceptions of my inability and barred me from entering the gym. The attitudes of people surrounding me further contributed to my disability experience as I internalized my new identity (Titchkosky, 2011). I truly felt that I *was* disabled, because they pitied me for my inability and vulnerability.

However, my body's functional limitations and the societal attitudes related to them were not the only factors that contributed to my disability experience (Masala & Petretto, 2008; Roush & Sharby, 2011; Shogan, 1998, 2003). The *built environment* also presented a challenge (Oliver, 1990, 2009). There was no accessible ramp or elevator at the main entrance of the gym; there was no accessible curb cut for the 1.5 foot rise at the corner of the building. Likewise, the *policy*

for building accessibility prevented me from entering the building (Oliver, 1990, 2009). The accessible entrance was locked during the business hours of the gym, and there was no signage explaining where the accessible entrance was.

In sum, the loss of physical function, societal attitudes, and environmental and policy barriers all shaped my disability experience (Oliver, 1990, 2009; Shakespeare, 2006, 2007). My understandings of disability were thus also influenced by the interaction of the medical and *social model of disability*. A social model of disability posits that disability is socially constructed (Oliver, 1990, 2009; Shakespeare, 2006, 2007; Shogan, 1998, 2003; Titchkosky, 2003; Tremain, 2005). From the social perspective, disability is experienced when the social and built environment fails to take account of individual differences by not accommodating individuals' unique needs to access desired places (Barnes & Mercer, 2010; Campbell, 2009; Roush & Sharby, 2011). When there are negative societal attitudes towards people with impairments—attitudes that may discourage or isolate them from full participation in society—the disability experience is created and perpetuated (Barnes & Mercer, 2010; Campbell, 2009; Roush & Sharby, 2011).

Based on these experiences, and my subsequent reflections, I therefore came to understand disability from both the medical and the social perspectives. I believed that disability was a medically oriented individual *problem*, which was intensified by disabling elements within society (Oliver, 2009; Roush & Sharby, 2011; Shakespeare, 2007).

Reflection: My own “best” practices. My disability experience strongly influenced my aspirations to enter and excel in the Master's program at Yonsei University (Campbell, 2009; DePauw, 2000; Northway, 2000; Wolbring, 2008b). I decided that my task as an APA Master's student would be to learn how to integrate people with impairments into mainstream physical

activities (i.e., physical activities which are regarded as typical and conventional for people without impairments) (Block, 1994; Jang, Kim, Jang, & Choi, 1998; Lieberman & Houston-Wilson, 2002). I sought to learn how to promote opportunities for equal *placement* (Block, 1994; Jang, Kim, Jang, & Choi, 1998; Lieberman & Houston-Wilson, 2002).

During my Master's coursework, therefore, I focused on learning effective and efficient adaptation methods for maximizing the participation of people with impairments in physical activities (Auxter, Pyfer, & Huettig, 2001; Block, 1994; Jang, Kim, Jang, & Choi, 1998; Lieberman & Houston-Wilson, 2002; Sherrill, 1998). I thus tended to follow what Jang, Kim, Jang, and Choi (1998) describe as a *for all and together* approach (and which, I now understand, involves a focus on placement rather than on individual choices). My Master's research activities thus focused on how to ensure that people with impairments had equal access to preferred physical activities (Im, Yi, Lee, & Jeon, 2006; Yi, 2005, 2006; Yi & Kim, 2005; Yi, Im, Lee, Kim, Ahn, Yeo, & Jeon, 2006).

During my Master's program, I also decided to actively engage in social activism as a way of resisting and transforming the disabling elements of society (Charlton, 1998; Oliver, 1990; Radermacher, Sonn, Keys, & Duckett, 2010). I believed this was what I could do "for" vulnerable, oppressed, and marginalized people with impairments (Masala & Petretto, 2008; Polloway, Smith, Patton, & Smith, 1996; Reid, 2003; Roush & Sharby, 2011). As a member of a student group advocating for the rights of people with impairments, I protested at university town hall meetings and participated in public marches to increase awareness of the need for accessibility at the university's sports facilities. I sought to prevent discrimination against people with impairments who wished to access the campus sports facilities (Allan, 2005; Atkinson & Walmsley, 2010). I also participated in disability sport demonstrations at a disability awareness

street performance. I hoped to challenge beliefs that people with impairments are not capable of doing sports (Shakespeare, 2006).

In short, my beliefs about best practices in APA, at that time, were founded in providing help for people with impairments to participate in mainstream physical activities (Block, 1994; Jang, Kim, Jang, & Choi, 1998; Lieberman & Houston-Wilson, 2002). I truly wanted to help people with impairments who were going through *personal tragedy* because of their vulnerability and marginalization (Clapton, 2003; Polloway, Smith, Patton, & Smith, 1996; Reid, 2003).

During the two years following the completion of my Master's program, there was a huge transition in my life. At age 28, I came to Canada as a visitor and APA instructor at the Steadward Centre for Personal and Physical Achievement at the University of Alberta. I worked daily for specialized adult fitness programs and volunteered for several adapted programs for children with impairments. I pledged to be the best "caregiver" I could be by providing as much help I could in order to satisfy my strong beliefs about best practices in APA.

However, my daily encounters with the people at the Centre caused me to think differently about APA practice. People with impairments became frustrated when I took for granted that they were always in need of help (Goodwin, 2001, 2008). One day, I changed a machine setting for one of the members of the Centre without asking, because I thought I knew the appropriate setting. I truly wanted to help her in order for her to have better fitness experiences. I expected her to say, "Thank you very much for your kind help," but she said, "Please don't do that again." My charitable and professional approach was troubling, both to them and to me (DePauw, 2000). I became terribly confused about my own beliefs about best practices in APA (Macbeth, 2010; Northway, 2000).

My Story, Part 2: A Troubling Assignment

While finishing my time at the Steadward Centre for Personal and Physical Achievement as a visitor, I experienced other huge life transitions. I got married, and I became a PhD student at the University of Alberta. I began my PhD program with the aspiration of studying the experiences and perspectives of people with impairments who participated in physical activities. I wanted to study what constitutes best practice in APA from their perspectives. However, during the first term of my PhD program, I faced another significant shift in my life—a shift in my research interest. The turning point began one day at dinner with my wife.

"David, how is your first PhD assignment writing going?" she asked while mixing her salad with dressing.

"It seems all right. . . .Well. . .at least, I'm enjoying it. I'm writing about Oscar Pistorius, the guy. . .the fastest guy with no legs."

"Oh, the guy on Youtube you showed me?"

"Yeah," I said. "Some people are really mad about him running at the Beijing Olympics. I cannot understand them, so I am going to write about it."

"Oh, really?" she responded cautiously. "But. . .I think. . .he shouldn't be allowed to compete at the Olympics."

"How come?" I replied with a frown.

"Nobody is running with artificial legs in the Olympics. . . ." she said carefully.

"Oh, excuse me, honey!" I said, almost yelling. "No matter whether he uses the prosthetics or not, he has a right to compete at the Olympics! Having no legs shouldn't be the reason for banning him from the Games!"

"Whoa-whoa. . . calm down, David. I actually agree with you that he has the right to be included in the Games, but I think his participation might cause lots of problems. . . ."

Calming down, I let her know there were people who thought in a similar way.

"Okay, honey. . . what you were referring to was the way people talked about his eligibility for the Olympics. Some people are saying that Oscar Pistorius has an unfair advantage over other athletes by using the advanced technological artificial legs instead of using 'normal' human legs. Others argue that his running cannot be counted as normal human running, because his prosthetics perform differently than normal human legs do. Some even say that legitimating Oscar Pistorius' eligibility will cause future chaos in 'able-bodied' sporting events. They argue that people might use artificial lungs that prevent them from being tired during marathons, ultra-powerful artificial arms that help them throw the javelin, and so on. They even say that we would be unable to stop future Olympics from becoming competitions for people with cutting-edge artificial body parts. I've been very upset about these thoughts. . . and I couldn't tolerate that people called Oscar Pistorius a 'cyborg' or 'Six Million Dollar Man.' I am hoping you are not one of them."

Having tried to convince her that her ideas were wrong, I expected her to acknowledge that I was right. However, she quickly shot back, "See? Don't you think it's problematic? Are you thinking he should be eligible, even with all of these issues?"

"Yes, absolutely I do!" Then I continued, "You know what? I will make sure to write my assignment arguing his rightful participation in any sporting event for people without impairments! There shouldn't be any kind of exclusion for people with impairments, because they have impairments!" I stood up from my chair and left the dinner table, shouting, "Thanks for the dinner!"

"Oh, then, good luck with that, David!" she yelled at my back.

Thereafter, the assignment became a very important project for me as a way of defending my strong beliefs about integration and equal placement opportunities in sport. For several days after the conversation at the dinner table, I began gathering information related to the Oscar Pistorius eligibility controversy. I gathered media reports, academic journal articles, and pictures and video clips of him. I used them to support my argument for the assignment. A few days before the submission deadline, I watched a recently released Youtube video clip, showing Oscar Pistorius sprinting with athletes without impairments at the South African qualification competition for the Beijing Olympics.

After watching the video clip, I thought, "Oh, it was so close. He almost made the qualification! It was so unfortunate for him to miss the Olympic qualification by just 0.02 seconds. He could have showcased his ability to compete against athletes without impairments. It is going to take another four years to make history: a Paralympic sprinter's debut in the Olympics."

Then, I clicked the video clip again to enjoy watching it one more time. That time, however, I unexpectedly observed that something was not "correct" at the end of his race:

he was involuntarily bouncing. I watched the video again. I then clearly noticed that his prosthetics were making him bounce uncontrollably even after the race was over. Suddenly a thought floated through my mind. "Hang on. . .he couldn't stop himself. . . . He should be able to stop after running. . . . No way! The spring effects of his prosthetics must be strongly influencing his running abilities. . . . The effects enabled him to compete against other athletes without impairments. . . ." I began wondering whether the race really was unfair for the other athletes. After that, my writing plan for the assignment became undone.

Reflection: What does it mean to me to be “disabled” or “abled”? Based on my disability experience during my undergraduate program, I held a firm belief: excluding people with impairments from mainstream society was an obvious form of discrimination (Allan, 2005; Charlton, 1998; Jaeger & Bowman, 2005; Oliver, 1990). While preparing my writing assignment, I had no doubt that people with impairments had the right to participate in mainstream physical activities (Burkett, McNamee, & Potthast, 2011; Crincoli, 2011; Edwards, 2008; Wolbring, 2008b). I strongly believed that there should be no reason for excluding them (Allan, 2005; Crincoli, 2011; Reel & Bucciare, 2010). Accordingly, I could not accept the notion of others arguing for Pistorius’ ineligibility based on his body looking *abnormal* (Butryn, 2003; Corrigan, Paton, Holt, & Hardin, 2010; Culbertson, 2007; Howe, 2011; Howe & Jones, 2006; McNamee, 2007; Norman & Moola, 2011; Scully, 2008; Swartz & Watermeyer, 2008; Yi & Lee, 2011) and his running form and body functioning *abnormally* (Camporesi, 2008; Culbertson, 2007; McNamee, 2007; Potthast & Brueggemann, 2010; Swartz & Watermeyer, 2008; Wasserman, 2008; Weyand, Bundle, McGowan, Grabowski, Brown, Kram, & Herr, 2009; Yi & Lee, 2011). At that time, I was also strongly opposed to the idea that he should be banned

from mainstream sporting events—an idea based on the belief that, on one hand, he was not able-bodied, and on the other that his impaired body was enhanced by advanced technology (Edwards, 2008; Miah, 2007; Moses, 2009; Ouellette, 2011; Reel & Bucciare, 2010; Scully, 2008; Tamburrini & Tännsjö, 2007; Wolbring, 2008a; Yi & Lee, 2011).

On the day that I recognized Pistorius' involuntary bouncing at the end of his race, I became extremely frustrated. I was so disappointed, not just in his inability to stop bouncing, but also because I realized that his prosthetics could be providing an unfair advantage (Burkett, McNamee, & Potthast, 2011; Chockalingam, Thomas, Smith, & Dunning, 2011; Dyer, Noroozi, Sewell, & Redwood, 2011; Jones & Wilson, 2009; Kram, Grabowski, McGowan, Brown, & Herr, 2010; Lenk, 2007). I also began doubting that his achievements in sprinting events were purely the results of his endeavors as an athlete (Lenk, 2007; Mokha & Conrey, 2007; Sherrill, 2009; Tamburrini & Tännsjö, 2007; Wasserman, 2008). However, what frustrated me most was the recognition of my own unsettled attitudes about “disability” and “ability.” I found myself thinking that he was too-abled (Cole, 2009; Corrigan, Paton, Holt, & Hardin, 2010; van Hilvoorde & Landeweerd, 2008, 2010).

All of this caused me to rethink my own perceptions and assumptions about people with impairments. Initially, I had presumed that they were people with impaired bodies that lacked physical function, and that left them incapable, weak, vulnerable, and in need of help (Clapton, 2003; Corrigan, Paton, Holt, & Hardin, 2010; Edwards, 2009; Reel & Bucciare, 2010; Thomas, 2004). I had assumed that “such people” always required help from professionals or people without impairments, like me, in order to participate in mainstream society (Goodwin, 2001, 2008; Roush & Sharby, 2011).

Upon careful consideration of Oscar Pistorius' running ability, however, I realized that I might have been devaluing or overlooking the ability of people with impairments (Barnes & Mercer, 2010; Campbell, 2009; Clapton, 2003; Reel & Bucciere, 2010; Schillmeier, 2010). I also recognized that I might have felt superior to people with impairments based on my able-bodiedness (Campbell, 2009; Edwards, 2009; Reel & Bucciere, 2010; Shakespeare, 2006). I was worried and uncomfortable. "Would I become an APA academic with unexamined attitudes toward the people I care about?" I reflexively asked myself what it meant to be disabled or abled (Keso, Lehtimäki, & Pietiläinen, 2009; Macbath, 2010; Northway, 2000).

This questioning prompted me to consider new possibilities. What if my own best practices were based on my unexamined meanings of disability and ability and the role that I played in them (Edwards, 2009, Kinsella & Whiteford, 2009)? What if I was unwittingly perpetuating disability due to this lack of critical thinking about my own assumptions (Campbell, 2009; Macbeth, 2010; Northway, 2010)? What if I was ascribing and re-ascribing negative beliefs about identity onto people with impairments without being aware of it (Campbell, 2009; Reel & Bucciere, 2010; Schillmeier, 2010; Shakespeare, 2007)? What if I was unconsciously contributing to a discriminatory society against people with impairments (Oliver, 1990; Shakespeare, 2006; Wolbring, 2008b)? In sum, what if the real problem was me? How would my own assumptions about disability and ability influence my practices in APA (Campbell, 2009; Clapton, 2003; DePauw, 2000; Grenier, 2004; Shakespeare, 2007; Smith, 2009; Watermeyer, 2013)?

I came to realize that I had never reflected deeply upon how I had come to understand the meanings of disability and ability (Keso, Lehtimäki, & Pietiläinen, 2009; Macbath, 2010; Northway, 2000). I thus became desperate to inquire into the ways in which I constructed the

ideas of disability and ability (i.e., my own disability construction) and how it was expressed and enacted within my APA practices (e.g., research, teaching, and service delivery). This was the beginning of my doctoral dissertation journey—a project of studying my own lived experiences of the diverse meanings of disability and ability.

Objectives and Potential Contributions

Clandinin and Connelly (2000) note, “To *experience an experience* is to do research into an experience” (p. 50). In my PhD dissertation research, therefore, I aimed at *experiencing* my own lived experiences of disability construction and their potential implications for my professional and scholarly practices in APA (Clandinin, 2013; Clandinin & Connelly, 1994, 2000; Clandinin & Murphy, 2009; Clandinin & Rosiek, 2007; Polkinghorne, 2010; Rosiek, 2013).

Specifically, I intended to study my own experiences as they were lived by exploring their temporality (i.e., the timeframes—past, present, or future—in which they occurred), their sociality (i.e., the ways in which they intersected with socio-cultural influences), and their place (i.e., the physical and topological locations where they took place) (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Connelly & Clandinin, 2006). Furthermore, by attending critically to my own lived, told, retold, and relived stories of these experiences (Clandinin & Connelly, 2000), I sought to understand how my own disability constructions were “constituted, shaped, expressed, and enacted” (Clandinin & Rosiek, 2007, p. 46) within and against grand narratives (e.g., cultural historical traditions and assumptions about disability and ability; common ways of thinking about them in certain societies; theories, paradigms, and ideologies related to APA) (Burr, 2003; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Gergen, 2009; Huber, Caine, Huber, & Steeves, 2013). Finally, by composing “interesting, thought provoking, and

evocative” stories and reflections (Markula & Denison, 2005, p. 168), I hoped to inspire the readers of my dissertation to reflect on and think critically about their own disability construction and practices (Clandinin, 2013; Clandinin & Connelly, 2000; Huber et al., 2013).

The meaningful outcomes of this journey may be: increased awareness and acceptance of lived experiences as valuable sources and sites of understanding disability (Clandinin & Caine, 2012; Clandinin & Connelly, 1994, 2000; Clandinin & Murphy, 2009; Clandinin & Rosiek, 2007; Connelly & Clandinin, 1990, 2006; Hawkins, 2010; Macbeth, 2010); recognition of the self as an integral aspect of disability knowledge generation (Clandinin & Connelly, 2000; Connelly & Clandinin, 1999; Georgakopoulou, 2006; Huber et al., 2013; Kinsella & Whiteford, 2009; Schnee, 2009; Yi, Lee, & Kim, 2011); acknowledgment of the socially interactive and relational nature of disability knowledge generation (Clandinin, 2013; Clandinin & Caine, 2012; Clandinin & Connelly, 2000; Clandinin & Murphy, 2009; Clandinin & Rosiek, 2007; Kim & Latta, 2010; Standal, 2008; Tregaskis & Goodley, 2005; Yi, Lee, & Kim, 2011); appreciation of the importance of reflexivity to understanding disability and its implications for APA practice (Bishop & Shepherd, 2011; Forbes, 2008; Huber et al., 2013; Keso, Lehtimäki, & Pietiläinen, 2009; Northway, 2000); enhanced visibility of diverse perspectives in the construction of disability and APA practice (Bredahl, 2008; Clandinin, Pushor, & Murray Orr, 2007; DePauw, 1997; Henwood, 2008; Macbeth, 2010; Radermacher, Sonn, Keys, & Duckett, 2010; Yi, Kim, & Lee, 2011); and recognition of narrative knowing as a way of understanding disability (Caine, Estefan, & Clandinin, 2013; Clandinin & Murphy, 2009; Markula & Denison, 2005; Markula, Grant, & Denison, 2001; Richards, 2008; Smith & Sparkes, 2008; Sparkes, 1999, 2002; Stephens, 2011; Yi, Kim, & Lee, 2011).

Chapter 2: Narrative Inquiry as Methodology

Narratives form the basis, and the subject, of my chosen inquiry (Carter & Little, 2008). According to Clandinin and Rosiek (2007), narratives are “the form of representation that describes human experience” (p. 40)—that is, the storied representation of one’s lived experiences (Clandinin, 2013; Clandinin & Connelly, 2000). Narrative inquiry studies the storied experiences by exploring them as they are lived (Clandinin, 2013; Clandinin & Connelly, 1994, 2000; Clandinin & Rosiek, 2007; Connelly & Clandinin, 1990; 2006). Engaging in narrative inquiry is, therefore, *experiencing experiences* (Clandinin, 2013; Clandinin & Connelly, 2000).

Underpinning Philosophy: Dewey’s Notion of Experience

The educational theorist John Dewey, writing from a pragmatic perspective, viewed experience as “*relational, temporal, and continuous*” (Clandinin & Rosiek, 2007, p. 44). Experience is *relational* because people are always in relationships with each other within social contexts (Clandinin & Connelly, 2000). Experience is also *temporal* because it is constantly changing as it unfolds through time (Clandinin & Connelly, 2000). Finally, experience is *continuous* because it grows “out of other experiences, and experiences lead to further experiences” (Clandinin & Connelly, 2000, p. 2).

What Do Narrative Inquirers Do?

Following Dewey’s notion of experience (an ontological concept), narrative inquirers conceive that reality can be known by studying lived experience (an epistemological claim) (Caine, Estefan, & Clandinin, 2013; Clandinin, 2013; Clandinin & Connelly, 2000; Clandinin & Murphy, 2009). Thus, in pursuing narrative inquiry, they argue that lived experience is a fundamental “source of important knowledge and understanding” (Clandinin, 2013, p. 17). Additionally, narrative inquirers understand themselves as *lived embodiments of their experience*

(Clandinin & Connelly, 2000; Johnson, 1987), because they acknowledge that “experience is always . . . dual. . . always the inquirer experiencing the experience and also being a part of the experience itself” (Clandinin & Connelly, 2000, p. 81). As such, they recognize that lived experience is a phenomenon under study and a fundamental site of inquiry (Connelly & Clandinin, 2006; Clandinin & Rosiek, 2007). For narrative inquirers, as Clandinin and Rosiek note (2007), “the regulative ideal for inquiry is to generate a new relation between a human being and [their] environment” (p. 39) by seeking “to examine experience with an eye to identifying new possibilities within that experience” (p. 55). Accordingly, they understand that lived experience is “the ultimate validation for knowledge” (Clandinin & Rosiek, 2007, p. 50).

Building upon these ontological and epistemological assumptions (Clandinin & Murphy, 2009), narrative inquirers regard inquiry as an ongoing and a relational methodology for studying experience (Caine, Estefan, & Clandinin, 2013; Clandinin, 2013, Clandinin & Connelly, 2000; Rosiek, 2013). Accordingly, they expect to open up opportunities for future “relational living alongside” (Clandinin, 2013, p. 23)—that is, to “[seek] ways of enriching and transforming experience for themselves and for others” (Clandinin & Rosiek, 2007, p. 42) by composing and sharing storied experiences (Clandinin & Connelly, 2000; Koch, 1998; Rosiek, 2013). This is a way for them to seek possibilities for growth and change (Clandinin 2013; Clandinin & Caine, 2012) through *relational living*, *telling*, *retelling*, and *reliving* (Clandinin, 2013; Clandinin & Caine, 2012; Clandinin & Connelly, 2000). In sum, what narrative inquirers do is simply to *think narratively* (Clandinin, 2013).

Narrative Inquiry Framework

Clandinin and Connelly (2000) provided the conceptual framework for my study of experience: *puzzling* in a metaphorical *three-dimensional narrative inquiry space*. According to

Clandinin and Connelly (2000), “Narrative inquiry carries more of a sense of a search, a ‘re-search,’ a searching again. Narrative inquiry carries more of a sense of continual reformulation of an inquiry” (p. 124). Accordingly, they conceptualized narrative inquiry as a *research puzzling*, a way of experiencing the wholeness and continuity of one’s experience (Clandinin & Connelly, 2000). Like a person putting together pieces of a puzzle, narrative inquirers need to search and re-search for pieces of the experience puzzle and to continue puzzling until the puzzle becomes as a whole (Clandinin & Connelly, 2000). The pieces of an experience puzzle are “*personal and social* (interaction); *past, present, and future* (continuity); combined with the notion of *place* (situation)” (Clandinin & Connelly, 2000, p. 50).

The terms *personal* and *social* refer to the *sociality* dimension of experience (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007). As Clandinin and Rosiek (2007) observed, “People are always in interaction with their situations in any experience” (p. 69). Thus, people experience their personal *inward* reflection in any experience (e.g., feelings, emotional reactions, and thoughts) (Clandinin & Connelly, 2000). People also experience *outward* interactions with societal environments in any experience (e.g., the influences of culture and traditions on one’s assumptions) (Clandinin & Connelly, 2000). Thus, Clandinin and Murphy (2009) described a narrative inquirer as one who “asks questions, collects field notes, derives interpretations, and writes research texts addressing both personal and social issues” (p. 50).

The *past, present, and future* dimensions of narrative inquiry refer to the *temporality* dimension of experience (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007). Clandinin and Rosiek (2007) noted that, “Every experience both takes up something from the present moment and carries it into future experience” (p. 69). This continuous nature of experience

prompts narrative inquirers to look not only to the present of experience, but also to its past by looking *backward* and to its future by thinking *forward* (Clandinin & Connelly, 2000).

Place refers to the third dimension of experience (Clandinin & Connelly, 2000).

According to Clandinin and Rosiek (2007), every experience takes place in specific, concrete, physical, and topological boundaries of place. As such, situating a narrative inquirer's self in a place where experience takes place enables the inquirer to move in four directions (i.e., backward, forward, outward, and inward) from that particular place (Clandinin & Connelly, 2000). Such aspects (i.e., temporality, sociality, and place) played a key role in my "attending" to my lived experiences of disability construction (Clandinin & Connelly, 2000, P. 185).

My Story, Part 3: My Great Fear

It was one Sunday afternoon during the third term of my PhD program. I was sitting on a rocking chair in my room, lost in thought.

"Knock, knock! Hey, what are you doing?" My wife asked, coming into the room.

"Hmm. . .just thinking. . .thinking about my dissertation."

"How is it going?" she asked while gently rubbing my shoulders.

"It's going well. . . . I've been using a philosophy as a conceptual framework to study my own perceptions and assumptions about disability and ability. It seems to make a lot of sense."

"Oh, good for you! What's the philosophy?" she asked curiously.

"It's social constructionism."

She asked me to elaborate. "Hmm," I said, "It's a philosophy. . . . Well. . .how can I explain it easily? It's saying that there is no one truth... and there should be multiple ways of understanding things. . . ."

She suddenly stopped me while I was speaking. "Hey, are you sure that you believe in this philosophy?"

"Yeah. . .why?"

"Do you really think there is no one truth? Pastor Kim said today that God is the only truth for Christians. Remember? I am pretty sure you understand what this means! How come you are using philosophy to reject this?" She frowned.

*I became silent, as I could not answer her. That night, I sat in front of my desk and pulled out the Bible and read the scripture from that morning's sermon: "You are truly my disciples, if you remain faithful to my teaching. Then you will know the truth, and the truth will set you free" Jn. 8:31-32 (New Living Translation). *The sermon was about living a Christian life in a pluralistic society. My pastor preached that God was Christians' only truth. He finished his sermon with the scripture from Col. 2:8: "See to it that no one takes you captive through hollow and deceptive philosophy, which depends on human tradition and the basic principles of this world rather than on Christ" (New International Version). I read and re-read the scripture. Then, I turned my computer on and retrieved my work-in-progress draft of my dissertation proposal. I rapidly searched for a certain page, and I found the place where I said clearly: "I follow the notion that there cannot be any given, determined nature to**

the world, or people. As such, there are no essences inside things or people that make them what they are.”

"Oh. . .my. . .God. . . . Am I really against God?" My heart collapsed, and I was paralyzed with fear. The night became very long, as I thought about these things. For the next few days, I struggled to make sense of my use of a philosophy that seemed opposed to my strong religious beliefs.

Reflection: My own turn to narrative. I struggled a lot at the beginning of my dissertation research journey, because I was not confident enough to critically reflect on my own experiences or to showcase my own perspectives in public (Dickson-Swift, James, Kippen, & Liamputtong, 2008). I imagined that this would be emotionally painful, because I might discover a dark side to the ways I had understood disability at different times in the past (Henwood, 2008). I feared that I might have to confront disappointment by recognizing my potential weaknesses as an APA academic during the journey (Henwood, 2008). I also presumed that other people might judge and criticize me or my contribution to disability construction by reading my narratives (Dickson-Swift, James, Kippen, & Liamputtong, 2008). In sum, I was hesitant to commence my inquiry, because I felt I might be under scrutiny and “naked” in public.

As a result, as soon as my inquiry commenced, I tried to convince myself that my perceptions and assumptions were based on sound reasoning (Tavallaei & Abu Talib, 2010; Willis, Daly, Kealy, Small, Koutroulis, Green, Gibbs, & Thomas, 2007). During the third term, I relied on a particular conceptual framework (i.e., social constructionism) to showcase how my understanding of disability played out within the framework (Cunliffe, 2011; Wu & Volker, 2009). I thought I would be on firm ground if later confronted with other people’s competing perceptions and assumptions (Tavallaei & Abu Talib, 2010; Willis, Daly, Kealy, Small,

Koutroulis, Green, Gibbs, & Thomas, 2007). At that time, I also began to study how others understood the meanings of disability and ability. I looked for grand narratives that shaped people's understanding. *Grand narratives* are dominant stories, which are based on diverse perspectives, models, ideologies, paradigms, philosophies, and/or theories. They are socially constructed and sustained within a particular culture as largely accepted assumptions or common ways of thinking (Burr, 2003; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Gergen, 2009). I felt safer representing my own disability construction within grand narratives of disability and ability. I felt less naked.

As I experienced the fear associated with the tension between the ontological assumptions underlying my research methodology and my strong religious beliefs, I began to reflect deeply upon who I was and who I should be in my research journey: a graduate student or a Christian (Cherry, 2007; Clandinin & Connelly, 2000; Orr, 2007). This eventually led me to remember that my inquiry was about me, my own experience: I wanted to study how "I" experienced myself as part of my own experiences. At that time, I finally recognized that I was the lived embodiment of my experiences (Clandinin & Connelly, 2000, p. 43). Thereafter, it became apparent to me that my experiences were fundamental "sources" and "sites" of my inquiry (Clandinin & Rosiek, 2007, p. 50).

While carefully considering my lived embodiment, I also acknowledged that my inquiry had been unconsciously transformed during the early stage of my research journey. I realized that my transformed inquiry was about making sense of my experience based on a certain framework (Clandinin & Connelly, 2000). It was about arguing how disability and ability should be understood according to a certain perspective, model, ideology, paradigm, philosophy, or theory (Burr, 2003; Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Gergen, 2009). It

was also about comparing or contrasting my own experience to others' common ways of understanding the meanings of disability and ability (Clandinin & Connelly, 2000).

I reflected again upon why I commenced my dissertation research. I was very interested in studying how my experiences were experienced. As such, my inquiry involved “living” and “attending” to my experiences as they were lived (Clandinin & Connelly, 2000, p. 120). My inquiry also involved studying how my own assumptions and perceptions of disability were “constituted, shaped, expressed, and enacted” within and against grand narratives of disability (e.g., assumptions that perceiving disability as a medically oriented individual problem; or disability as a result of disabling elements within society) (Clandinin & Rosiek, 2007, p. 46, Roush & Sharby, 2011). Accordingly, I realized that the regulative ideal for my inquiry would not be “to generate an exclusively faithful representation of a reality independent of the knower” (Clandinin & Rosiek, 2007, p. 39), but rather to generate personal practical, socially interactive, and relational knowledge (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Hawkins, 2010).

Recognition of the self as an integral aspect of inquiry was the critical moment in my own narrative turn. At the end of the third term of my PhD program, I began to *think narratively* (Clandinin & Connelly, 2000). “Narrative inquiry is a process of learning to think narratively, to attend to lives as lived narratively, and to position inquiries within a metaphorical three-dimensional space” (Clandinin & Connelly, 2000, p. 120). After that, I no longer hesitated to begin my research puzzling (Carter & Little, 2007; Clandinin & Connelly, 2000). I situated myself in times and places where my experiences of understanding diverse meanings of disability and ability took place (Clandinin & Connelly, 2000). From those particular contexts, I began moving in four directions following the temporal and social dimensions of my experiences

(Clandinin & Connelly, 2000). I opened up my reliving opportunities by thinking narratively. I began seeking “new directions and new ways” of thinking about disability and engaging in APA practice (Clandinin & Connelly, 2000, p. 189).

Place of Theory

In thinking about my experiences narratively while composing this dissertation manuscript, I explored how perspectives, models, ideologies, paradigms, philosophies and/or theories contributed to grand narratives of disability and ability. I also attentively examined the roles they played in my own disability construction. Furthermore, I carefully considered how grand narratives have interacted with my own assumptions and perceptions of disability and ability. For example, social and medical models of disability (e.g., Barnes & Mercer, 2010; Oliver, 2009; Shakespeare, 2006; Smith, 2009; Withers, 2012) and theories of the disablement process (e.g., Lawrence & Jette, 1996; Masala & Petretto, 2008; Oliver, 1990; Peters, 1995, 1996; Verbrugge & Jette, 1994) were carefully considered when I reflected on my story of entering the field of APA. Diverse perspectives on Oscar Pistorius’ eligibility were also examined thoroughly in order to explore my own assumptions and perceptions about disability and ability at the time (e.g., Burkett, McNamee, & Potthast, 2011; Cole, 2009; Edwards, 2008; Swartz & Watermeyer, 2008; Wolbring, 2008a; Yi & Lee, 2011).

I tried to weave diverse perspectives, models, ideologies, paradigms, philosophies and/or theories continuously and seamlessly into my lived experiences of disability construction (Clandinin & Connelly, 2000). As such, I presented stories and reflections illustrating how they interacted with my disability construction and my APA practice. I did not provide a separate literature review section as a conceptual framework (Clandinin & Connelly, 2000). For narrative inquiry, as Clandinin and Connelly (2000) note, “it is more productive to begin with explorations

of the phenomena of experience rather than in comparative analysis of various theoretical methodological frames” (p. 128).

Chapter 3: Methods

This is more the process we engage in—a kind of back and forth writing, receiving response, revising, setting it aside, writing another chapter or section following a similar process, then holding it up against the other chapter, until finally there is a sense of a whole, a piece that feels like it could stand, at least for this moment, alone. (Clandinin & Connelly, 2000, p. 167)

Narrative Inquiry Process

Narrative inquiry methods involve *composing field texts, moving from field texts to research text, composing interim texts, and composing a research text* (Clandinin & Connelly, 2000). According to Clandinin and Connelly (2000), *field texts* are data sources and parts of a research puzzle, which are composed of subjective representations of the inquirer's experiences. *Research text* refers to the final written report of the inquiry, representing the sense of wholeness of experiences in the final phase of the inquiry. *Interim texts* are “part and parcel of ongoing research,” that are situated “in the spaces between field texts and final, published research text” (Clandinin & Connelly, 2000, p. 133).

According to Clandinin and Connelly (2000), the writing processes of narrative inquiry can be described as “back and forth writing,” involving ongoing processes of writing between field texts and the research text (p. 167). They further argued that these processes occur repeatedly and simultaneously as a *work in progress* (Clandinin & Connelly, 2000). For example, while I composed interim texts (e.g., work-in-progress dissertation proposal), I simultaneously composed field texts as a way to “re-search” and bring pieces of my experience puzzle together into my three-dimensional narrative inquiry space (Clandinin & Connelly, 2000,

p. 124). I continued my “back and forth writing” until I felt a sense of wholeness for the writing of my research text, this final dissertation manuscript (Clandinin & Connelly, 2000, p. 167).

Composing Field Texts

In order to compose my research text, I began by composing field texts. These included

- annals and chronicles;
- autobiographical stories;
- family stories;
- field notes on memory boxes; and
- daily journals (Clandinin & Connelly, 2000).

Annals are a “list of dates of memories, events, stories, and the like,” and *chronicles* are the “sequence of events in and around a particular topic or narrative thread of interest” (Clandinin & Connelly, 2000, p. 112). These texts provided me with the outlines of the temporality and place dimensions of my three-dimensional research puzzle. I continued to identify turning points and critical moments that contributed to the ways in which I constructed my understandings of disability. As I unfold my lived stories from particular times and places, more turning points and critical moments were identified and brought to my research puzzle.

Autobiographical stories are stories of “a very small slice of time and of a very particular event” (Clandinin & Connelly, 2000, p, 101). The opening story in my narrative beginnings (i.e., the story about my disability experience during my hospitalization due to an ankle injury) is an example of an autobiographical story. The opening story was based upon my recollection of an event that troubled me during the fourth year of my undergraduate program. In writing this story, I situated myself in the particular time, place, and social context. The story also enabled me to look further backward to my early childhood and compose other autobiographical stories, such as

that of my love for soccer during my childhood. In addition, composing other autobiographical stories (e.g., stories acknowledging my own unsettled attitudes about disability and ability) enabled me to think forward to the ways I later constructed the ideas of disability and ability.

While I followed this temporal dimension of my experiences, I also explored the social dimension. I inwardly reflected on my feelings and thoughts in writing autobiographical stories and continued to think about how I outwardly responded to social conditions, such as attitude toward disability. Composing these stories also caused me to think deeply about details of the contexts, situations, and places (e.g., understandings of disability at Yonsei University and the University of Alberta). I continued writing autobiographical stories based on identified turning points and critical moments from my annals and chronicles.

My family stories, which are stories “handed down across generations about family members and family events” (Clandinin & Connelly, 2000, p. 112), provided accounts of how I was raised, in what contexts, and how my family stories shape and sustain my identities. I continued to compose stories of my family, including stories about our family values and religious beliefs.

Memory boxes refer to “collections of items that trigger memories of important times, people, and events” (Clandinin & Connelly, 2000, p. 114). My memory boxes included my previously published research articles; books and academic journal articles that contributed to my constructions of disability; photographs, video clips, and movies related to people with impairments; a statement of my prospective research program in APA; work-in-progress APA related course outlines that I might teach in the future; and submitted research abstracts. Based on these memory boxes, I continued to compose *field notes*, which are the descriptions of my own reflection and introspection of the memory boxes (Clandinin & Connelly, 2000). My field

notes enabled me to reflect on and critically think about my disability construction and its interaction with grand narratives.

During the second term of my PhD program, I also began writing *daily journals* as field texts. My journals contain descriptions of day-to-day life experiences (Clandinin & Connelly, 2000). Because my other field texts (i.e., annals and chronicles, autobiographical stories, field notes, and family stories) rely on my recollection and reflection, routinely composing daily journals provided me with insights into “where I really am” in my journey (Sarton, 1982, p. 25).

I composed the field texts as descriptively as possible and ensured that they were richly detailed (Clandinin & Connelly, 2000). Furthermore, I continued to allow my field texts to change and grow, rather than fixing relations between the facts and my ideas (Clandinin & Connelly, 2000).

Moving from Field Texts to a Research Text

To begin composing research text based on my field texts, I *narratively coded* my field texts (Clandinin & Connelly, 2000). *Narrative coding* involves situating and interweaving field texts in a three-dimensional narrative inquiry space in relation to other field texts, while responding to the questions regarding the meaning and social significance of one’s own experience (Clandinin & Connelly, 2000).

In order to narratively code my field texts, I used a “visualized” three-dimensional narrative inquiry space. The visualized research puzzle is presented in *Figure 1*. The long horizontal black line in the diagram represents the time frame of my life (past, present, and future). The small horizontal lines with specific starting and ending points thus indicate particular periods of my life (e.g., the period when I was hospitalized). I drew red lines with arrows in order to connect and show the relationships between different events that occurred in

different times and places. I also used multiple-coloured codes. I used white Post-It notes to indicate key events, which constituted my experiences of disability construction; yellow notes to indicate my outward interactions with societal environments (e.g., the ways in which I interacted with policies, built environment, and people's attitudes within my disability experience during undergraduate program); blue notes to indicate my personal, inward reflections and feelings; and pink notes to identify grand narratives that influenced my experiences. Furthermore, I used circles to represent places where the events took place. Finally, the side of the diagram to the left of the vertical green line contains the key events that occurred in Korea, and the other side includes the events that took place in Canada.

Through this narrative coding, composed field texts were situated within my research puzzle and interwoven with other field texts. In this process, I continued to ask how my experiences of disability construction were experienced in relation to particular times, places, and social contexts. Furthermore, I continued to inquire how socially meaningful and significant relational reliving might be opened up through my journey.



Figure 1. "Visualized" three-dimensional narrative inquiry space.

Composing a Research Text

I presented the analytic insights of my journey as stories and reflections in the final research text, in the representational style of *essayistic personal experience narrative*. This can be characterized as:

Personalized and revealing texts in which authors talk openly about their own lived experiences. The idea behind telling revealing personal stories, however, is not to hang your heart out on a sleeve but to enable the reader to share or to learn from how personal experiences are lived. (Markula & Denison, 2005, p. 171)

I composed the stories following the phases of *description*, *interpretation*, and *explanation* (Markula & Denison, 2005). I began with a *description* of my experience. I described my experience in as detailed a manner as possible considering who was involved in the event(s), how the experience took place (e.g., what people said and how they said it, including their body actions, gestures, and facial expressions), and where the experience took place (i.e., descriptions of the place[s] the experience occurred) (Clandinin & Connelly, 2000; Markula & Denison, 2005). For example, when I wrote the opening story in my narrative beginnings section, I described details of my conversation with the staff member of the gym, including our physical actions (e.g., covering my discouraged face), facial expressions (e.g., the staff member's annoyed look), and the physical and topological aspects of the place in which the experience occurred (e.g., physical location and structure of the gym building).

Once I describe the events, I *interpreted* them, considering the interactions and relationships amongst personal and social influences, time, and places (Clandinin & Connelly, 2000). In this phase, I wrote these interpretations into the story, crafting them aesthetically using

a mixture of dialogue and exposition, so that the reader would *lean in* to the text (Clandinin & Connelly, 2000; Markula & Denison, 2005). For example, in my opening story, I interpreted the reasons why I acted in a particular way, recalling my personal emotions and the societal attitudes of others at a public place in front of the gym building. I demonstrated the reason that I said “Excuse me” and wheeled very quickly to my ward: I had heard sympathetic exclamations from the people surrounding me.

Following the interpretation phase of my story writing, I *explained* the wider implications, tensions, and/or reasons the people in my stories had for acting by moving in four directions: forward, backward, inward, and outward (Clandinin & Connelly, 2000; Markula & Denison, 2005). For example, I explained how my experiences were experienced within and against the personal and social contexts of my life in particular time and places (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007). In my opening story, I showed how my awareness of the disability experience caused me to withdraw from the larger community and stay within the medical setting. I also revealed how the experience prompted me to become a graduate student in the field of APA, explaining the goals and motivations behind this choice.

I continued to attend to my three-dimensional narrative inquiry space while composing subsequent reflections on the presented stories. My reflections focused on elaborating personal and social meanings, and on the significance of my storied experiences, attending to their temporality, sociality, and places. My interwoven stories and reflections composed through the above analytic and representational practice included the processes of constructing my own ideas of disability, the experiences of my own disability construction within and against grand narratives, and the potential implications of my own assumptions about disability and ability for my past, present, and future APA practice.

Quality Criteria for My Research Text

The criteria of *substantive contribution*, *aesthetic merit*, *reflexivity*, and *impact* guided my writing of the research text (Richardson & St. Pierre, 2005). Substantive contribution is related to whether research texts contribute to “our understandings of social life” (Richardson & St. Pierre, 2005, p. 964). Aesthetic merit refers to whether research texts are “artistically shaped, satisfying, complex, and not boring” (Richardson & St. Pierre, 2005, p. 964). Reflexivity is related to whether there is “adequate self-awareness and self-exposure for the reader to make judgments about the point of view” (Richardson & St. Pierre, 2005, p. 964). Finally, impact refers to whether research texts “move” readers “to try new research practices or move [them] to action” (Richardson & St. Pierre, 2005, p. 964).

In order to ensure that I made a substantive contribution to the field, I documented the social meanings of my own experiences by composing “a ‘seamless’ [research] text in which previous literature, theory, and methods are placed in. . .meaningful ways” (Richardson & St. Pierre, 2005, p. 974). To ensure the study’s aesthetic merit, I shared the drafts of my research text with fellow graduate students to receive feedback on whether the text was readable and interesting as a literary format. I also carefully reflected upon advice from professional editors (e.g., a graduate writing advisor). As a way to produce reflexive research texts, I engaged in rigorous and in-depth introspection based on my experiences. For example, I did not avoid reflecting critically upon the dark side of my own contribution to disability construction. Finally, I tried to compose compelling and thought-provoking research texts to enhance the impact criteria. Accordingly, my *essayistic personal experience narrative* focused on serving as a tool for readers to reflect on and think critically about their own disability construction and its implications, by sharing my stories and reflection as vividly and thoroughly as possible.

Quality Criteria for My Narrative Inquiry

I was also aware that producing a quality research text was not the sole purpose of my inquiry. As Clandinin and Connelly (2000) argue, merely thinking about “what makes a good narrative research text” does not provide the criteria for “what makes a good narrative inquiry” (p. 185). A good narrative inquiry is being “wakeful” to “attending” to thinking narratively and living narratively during the entire journey of inquiry (Clandinin & Connelly, 2000, p. 185). As a result, I carefully considered twelve quality criteria for narrative inquiry (Clandinin, 2013; Clandinin & Caine, 2012).

Throughout my journey, I have been wakeful and attentive to

- “relational responsibilities” (e.g., by carefully thinking about social responsibility and responsiveness of my inquiry to issues of equity and social justice);
- the notion of “in the midst” (e.g., by continually acknowledging the ongoing and transformative nature of my inquiry);
- “negotiation of relationships” (e.g., by taking into consideration socially ethical interactions with others within my journey);
- “narrative beginnings” (e.g., by providing my personal justification for inquiring into my own experiences in opening stories and reflections);
- “negotiating entry to the field” (e.g., by contemplating ways of protecting the privacy of others appearing in my research texts through the use of pseudonyms and fictionalization);
- “moving from field to field texts” (e.g., by continuously puzzling and writing back and forth in my three-dimensional narrative inquiry space);

- “moving from field texts to interim and final research texts” (e.g., by continuously weaving and seamlessly linking personal, social, and contextual influences into my experiences);
- narrative representations of experience “in ways that show temporality, sociality, and place” (e.g., by elaborating personal and social meanings, and significance of my own experiences);
- participating in “relational response communities” (e.g., by engaging in collaborative and reflective discussions with fellow graduate students and supervisory committee);
- “justifications—personal, practical, social” (e.g., by elucidating potential contributions of my inquiry);
- allowing for interpretation by “multiple audiences” (e.g., by providing expansive and compelling entry points to my experiences through storied representation); and
- “commitment to understanding lives in motion” (e.g., by reflecting on my personal growth and changes in and through the inquiry) (Clandinin, 2013, p. 212).

Ethical Considerations

The institutional ethics review board at the University of Alberta confirmed that there was no need for ethics approval for this dissertation research because there was no human participant component, apart from information about my own experiences and the people integral to those experiences. While I was composing this research text, however, I came to realize that I should consider carefully the *ownership* of my stories, as Clandinin and Connelly (2000) note:

Who owns stories. . . . The question is. . . whether the characters named in the inquirer’s story own the story or whether the inquirer owns it. For example, students writing about their school experiences ask whether or not they need to get approval from teachers,

students, siblings, or others mentioned in the story. Do they own story because they tell it? (p. 176)

As a result, I tried to be wakeful and attentive to the relational responsibilities for the stories of the people in my own lived and told stories (Clandinin, 2013; Clandinin & Connelly, 2000). I also used pseudonyms for all the names, changed the descriptions of people in my stories, and fictionalized some parts of my stories in order to protect the privacy of others who appeared in this dissertation manuscript (Clandinin, 2006; Clandinin & Connelly, 1994, 2000; Clandinin, Murphy, Huber, & Murray Orr, 2010; Markula & Denison, 2005).

My family members were present in this manuscript (i.e., my wife and children). I acknowledged that they might feel uncomfortable about appearing in a public text. As a result, I continually and sincerely communicated with them, explaining how they may appear, in what contexts, and with what associated meanings. My wife granted her verbal permission to appear in my stories. I also tried my best to protect my children's dignity. They were both of preschool age.

Since I acknowledged that my inquiry journey could be emotionally painful for me, I took into consideration ways of protecting myself from hidden risks of undertaking this inquiry journey by (a) obtaining private supports (e.g., casual conversation with a close friend or family member), (b) taking courses (e.g., ethics course, graduate student seminar on the risk management in research), and (c) establishing a support system (i.e., direct and close support from my supervisory committee) (Dickson-Swift, James, Kippen, & Liamputtong, 2008).

Chapter 4: My Own Disability Construction

The methods described in the previous chapter helped me to articulate a series of stories related to the ways in which I construct the ideas of disability and ability within my personal and social contexts. As I did so, I was able to critically unpack my own disability construction, reflecting on my own limiting perceptions and assumptions, and consider new ways of thinking about the meanings of these terms. In this chapter, I will present my stories and my subsequent reflections. In so doing, it may offer readers a set of tools for reflecting on their own understandings of disability and ability. This may also create a space for them to critically assess the process of their own disability construction.

My Story, Part 4: Fearing a Tragedy for My Beloved Child

My son had just turned one. We were living in a University residence for students with families. The townhouse-style home was a two-story building with very steep stairs. I was playing on the second floor with my son. I was rolling a rubber soccer ball and watching him chase it. Once I rolled it in the wrong direction, and the ball fell down the stairs. I quickly ran down to the bottom to bring the ball back to him. When I grabbed it on the first floor, I suddenly heard heavy bumping sounds. My son was falling from the top of the stairs all the way down to the first floor.

I had no chance to catch him. He hit his head heavily on the wooden floor. I ran to him frantically. He had closed his eyes and was not moving, and I realized that he was unconscious. I panicked. I kneeled down close to him, hesitant to shake him awake, because I was worried about making his condition even worse. I just shouted his name hoping that

he would wake up. My wife came and cried out his name beside me. I felt numb and frozen, as if I were in a nightmare. Time seemed to stop.

Finally, about a minute had passed. I noticed his face redden. To our relief, he started crying. Telling my wife to prepare to go to the emergency department, I began checking that his arms and legs were moving. They seemed to be. I grabbed my car keys and carefully carried him to the car. My wife rushed in, and I started the engine. I drove rapidly to the hospital, ignoring the traffic laws, but it felt like the trip took forever.

"Oh God, please. . .do not let anything happen to him. . . ." My wife kept praying beside him.

We registered him at the triage room. He seemed to settle down while waiting for a doctor. He stopped crying and nestled in my wife's bosom. She also leaned on my shoulder. I caressed her hair. "Honey, he will be fine. God will protect him."

"Yeah, he should be fine," she nodded sturdily. Then she paused for a few moments.

"David," she said finally. "I've been worrying about some bad things happening to us."

"What do you mean?"

"I thought we could have disabled kids."

I was baffled. "Why?"

"I worried about God's purpose for you. . . . David, you always wanted to learn about how disabled people live. I was very nervous that God would try to teach you through our kids. . . . I asked Him so many times that our baby not have a disability." She held the little one more tightly to her bosom. "David, I am so nervous. He should be fine, right?"

"Don't worry, he will be fine." I said, hugging her tightly. I wanted to believe my words, but I felt powerless to help.

A nurse called us, and we brought him to the examination room. An emergency doctor began examining him. I became really anxious. Once again, time seemed to go very slowly. I closed my eyes and prayed, "God, please protect him." A few moments later, thankfully, the doctor informed us that our little one was fine. I embraced my wife as she wept, and I nearly cried too, out of relief. The doctor told us to stay overnight at the hospital to monitor his condition. We were brought in to a small ward within the emergency department. All three of us settled down in the room. My wife asked me to go back home to bring some feeding materials and clothes for her. She had come to the hospital without even changing.

I drove back home in silence, reflecting on what my wife had said at the triage room. I recalled that I had had similar thoughts when we met with an obstetrician to get a prenatal diagnosis test. I was also worried that God might give impairments (and the disabilities associated with them) to our baby. I prayed while meeting with the obstetrician that our baby would not have any. These two events caused me to think deeply about what caused my wife and me to think in that way.

When I got home, I rushed around the house to throw a can of baby formula, several baby bottles, and any of my wife's clothes that I could see into a big grocery bag. I wanted to go back to my son as soon as possible.

Even as I did this, a childhood memory popped into my head. I remembered Ms. Myoung-Hee Song's speech at my church. She was a famous Korean poet and composer of gospel songs, who had multiple impairments associated with severe cerebral palsy. When I was in Grade 3 or 4, she was invited to the annual concert of my church with her team of gospel singers. They performed several of her songs, including one entitled,

I Have

I have no wealth

I have no wisdom

I have no health

But I have more than others.

I see what others cannot see

I hear what others cannot hear

I comprehend what others cannot comprehend

I am more beloved than others.

God's righteousness

I have less than others

God's righteousness

I have more than others.

(Song, 1985, my trans.)

After the performance, Ms. Song was brought to the stage with the help of her aides. She was then moved to the floor from her wheelchair. I remembered that, to my eyes, she looked hunched, tight and twisted. One of her aides put a pen into her mouth. She struggled to write something on the board. The aide read what she had written there, sentence by sentence:

You might think I am ruined.

You might think I am hopeless.

You might think I am nothing.

But, I am blessed, because God has a purpose for me.

I am blessed, because God gave me severe disabilities to fulfill His purpose.

So I am not ruined.

So I am not hopeless.

So I am not nothing.

She then finished her address, encouraging us to seek God's purpose for each of us.

Driving back to the hospital, I thought deeply about this childhood memory.

Carefully reflecting on Ms. Song's verses, I recognized that my wife and I were worried that God had a purpose for us—that He might create impairments in our child in order to help me to better understand the lived experiences of people with such impairments, the experiences of disability. Walking into my son's room and watching him sleep, I thanked

God that our son did not acquire any impairment associated with the fall on that day. I thanked God that this "tragedy" was not His purpose.

Reflection: The complexity of my disability construction. The incident happened during the third year of my PhD program. As I wrote previously, I seemed to understand the meanings of ability and disability on the basis of both the medical and the social models of disability (Barnes & Mercer, 2010; Campbell, 2009; Lawrence & Jette, 1996; Masala & Petretto, 2008; Peters, 1995, 1996; Roush & Sharby, 2011; Shogan, 1998, 2003; Tremain, 2005; Verbrugge & Jette, 1994). I viewed disability as a medically oriented restriction or lack of ability, and perceived that disability was intensified by disabling elements within society, such as built environment, policies, and societal attitudes (Oliver, 1990, 2009; Reel & Bucciare, 2010; Roush & Sharby, 2011; Shakespeare, 2006, 2007; Titchkosky, 2011).

Reflecting upon the events, I was awakened to the realization that I also understood disability in a different way. As my prayers and conversations with my wife revealed, I perceived that disability was something *from* God (Barnes & Mercer, 2010; Roush & Sharby, 2011). I prayed to God to “protect him” from acquiring an impairment and the disabilities associated with it. As well as the medical and social perspectives, I thus understood disability on the basis of the *religious model of disability*, a traditional framework that is still common among members of some Muslim, Buddhist, Hindu, Jewish and Christian communities (Barnes & Mercer, 2010; Roush & Sharby, 2011). The religious model may consider disability as a condition or defect created by God that is associated with tests of faith, or with punishment caused by moral sins or failures of faith (Roush & Sharby, 2011).

Ms. Song’s experience of disability was also understood through this religious perspective. She perceived disability to be a condition that God had given to her (Roush &

Sharby, 2011). In addition, she held a sense of greater purpose related to her disability and positively accepted that she had been selected and had a special relationship with God (Roush & Sharby, 2011). As such, Ms. Song also understood the meaning of the term on the basis of the *affirmative model of disability*, a positive perception about disability (French & Swain, 2012; Shakespeare, Gillespie-Sells, & Davies, 1996; Swain & French, 2000). According to French and Swain (2012), “living in a disabling environment can be difficult and frustrating,” but “being disabled is not necessarily viewed as a problem,” and “life may become better or be just as good following disablement by the opening of different opportunities, discoveries, and insights” (p. 23). As Ms. Song declared in her verses (1985), she perceived to have “more than others” because she believed that God had purposefully given a disability to her: She viewed disability as the grace of God (Roush & Sharby, 2011).

Unlike Ms. Song, however, I did not view disability positively at that time. As I thanked God for saving my son from “tragedy,” I regarded disability as a severe hardship for an individual (Clapton, 2003). The *tragedy model of disability* refers to a way of considering disability as “something to be avoided at all costs,” (Oliver & Barnes, 1998, p. 66), “a personal burden” (Wilder, 2006, p. 2), the loss of any enjoyment in life rendering a person a burden to society (Saxton, 2000), and a condition “thought to strike individuals at random, causing suffering. . . lives” (French & Swain, 2004, p. 34). I also perceived that disability was a tragic condition for families, as Parens and Asch (2000) note:

There are many widely accepted beliefs about what life with disability is like for children and their families. [These] include assumptions that people with disabilities lead lives of relentless agony and frustration and that most marriages break up under the strain of having children with a disability. (p. 20)

While carefully considering my son's fall down the stairs, the hospital conversation with my wife, and my prayers that he not be injured, I realized that my understandings of disability was based not merely on the medical and the social models of disability, but also within and/or against the religious, affirmative, and tragedy models. Disability, to me, meant something *from* God (Barnes & Mercer, 2010; Roush & Sharby, 2011), but also "something to be avoided at all costs" (Oliver & Barnes, 1998, p. 66). At the same time, I made sense of it through medical and social perspectives of disability. I came to acknowledge that my understanding of disability involved more than meaning making according to certain models of disability. In fact, it was a complex process that occurred within complex personal and social contexts (Edwards, 2009; Shakespeare, 2006).

My Story, Part 5: The Boy Who Seemed to Have Down Syndrome

During the second year of my Master's program, I was working as a program director and research assistant for an action research project. The project aimed at developing an adapted Taekwondo program for children with developmental impairments, with ages ranging from six to 12 years. Approximately 15 children participated in the program. The program was conducted in the gym of a local rehabilitation centre; the primary investigator, Dr. Lee, and his two assistants taught it. The centre supported the program by providing two youth volunteers per session.

It was the first day of the program. I had gone to the centre early to prepare the session. Entering the gym to check the equipment requested for the session, I saw a teenaged boy sitting by the door of the gym. He was alone. His facial appearance looked like that of a boy with Down syndrome, and so I assumed that he was. As he looked too old

for our program, I also assumed that he was a participant in one of other adapted programs in the centre. I approached him hesitantly, since I was not sure what his reaction would be.

"Hello," I greeted him.

"Hi. Are you Mr. Yi?" I was a bit surprised. He did not react as I expected. I had imagined that he would not be able to speak, or that his speech would be unintelligible, since I perceived that people with Down syndrome had difficulty interacting with others.

"Yes, I am. . . . Um, you are. . . ."

"I'm Min-Joon. I'm a volunteer today."

"Oh, great. . . . You are. . .one of the volunteers. . . ." I was faltering and paused for a while. Based on my knowledge at that time, over 99% of the Down syndrome population was characterized as intellectually impaired (e.g., Intelligence Quotient below 70). I was concerned that he would not serve well as a volunteer, because I also had learned that people with Down syndrome would have difficulty in carrying out complex tasks.

"I am very excited," Min-Joon keenly said, breaking the silence.

"Oh, that's great. . . ." I paused again. I thought he was out of the ordinary. He kept talking like a "normal" boy while looking obviously Down syndrome. He certainly seemed to have a proficiency in verbal communication. I wanted to test his ability to answer a complex question. "How did you know about this volunteer work?" I asked.

Without a pause, he answered, "My dad works here. I've been volunteering here since I was 12. I was so excited when I saw the volunteer ad poster. I got a Poom (junior black belt) last year. I think I can be a really good volunteer."

He really seemed to be a smart boy. I was puzzled. He did not fit what I knew about people with Down syndrome.

"Great, Min-Joon. I've got to go to the office to pick up something. I will see you soon at the orientation." I turned and walked to the office immediately. I wanted to check with a volunteer organizing staff of the centre in order to make sure that he had the ability to successfully support our program. I was concerned whether it would be appropriate to let a boy with Down syndrome provide one-on-one aid to a child with developmental impairments, even though he looked smart enough. As a program director, I doubted that it was a well thought-out plan for the first day of the session.

"Mr. Yi, please let me know if you need help." He talked loudly at my back. I kept walking to the office, nodding quickly.

On the way, I thought about the movies, I Am Sam and The Eighth Day. I had watched them prior to the first session in order to promote my understanding of developmental impairments. Very different from the characters I observed in the movies, he seemed to have exceptional intellectual and interpersonal abilities. I assumed that Min-Joon must have exceptional abilities compared to other children with Down syndrome.

Arriving at the office, I looked for the staff member. I asked her whether he would have the ability to serve as a volunteer.

"Absolutely," she answered. "He will be a great supporter for your program."

"I am concerned that he might have difficulties in helping other kids in the program because of his disability," I said cautiously.

"Well, Mr. Yi," she replied hesitantly. "I guess you are thinking that he has Down syndrome. . . . But actually. . .he doesn't. . . . He just looks a bit like that. . . . I know many people make that assumption, like you."

I became extremely ashamed of my prejudice. My face reddened and my ears burned. I rushed out of the office, mentioning to the staff member that had I misjudged him. I ran back to him. He was still sitting by the door.

"Min-Joon," I said. "Can you help me to set up?"

Reflection: The continuity of my disability construction. Reflecting upon the event, I realized that my past experiences with people with Down syndrome influenced my prejudice against Min-Joon. At my junior high school, I had had a classmate with Down syndrome. I recalled that some of my other classmates used to play what they called "Hit-The-Fugly-Mong"¹ game. They threw things like pebbles and leftover parts of their lunch at him.

For the classmate, the game was a form of *real violence*, "an embodied encounter. . .of pain inflicted by [other classmates]" (Goodley & Runswick-Cole, 2011, p. 606). It was also a form of *systemic violence* against him. According to Žižek (2008), *systemic violence* refers to "the violence inherent in the system: not only of direct physical violence, but also the more subtle forms of coercion that sustain relations of domination" (p. 5). My school ran "mandatory"

¹ "Fugly" is vulgar slang, meaning very ugly or unattractive. It is a blended form of words, "fucking" and "ugly." "Mong" is a shortened form of "mongoloid," an offensive and derogatory term for a person with Down syndrome.

specialized sessions for students with impairments. The participants were thus segregated and excluded from their peers while they took part in the sessions. This policy made the participants' "differences" highly visible to us. Based partly on this discourse of *othering* (i.e., the process of marginalization that occurs when those thought to be different from ourselves due to individual differences are rejected), my classmates (and I) tended to believe that the classmate with Down syndrome had a different appearance, different cognitive and intellectual abilities, and different interpersonal skills, than we did (Schillmeier, 2010; Simpson, 2012). These ideas might have created a sense of superiority and dominance among other classmates (and me), and contributed to my classmates carrying out their violence as a way of expressing their power.

Reflecting upon the game, I also acknowledged that it involved *direct* and *indirect psycho-emotional violence*. *Direct violence* "can be found in . . . acts of invalidation. . . and hate crimes such as the destruction of group symbols and hate literature," and *indirect violence* refers to "the side effects of structural disablism or . . . words." It involves "the impact of these ingredients of disablism on the ontological security or confidence of disabled people, [including] the re-injuring of self through internalizing discriminatory values, lowering self-worth, and lessening a sense of intrinsic value" (Goodley, 2011, p. 90). The classmate was called a "mong," and his appearance was described as "fugly"; his feelings might therefore have been hurt directly through these offensive and hurtful terms. Furthermore, he could have felt that his appearance *was* ugly, and his identity *was* that of an outsider, as he might have internalized an undervalued identity through these forms of indirect violence.

Ultimately, however, it would be presumptuous to judge from his reactions exactly how the game affected him. It saddens me now when I recall that he twirled and cackled with laughter when he got hit. He may have interpreted the interaction with the other students as playful, rather

than an assault on his dignity and personhood (Nordenfelt, 2004). His reaction seemed to be different from the “dominant cultural notion” of a reaction against violence: he did not resist or try to ask for help. His individual differences (i.e., his “other” ways of reacting against the real violence due to his inability to recognize that he was a victim of the violence that can be associated with disablement) were thus vulnerable to *cultural violence* that tends to occur when people with disability react and respond differently to the dominant cultural notions of certain ways of acting, communicating, and thinking (Goodley & Runswick-Cole, 2011).

Upon careful reflection, I came to conclude that my classmates’ misbehaviour was therefore “not just a matter of bullying. . .not something that people can just ignore or laugh off” (Shakespeare, 2010, para. 6). It was instead a moment of a “hate crime” against the classmate and a moment of ableistic violence, a form of violence caused by discrimination and social prejudice against people with impairments (Goodley & Runswick-Cole, 2011, p. 604). I did not actively participate in the real violence. However, I did not act to stop it either. Perhaps I was not fully aware that the acts were the violence, and how terrible the violence was. In fact, I served as an onlooker to the crime, and because of it, I began to perceive that people with Down syndrome *were* unintelligent, pitiable and helpless sufferers. As such, I might have indirectly and unwittingly participated in the violence by shutting my eyes to the hate crime and by feeling superior and dominant over him.

I had another opportunity to interact with children with Down syndrome during my high school years when I volunteered at a residential facility. Together with a few friends, I participated in a program aimed at teaching introductory-level skills in singing and dancing. As I recall, the program did not go well. We taught very simple songs and easy dance movements. However, the participants did not sing or perform as we expected: many times, they moved to

their own rhythms or sang their own notes. We did not, however, make other significant educational efforts to change the situation except for bringing them back to the play area. Perhaps we perceived that their reactions were based on a lack of ability to learn—we might have taken for granted that these were the *characteristics* of children with Down syndrome. Furthermore, in my eyes, the participants looked quite similar to each other. As such, I might have reinforced my own assumptions about their *typical* appearance.

Through these experiences, I created my own ideas about the images of people with Down syndrome: how they look, act, and think. These images might also have affected my perceptions of Min-Joon (Campbell, 2009; Jaeger & Bowman, 2005). I did not see Min-Joon the person: I saw my junior high school classmate and the music/dance program participants. As a result, when I saw Min-Joon at the entrance of the gym, I immediately labelled him as a boy with Down syndrome and made assumptions about his abilities—cognitively, intellectually, and interpersonally ‘retarded.’ I therefore judged him through a *medical gaze*—that is, an understanding based on the notion that “disabled people’s diagnoses become the singular point through which all other information about them is viewed” (Withers, 2012, p. 39). I “diagnosed” Min-Joon as a boy with Down syndrome based on my preconceived notions and stereotyped his reactions and abilities through this medical gaze (Withers, 2012).

My past experiences, in sum, strongly contributed to constituting and shaping my own ideas about people with impairments. I also acknowledged that my understandings of disability would change over time through my ongoing life experiences. I came to realize that my construction of disability was *continuous* in nature (Clandinin & Connelly, 2000): it grew out of other experiences, and would influence my understanding of future experiences (Clandinin &

Connelly, 2000; Clandinin & Rosiek, 2007; Rosiek, 2013). The continuity of my disability construction prompted me to think carefully about my ‘medical gaze.’ As Withers (2012) notes:

The filtering of people’s experiences through their diagnosis can have intense implications for people who are disabled. . . . The filtering. . . is a trademark of the medical model that has real, sometimes devastating implications on the lives of disabled people. Experts continuously tell us what our experiences are, and our identities, in their view, revolve around our diagnoses. This is one of the ways the medical model is able to retain a tight control on the identities and lives of disabled people. (Withers, 2012, p. 40)

My Story, Part 6: Worth Living?

One day during the fourth year of my PhD program, my wife and I were preparing to go out for lunch with our two children. One of my best friends called me at that time to inform us that he had just had a baby boy. My wife and I decided to visit his family before having lunch.

We arrived at the hospital. My wife and my daughter went into a shop to buy a card and some flowers. I waited in the hospital lobby eating a granola bar with my son.

"Hey, David!" a familiar voice greeted me from behind. I looked around. It came from a former co-worker from a group home for people with impairments where I had worked as a part-time caregiver. During the second year of my visiting program at the Steadward Centre for Personal and Physical Achievement, I was looking for an opportunity to closely observe the daily lives of people with impairments in order to deepen my insights about their everyday life experiences. With permission from the supervisor of my visiting

program, I began to work at the group home. In the assisted living setting, there were three adults with impairments. I was paired with one of them, whose name was Max. He had severe and multiple sensory, physical, and cognitive impairments.

Here in the hospital lobby, the co-worker was feeding Max a thick brownish juice. Based on my experiences working with Max, I recognized that he was having a snack before starting his volunteer work. Watching him drinking the juice, I began feeling sick. The juice strongly evoked an earlier memory of feeling nauseous while working with Max at the group home. Quickly saying goodbye, I brought my son into the shop where my wife was buying gifts. I really wanted to get away from them to avoid recalling the experience. However, I could not stop thinking about it—the memories were too vivid.

The work I did for Max was quite demanding physically, psychologically, and emotionally. I worked the day shift (8 a.m. to 4 p.m.) three days a week. Max's morning routine consisted of waking him up at 8 a.m. in the morning, taking his diaper off, giving him a shower, feeding him breakfast, putting his new diaper and clothes on, and preparing him for an outing. One of my tasks during the morning was to successfully empty Max's bowel before going out for activities. I was told to use Fleet Enema, a rectal injection product, to do so. Other co-workers emphasized that it was the most important task in the morning, because this would prevent an embarrassing situation for the caregiver during their out-of-home activities. After having lunch, Max was usually brought to a local hospital to participate in a volunteer program. At the hospital, caregivers performed the volunteer tasks for him.

By the third week of my work at the group home, I had gotten used to completing the routine for Max. One day, I completed my preparations for Max's outing earlier than usual. I sat on a couch watching a caregiver preparing Max's lunch. Following the meal plan, she steamed vegetables and rice. While cooking them, she grilled a beefsteak so that it was rare—she said that was her favorite. She then put everything into a blender and puréed the rare steak, cooked vegetables and rice.

She informed me that his lunch was ready, pouring the purée into Max's green bowl. I brought Max to the dining table and took the green bowl to feed him. I looked inside of the bowl. There was a pinkish liquidized mixture in the bowl. It looked disgusting and gross to me, and smelled repulsive. It was a really tough task to complete. Nevertheless, I began to feed him, struggling against the urge to be sick.

I finally completed my task. Max's green plastic bowl was empty. Then, I threw his bowl into the sink and ran to the bathroom in the basement. I barely made it before I vomited.

Waiting in the shop, the brownish juice that Max had drunk brought back that feeling. I packed up my granola bar and put it in my pocket. I could not eat it anymore.

After my wife bought gifts for my friend's newborn baby, we went up to the ward to see the baby. My friend's family looked really happy. I was also very happy for them. However, I felt distracted, because I was thinking about Max at the same time. I recalled that he suffered a lot in his everyday life because he wasn't capable of making his own

choices. I wondered again, as I often did while working at the group home, "Is Max's life worth living?"

Later that night, I reflected upon Max's daily life. It brought to mind experiences that I had had with my late grandmother. We had lived together until I was in Grade 9, when she passed away. I heard that she had had a series of strokes when I was very young. In my memory, therefore, she had always lived with triplegia, being unable to move her left arm or either of her legs.

She gave birth to 10 children, and my father was her last one. She lost her husband and six of her children during the Korean War. My father never saw my grandfather, because he had died during my grandmother's pregnancy. I heard from my father that grandmother's love and care towards her remaining children, especially him, were very special for this reason. As the grandson born from her last child, I was the one my grandmother loved most.

I relied on her very much. I often ran to her room when my parents disciplined me. I also stored my favorite toys underneath her bed, which I perceived as the most secure place in my house. I loved her very much, just as she loved me.

I remember that she never left home. She tried to avoid showing her left arm and legs to others. She socialized with people by inviting them to our home after dressing herself up and positioning herself in the special chair where she could present herself in the way she felt most comfortable. She did this not out of embarrassment, but out of pride.

During the last phase of her life, her medical condition worsened. The worst period was her last two years. I vividly remember how much she suffered from physical and emotional pain. She was not even able to eat and control bodily excretions by herself for a long time. However, the special relationship between her and me was no different during this hard time. She was my beloved grandmother and I was her dearest grandson. Everyday I lay on her bed singing her favorite hymns and talked to her what happened in my school and my life. She communicated with me by blinking her eyes—those were the only body parts she could move voluntarily.

I lost her on Christmas Day in 1993—one of the saddest days of my life. I felt like I had lost one of my greatest supporters, and that our special relationship was gone forever. At the funeral, I heard many people comforting our family by saying that she had a good life. People also consoled us that it was a "good" death for her, since she could be free from her suffering. I did not agree with them at all. I had observed that her life, even her later life, was more meaningful than they assumed. I was irritated to hear them. I never ever thought that my grandmother was "better to die" because of her suffering.

Reflection: My disability construction in my personal contexts and times. The cases of Max and my grandmother were different. Working with Max at the group home, I often wondered what gave him joy, what relationships with people meant to him, and what he looked forward to in his day. In thinking about this, I realized that, at times, I viewed his life as holding no meaning for him: there was no joy, I suspected, or connectedness with others, or hope for the future. As a result, I often wondered whether he would be "better off dying" in order to be free

from this suffering (Barnes & Mercer, 2010; Darling, 2013; Shakespeare, 2006; Watermeyer, 2013).

I questioned Max's *quality of life* (i.e., a quality which is "experienced when a person's basic needs are met, and is enhanced by integration and by enabling individuals to participate in decisions that impact their lives") (Wehmeyer & Schwartz, 1998, p. 4). According to Schalock (1996), the core dimensions of quality of life include (a) emotional well-being, (b) interpersonal relations, (c) material well-being, (d) personal development, (e) physical well-being, (f) self-determination, (g) social inclusion, and (h) rights. While working with him, it was difficult for me to clearly see that these core dimensions were satisfied.

Of these eight dimensions, I perceived that a lack of self-determination affected Max's quality of life the most. Self-determined behaviours, according to Wehmeyer and Schalock (2001), are observable when a person acts "autonomously" and initiates and responds to the event(s) in a "psychologically empowered" and "self-realizing manner," and these actions are "self-regulated" (p. 3). However, all of his choices and decisions were made by the caregivers (and me), and sometimes, we made them for our own sake (French & Swain, 2012; Shakespeare, 2006; Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998). He had to wake up at 8 a.m. every morning no matter how he felt. He was forced to empty his bowel before an outing for the sake of caregivers. He had to attend the scheduled volunteer work, even though he could not hear, see, talk, or move. He had to swallow unknown puréed meals and snacks regardless of his preference.

I came to realize that my questions about the meaningfulness of Max's life were further related to his *dignity* (i.e., "a special dimension of value" of a person who is "worthy of respect from others and from the person him or herself") (Nordenfelt, 2004, p. 70). I asked myself:

“What is the value of his life and who decides what a quality life for him is?” According to Brussel (2014), a lack of self-determination “increases the risk of intrusion into the private sphere of the sick. . .who depend on the care of others” (p. 181). She argues, “dignity cannot be asserted if one is totally institutionalized and loses control over one’s own fate” referring to “a terminally ill old woman asking ‘Who owns my body, Medicare, the hospital, the state, or me?’” (Brussel, 2014, p. 181). Likewise, I wondered whether Max’s life, with its institutionally imposed loss of self-determination, was dignified enough to be worth living.

As in Max’s case, I perceived that my grandmother’s experience of disability was painful. There seemed to be no big difference between her life and Max’s with regard to their medical conditions. Perhaps my own perspective, which viewed disability as a personal tragedy, was strongly influenced by this experience. However, my grandmother’s life with severe impairments and her painful disability experience was “not necessarily viewed as a problem” all the time (French & Swain, 2012, p. 23).

My interpretations of the value of Max’s life and that of my grandmother were in opposition. I began to wonder why I valued the meaningfulness of these two people’s lives so differently: “Why did I bring my ableistic assumptions to Max’s life but not to my grandmother’s?” Careful reflection on this question prompted me to realize that my grandmother and I shared more emotionally meaningful experiences together than just those related to her disability. Our special relationship provided a very different context from my relationship with Max (Barnes & Mercer, 2010; Campillo, Sáez, & Sánchez, 2014; Darling, 2013; Edwards, 2009; Sherwin & Winsby, 2011; Watermeyer, 2013). I began to think carefully about how I might feel if I had had something other than a caregiving relationship with Max—a connectedness with Max that was more than that of paid-caregiver and client. Through this recognition, I learned the

importance of establishing connectedness with those who I would work with in my future APA practice. I thus began to engage in much more thinking and learning about relationship building with people with impairments.

In the end, I came to realize that I perceived the value of Max's life and that of my grandmother through the values I hold for my own life. As such, I made particular sense about the meaningfulness of his life within and against my own personal contexts (Burr, 2003; Clandinin & Connelly, 2000). Furthermore, I acknowledged that constructs of disability have *temporality* (Clandinin & Connelly, 2000). As such, I understood the meanings of the term differently in different times and places. These recognitions awoke me to reflect on my own personal life contexts while studying my disability construction.

My Story, Part 7: Othering

"A monster!"

My two-year-old daughter scurried toward me with a panic-stricken face. My family was playing at the swimming pool. While my older child was practicing jumps with his mom at the children's pool, I had been watching the little one playing at the zero-depth entry of the pool. Now she cried in my lap. She seemed to be really afraid of something.

I hugged her firmly. "There is no monster, honey," I said, patting her. "No, there's a monster!" she screamed. I looked around to find out what made her so upset. However, I could not find any scary thing. Finally, I noticed a tall Black Canadian² man was standing up from the pool holding his baby girl. I realized that it must have been he who scared my little one, because she had never seen a Black Canadian man in a swimsuit. I chuckled at

² "Black Canadian" is a designation and accepted term in the Canadian context, used for people of Black African descent, including African Canadian and Caribbean Canadian (Magocsi, 1999).

the fright on her face. "There is no monster. Look! He is not a monster. He is a daddy of the little baby girl."

"No. That is a black monster!" She shouted again. I paused for a while to look for an easy explanation. I felt that this was an important educational moment for my little one. I wanted her to appreciate individual differences. I replied after a while, "Honey, he is a daddy with beautiful black skin. You know, we have a black bird, white bird, blue bird, rainbow bird... it's just like that. He is a daddy with black skin, like a black bird."

"Dad, does he roar?"

"No, he is a very good daddy, just like me." I then encouraged her to go back to the pool and resume playing.

A few moments later, she stood up and looked at me.

"Dad, don't go." She wanted to be sure I would be there for her if she felt frightened again. She still looked a bit worried.

"I won't," I replied with a reassuring smile. She began playing in the water, but stayed right next to me.

"Dad!" she called after a few minutes.

"Yeah?"

"Is he just a black dad?" Finally, she seemed to understand that there were people with different skin colours.

"Yes, he is a black dad. . . . See? I'm a light-beige dad. We just have different skin colours."

She nodded and showed me our special smile. She resumed playing and went further away from me. She did not seem to be bothered anymore. I was satisfied that she was able to comprehend the concept of individual differences.

As I watched my daughter, I recalled that I too had experienced first-hand the consequence of "othering," the process of marginalization caused by rejecting individual differences. This happened one day when I rejected a child's participation in my soccer club due to his impairment.

It was almost 15 years prior to that day. I was a first-year undergraduate student in the Sport and Leisure Studies department. At that time, I began my own business, a children's soccer club. I managed several children's soccer teams, with ages ranging from eight to 12.

One day, I received a phone call from a parent who would like his son to join my Grade 3 soccer team. There was one spot left for his son to be enrolled. I asked the parent to bring the boy to the training field fifteen minutes before the session to register him.

On the training day, I met with the boy and his parents. "What's your name?" I asked him.

"Soo-Young," he replied excitedly.

"Okay, Soo-Young. You can play with your new teammates while your mom and dad register you." He ran to the field right away. I smiled watching him. At that moment, I noticed that he walked with a limp. I asked the parents cautiously, "Your son walks. . . ."

"Yes, he has mild cerebral palsy," his mom replied immediately.

"Oh, does he? I didn't know that."

"We didn't let you know yesterday. . . . Is it a problem?" asked his dad.

I hesitated. My first impulse was not to allow the boy's participation—perhaps, I thought, soccer was too demanding physically for a boy with an impairment. But I was cautious about my reaction because I thought it would disappoint the boy and the parents; I assumed that this experience of being excluded from physical activity programs might not be the first for the boy. As such, I tried to look for excuses:

"I've never taught a child with disabilities in my training sessions. I am sorry, but. . . I am not sure I can have him on my team and teach him well. . . . I also worry about your son getting injured in our challenging training. . . ."

The parents looked frustrated.

"Coach, he will be fine," the boy's dad said firmly. "I have been playing with him, and he is quite good at soccer." He looked desperate.

I rubbed my face, sighing. Many thoughts flitted through my mind. I could not stop wondering whether I could be a good coach for the boy, as I had no experience. I also assumed that other children on the team would not like to play with him. They would not think that he could be a competent player, I imagined; indeed, it was also difficult for me to believe it.

I finally decided not to include the boy on my team. Struggling to find the right words, I told the parents hesitantly:

"I am sorry. . . . I am afraid I can't coach him well with other children on my team. I am so sorry. . . ."

There was a moment of silence.

Looking sad, the boy's dad said, "Well, okay then. . . . Thanks."

The parents walked over to the boy. I saw the boy's mom told him they had to leave the field. I saw the boy cry. My heart felt suddenly heavy; it was very hard to watch him. I turned around and realized how badly I had hurt the little boy by making him feel rejected and denying him the chance to train with other boys. I felt terribly sorry for excluding him from my team. To this day, my decision on that soccer field remains one of the worst things that I have ever done. I violated my own belief system and Christian values—particularly, the value of caring for others. A more Christian response, I think, would have involved welcoming the young boy and working to accommodate his difference.

Watching my daughter playing at the pool, my feeling of guilt towards the little boy and his parents arose again. I vividly recalled the boy's disheartened face. I prayed quietly that he would be able to forgive my awful misjudgment and misbehavior toward him and his family on that day—my lack of awareness and understanding, lack of patience, taken-for-granted soccer elitism, rigidness. . .and rejection.

I walked to my daughter and told her once again that there were different skin colours. I wanted this brief yet significant educational moment to contribute to my little one's appreciation of individual differences and her awareness about the consequences of "othering."

Reflection: My disability construction in particular social contexts and places.

Reflecting upon not including the boy on my soccer team, I revisited the social contexts and places where the event occurred in order to explore how they interacted with my own decision. What was my role in creating this disability experience for the boy and his family?

One of the admission requirements of my undergraduate program was passing a fitness test (i.e., a test examining high-performance abilities such as cardiovascular and muscular endurance, flexibility, and agility) and a skills-test for a particular sport (I had chosen a soccer test which examined shooting, dribbling, passing, and trapping skills). Meeting the criteria of the test was not an easy task. For example, candidates should be able to properly perform over 25 chin-ups, complete 75 sit-ups within one minute, and demonstrate proper techniques of soccer dribbling and shooting from different angles. Thus, candidates were usually required to be trained at a specialized academy for athletic development. I attended such a facility for about a year to prepare for the test.

In my training, shaping a fit body was a priority. I thus checked and recorded my weight and body fat ratio every day. I also practiced proper postures and movements related to specific soccer skills, based on the specified rubric for the sports skills test. In sum, I paid close attention to acquiring fitness in order to meet the criteria of the test. In the end, I was able to pass the test, exceeding all the criteria. I demonstrated my superior bodily abilities in high-performance settings by achieving a desirably fit body.

Throughout my preparation for the tests, I might have developed entrenched views on the meanings of fitness: having certain shapes of body and performing skills in particular ways of movement (Davis, 1995; Shogan, 1998, 1999, 2003). I might also have prioritized high-performing bodily capabilities (Davis, 1995; Shogan, 1999). I remembered that I had even teased

my fellow trainees who had not been able to meet the criteria of the test, calling them “sports cripples” (I now view the use of this inappropriate and hurtful language as a subtle form of violence of disablism. It also signified the absence of my disability awareness at the time) (Goodley & Runswick-Cole, 2011, p. 604). Perhaps I strongly believed that being unable to meet the norms for the tests would signify “disability” in sporting contexts (Davis, 1995; Shogan, 1998, 2003; Withers, 2012).

Thinking back carefully on the event, I realized that I had understood the meanings of sporting disability and ability according to the bodily shapes and functions of high-performance athletes (Burr, 2003; Clandinin & Connelly, 2000; Davis, 1995; Shogan, 1998, 1999, 2003). This entrenched view might have influenced the philosophy I held as a coach and the goals I set for my team: I had prioritized mastering soccer skills and team strategy, and winning at a local tournament. When I saw the boy’s limping gait, I thus perceived that he would not “fit” on the team (Waldschmidt, 2005; Withers, 2012); just as my daughter assumed that the Black Canadian was a monster. I tended to believe that his walking with a limp was a symbolic of *deviance* from a developmentally normative standard of sporting ability: I was holding an ableistic view (Davis, 1995; Shogan, 1998, 1999, 2003). I finally assumed that his mobility impairment would prevent him from performing soccer skills *properly*.

The deviance (i.e., his limping gate) became the reason for my othering (Schillmeier, 2010; Simpson, 2012). I worried that other boys on the team would not accept him as their teammate, because the boy had displayed a difference in mobility. I also doubted whether he would have the ability to play soccer with other boys without impairments. On that day, I was in the *expert* position to make a decision about “who is allowed” (Elling & Claringbould, 2005, p. 498). I made my decision based on my own moral legitimation, not based on the choice of the

boy and his family (Elling & Claringbould, 2005; Shogan, 1998, 2003). I was not confident enough in the boy's ability to "fit in" and excel on my soccer team. Finally, I excluded and marginalized him, feeling guilty, as I practiced othering based on my expertism (i.e., prioritizing the professionals expertise over participants' opinions) and soccer elitism (i.e., privileging the elite soccer over recreational participation) (Schillmeier, 2010; Shogan, 1998, 1999, 2003; Simpson, 2012; Waldschmidt, 2005; Withers, 2012). I also felt badly as I realized my lack of awareness and understanding, lack of patience, and rigidity, as well as my expertism and soccer elitism. I worried that I might negatively have impacted on the boy's and his parents' self-esteem and enthusiasm to play sport (Tsai & Fung, 2009). Remarks from the research participants of Tsai and Fung (2009) reflected on the same kind of rejection:

I told them about my son's age and conditions, the staff immediately said to me, "This place does not suit your son. Our instructors don't know how to manage your son. . . ." Why should I give myself more disappointment, one of this kind of disappointment is enough for me, I don't want more. . . . Now he doesn't say he wants to participate in any activities anymore. (p. 160-163)

I was not confident enough to coach him on my team either. I worried whether I could handle those issues well without having previous experience. When I made the decision on the field, I was alone. Reflecting upon the event, I wondered what would have happened if I had had somebody to help me through my 'fear' of accepting the boy on my team, just as I was there to support my daughter through her fear. I wondered whether my decision would have been different, if I had received formal education regarding inclusive approach in physical activity and sport settings (e.g., coaching certificate programs and undergraduate courses), if I had had

previous experiences of inclusive coaching or observing role models, or if I had had more opportunity of interacting with people with diverse impairments. I also began to carefully consider how grand narratives (e.g., discourses of able-bodiedness, norm-based ethics), my own social contexts (e.g., attending elite athlete training facility), and the contexts of particular places (e.g., the soccer field, my university) interacted with my rejection.

According to Clandinin and Connelly (2000), “People are always in interaction with their situations in any experience” (p. 69). I recognized that I had been deeply embedded in the fitness and high-performance culture of the specialized academy and my undergraduate program department when I rejected the boy (Allan, 2005; Davis, 1995; Shogan, 1999). My own ideas about disability and ability were strongly influenced by the social contexts of my life in specific places where I was located (Clandinin & Connelly, 2000). As a result, I began to carefully consider how particular social contexts of my life within particular places played roles in my own disability construction.

The Ways in Which I Came to Understand the Meanings of Disability

My stories and reflections illustrated the lived quality of my own disability construction and my contributions to it over time. I came to understand the meanings of ability and disability by “experiencing experience” (Clandinin & Connelly, 2000, p. 50). By thinking narratively, I reached a number of, at times, very painful insights about my own limiting understandings of disability. However, I was also able to identify my reliving opportunities for future disability construction.

I realized that my disability construction was not only the process of understanding the meanings of disability according to certain models of disability. In fact, it was a complex and interwoven process of attending to my lived experiences. I also recognized that my disability

construction was constantly changing as it unfolded through time; thus, it was a temporal and continuous experience. Furthermore, I acknowledged that I came to understand disability within and against my personal and social contexts and realized that particular places significantly contributed to constituting and shaping my own disability construction. As a result, I came to recognize that there is no single way of defining disability (Edwards, 2008). Instead, in the sense that Rosiek (2013) notes, meanings of disability are “transaction[al] across boundaries that have no set definition” (p. 695).

Clandinin (2013) uses the term *lives in motion* to refer to the fact that people are always *becoming* (Clandinin & Caine, 2012) and always *in the making* (Greene, 1995). Accordingly, I began to understand that my disability construction was in motion; thus, there would be “no final telling, no final story, and no one singular story” (Clandinin & Caine, 2012, p. 176).

This recognition prompted me to engage in new ways of reliving. *Ethical becoming* and *ethics in the making* thus became important aspects within my disability construction. As Goodwin and Rossow-Kimball (2012) suggest, “How disability is understood/created, or the ethical components of the *purveyor* of professional practice (expert), is worthy of ethical reflection” (p. 303). Furthermore, according to Clandinin (2013), “We need to think about the ongoingness of institutional, social, cultural, familial, and linguistic narratives in which each of our lives is lived, and is being lived, which are also in the midst” (p. 44). As a result, I began to carefully consider how I interact with grand narratives of disability construction within my personal and social life contexts as a way of “perhaps. . . shift[ing] the institutional, social, and cultural narratives in which we are embedded” (Clandinin, 2013, p. 34).

Chapter 5: Reliving My Own Disability Construction

In the previous chapter, I shared my stories of the ways in which I constructed the ideas of disability and ability. I also offered my subsequent reflections on them in order to highlight the meanings and social significances of these experiences. In the pages that follow, I will reflect on the potential implications of my own disability construction for my professional and scholarly practices in APA. Specifically, I will illustrate how my own assumptions and perceptions about disability and ability were expressed and enacted within my APA practice. My ambition in writing this chapter is to inspire readers to reflect on and think critically about how their own ideas of disability contributed to their professional practices. In doing so, they may identify opportunities to relive their future practices in new (and more ethical) ways.

My Story, Part 8: An Armchair Theorist

A “special” school bus might not be the one that students with impairments want to ride on; a “special” educational program might not be the one they want to participate in; a “special” school might not be the school they want to attend. Now is the time to move forward to include them in a “regular” program at a “regular” school. Now is the time for them to ride on a “regular” school bus, not a special school bus. (Jang, Kim, Jang, & Choi, 1998, p. 4, my trans.)

During my master's program, I carried this page copied from the first APA textbook I bought. I regarded these ideas as the underpinnings of my master's research. Based on my experience of exclusion—that is, being denied access to a gym, because I “looked” disabled after an injury—I regarded inclusion as an essential and mandatory societal action for promoting the human rights of people with impairments.

During the first term of my program, I joined a campus club called disAbility, a social activism group for advancing disability rights. Members of the club consisted of undergraduate students with diverse impairments. As a guest member, I participated in various events, including their weekly seminars. After a while, I was able to establish close relationships with some of the members of the club. We hung out often at local pubs and restaurants near the university.

One day while having a few pints of beer, we chatted about a weekly seminar we had just attended. The topic was what we called "armchair theories," which meant inadequate policies that had developed while overlooking the experiences and voices of people with impairments.

Min-Ji shared her experience with the group. "My plant biology prof told me to participate in all the group project meetings. I have to make trips to the greenhouse near the North Gate two times a week!" The gate was located approximately 1 km away from the main buildings of the university, and there were also several steep slopes on the way. She walked slowly and with much effort because she used a cane. I imagined her travelling to the greenhouse, and thought that this must be a difficult task for her.

"I told the prof that I would like to work on my own to avoid trips, which were demanding," she continued. "But the prof said, 'No, you have to work with your group, because it's a group project.' I think she is a good example of an 'armchair theorist!' She was trying to be inclusive, but she didn't think carefully about what would work best for

me." Other members also criticized the professor for not accommodating her educational needs.

But I disagreed. It seemed to me that Min-Ji was rejecting the professor's offer of an opportunity for inclusion. I felt that Min-Ji was not carefully considering the importance of inclusion—its value as a means of equity, accessibility, and social justice. However, I did not say anything. I was afraid of losing a good relationship with her by revealing that I had a different opinion.

Several minutes passed. I was still thinking about her comments when Ho-Jin asked me a question:

"David, have you decided on your research topic?"

"Not specifically, but it's going to be something about. . .inclusive physical education," I replied carefully.

"Why do you want to do that?" Ho-Jin asked again. I replied that I believed inclusive physical education was a good educational and pedagogical approach in regular physical education contexts.

Immediately, he began arguing with me, sharing his own negative experiences with inclusive physical education (IPE): "When I was Grade 7, my PE teacher told me to 'be' the first base when other friends were playing baseball," he continued. "Can you imagine how ridiculous I looked acting as the base in front of my friends?"

I was disturbed. I could not believe that the teacher had treated him as an inanimate object instead of as person. I tried to grasp how humiliated he must have felt in front of his peers.

After a pause, I told him cautiously, "Honestly, I've never thought that inclusive physical education could have negative effects. I really believed in this approach as a 'best' practice for students with and without impairments. . . ."

Min-Ji interrupted me. "I also had a similar experience. . . ." People turned to her.

"In Grade 9, I was told to compete against other friends in the 100m run. The teacher told everyone that she would give me an advantage because I had a disability. She let me start at the halfway mark. When I had barely run 30m in my ugly and awkward way, all of my other friends had finished 100m. She made me a laughingstock. I never went back to PE class for my entire life. I always asked for permission to stay in the classroom."

There was a moment of silence. I could see everyone frowning.

"Participating in PE should be good for mind and body," Yong-Soo broke the silence.

"But, I remember that PE, sometimes, wasn't good for my mind. . . ." Everyone looked at him.

"It was a soccer class. I think it was around Grade 5 or 6. The teacher also gave me some 'advantages' when we played the game. He said I would be exempt from the offside rule, and if I could score, it would be worth two points."

Yong-Soo took a drink of beer and continued:

"One of my classmates told me to stand in front of the opponents' net and shouted to everyone, 'Hit Yong-Sool!' They were basically trying to deflect the ball off of me to make a two-point shot. Guess what? The teacher said: 'What a smart strategy!'" There was another moment of silence with exclamations of anger and emotional discomfort.

I became even more displeased. I was lost in thought trying to make sense of the negative aspects of IPE while others were talking about their own experiences in physical education.

However, I soon returned to my firm belief that inclusion was necessary to ensure the human rights of people with impairments. I concluded that the negative consequences of inclusion did not stem from the idea itself, but from its faulty application. I still believed that inclusion in PE should be a "mandatory" educational action.

I was cautious but wanted to let other members of the group know about my position regarding IPE. As I did so, I also wanted them to recognize that the ideas informing inclusion were important and valid. Accordingly, I said carefully:

"Hey guys. . .I am so sorry to hear your bad stories. It must have been awful experiences. . . . I totally understand that you guys might not value an inclusive approach in PE as much as I do due to your previous experiences. . . . But, I can't stop thinking that you guys need to reconsider the real value of this approach. If inclusion is done properly, it could offer a lot more for you. . . . You know. . .ensuring equal opportunities. . . ."

"Hey, hey, hey, David! That's the problem with you guys!" Ho-Jin interrupted, almost yelling.

"Didn't you hear what we were saying? Didn't you hear what we were going through everyday? How come able-bodied people never listen to us? David, be careful not to become an armchair theorist!" I wanted to say that I did not mean to ignore what they said, and I cared very much about their dreadful experiences. However, I could not reply to him as he looked very upset. There was an awkward silence.

Reflection: Being attentive to reflexivity. As I noted earlier, I had adopted the medical and the social perspectives of disability while attempting to understand my own disability experience (i.e., the experience of being denied access to a gym) (Smith, 2009). At the time, I thus began to understand disability as a personal tragedy, which was intensified by disabling elements within society (e.g., inappropriate built environment, policies, and public attitudes) (Oliver, 1990, 2009; Reel & Bucciare, 2010; Roush & Sharby, 2011; Shakespeare, 2007; Titchkosky, 2011). I also perceived that people with impairments were vulnerable, oppressed, and marginalized (Charlton, 1998; Jaeger & Bowman, 2005; Oliver, 1990).

These ideas about disability and ability played a significant role in helping me to focus my research interest during the early years of my graduate program. I regarded inclusion as an “essential” and “mandatory” societal action for protecting and serving “such people.”

The quotes from Jang, Kim, Jang, and Choi (1998), which stress the importance of mainstreaming through equal placement (and which, I now understand, overlook the importance of individual choices within the mainstreaming process), thus underpinned my research activities in my Master's program. Accordingly, I assumed that the IPE approach would be the *best* practice for preventing the marginalization and exclusion of people with impairments, and for ensuring equal participation opportunities for them in physical educational settings (Block, 1994; Jang, Kim, Jang, & Choi, 1998; Lieberman & Houston-Wilson, 2002).

However, my beliefs about IPE as a research priority were challenged by the members of the club. At our meeting, Ho-Jin's outcry alerted me that I could be the "problem" for people with impairments (Bredahl, 2008; Berger, 2004; Peers, 2009). I recognized that I developed my research interests according to my own opinions about IPE without fully considering the members' lived experiences (Kitchen, 2000). I also did not carefully contemplate why my research question mattered to people with impairments or whether it was meaningful to them (Kitchen, 2000; Macbeth, 2010; Northway, 2000). Accordingly, as Ho-Jin warned, I could become a researcher whose work has "little interest to others who are disabled" (Berger, 2004, p. 799).

At the time, I firmly believed that my research focusing on this placement-focused "integral" approach would contribute to a positive experience for people with impairments within physical education contexts. I did not even think about inflicting inadvertent harm on them through my research practice. Reflecting upon Ho-Jin's opinion about my research interest, I thus became curious whether I was a *victimizing* researcher (Hunt, 1981; Kitchen, 2000). Was I following my "own research agenda," ignoring "the views of the people," and committing "continued academic 'abuse'" by prioritizing an agenda that led "to a growing dissatisfaction amongst [research participants]. . .and perpetuating the dichotomy and unequal power relationships between non-disabled and disabled?" (Kitchen, 2000, p. 26) Despite Ho-Jin's opinion, however, I did not seem to think I lacked interest in those I planned to research; I did not seem to believe that I was an armchair theorist, as I cared about them very much.

But his warning prompted me to consider that I might not have been reflexive enough to carefully identify the opinions, needs, and aspirations of people with impairments within my research activities, the research participants' agenda (Bishop & Shepherd, 2011, Northway,

2000). Furthermore, I came to realize that my lack of reflexivity could contribute to my becoming an armchair theorist, despite my good intention. For my future research practice in the field of APA, I also came to acknowledge that carefully identifying potentially harmful applications of ideas would be as important as studying these ideas.

My subsequent reflections on Ho-Jin's opinion thus helped me to recognize the importance of researchers' reflexivity within their scholarly practice—that is, being self-reflective on and critically thinking about their own research practice in order to be aware of ethical considerations throughout the research process (Bishop & Shepherd, 2011; Forbes, 2008; Hellowell, 2006; Henwood, 2008; Northway, 2000). In my dissertation journey, this awareness prompts me to continually attend to such questions: “Who am I in my research?” and “Why does my research question matter to me and to people with impairments?” (Clandinin & Connelly, 2000; Goodley, 2000; Pinnegar & Daynes, 2007, p. 9). My experience at the meeting with the members of the club and my subsequent reflections on it thus helped me to become aware of the importance of being attentive to reflexivity in and through my research activities (Clandinin & Connelly, 2000; Clandinin, Steeves, & Caine, 2013; Downey & Clandinin, 2010; Northway, 2000).

Reflection: Being attentive to “counter” stories. During my Master's studies, my own understandings of disability were reinforced through the program coursework. Two graduate-level APA-related courses focused on strategies for restoring and maintaining the medical conditions of people with impairments through corrective and therapeutic interventions (in a course called Therapeutic Exercise for Obesity and Chronic Diseases) and effective pedagogical approaches and instructional techniques within disability sports, APA, and IPE contexts (in a course called Advanced Adapted Physical Activity). The institutional narratives were thus

largely based on the medical model of disability (i.e., the perspective that disability is amenable to medical diagnosis and therapeutic treatment) (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). My selective readings of textbooks and research papers also influenced my understandings of disability. I was particularly interested in reading articles related to IPE. Most of the IPE-related texts published in Korea at that time highlighted the effectiveness of the inclusive approach and importance of providing equal placement opportunities. As a result, I became immersed in the taken-for-granted institutional narratives of IPE.

My Master's program served as my *professional knowledge landscape*. This term refers to both an intellectual and a moral landscape, which are often filled with "imposed prescriptions" (Clandinin & Connelly, 1996, p. 25) and a wide variety of components that shape professional knowledge (i.e., normative professional ethical principles that are learned through theories and formal educations) (Clandinin & Connelly, 1995; Goodwin & Rossow-Kimball, 2012). As a graduate student within this landscape, I began to live and tell *sacred stories* (Crites, 1971), stories based on ideas about "what is right" within a "theory-driven view of practice" (Clandinin & Connelly, 1996, p. 25). Thus my sacred stories guided my own actions in my Master's scholarly practice toward a predominantly medical perspective (Goodwin & Rossow-Kimball, 2012). Furthermore, privileging the IPE approach in physical activity contexts became one of my sacred stories.

During the meeting with the club members, I held my *secret story* (i.e., my perception that Min-Ji was rejecting the professor's offer of an opportunity for inclusion by not carefully considering the importance of inclusion) up against their stories of negative IPE experiences. *Secret stories* refer to practitioners' lived stories in a place where they are "generally free from

scrutiny” (Clandinin & Connelly, 1996, p. 25). Instead, I shared my *cover story*—a story that “fits within the acceptable range of the [sacred] story” (Clandinin & Connelly, 1996, p. 25)—with them. This was my argument that the negative consequences of inclusion did not stem from the idea of IPE, but from its faulty application. In telling these stories, I portrayed myself as *expert* in the approach (Clandinin & Connelly, 1996).

When I talked with the members, I recognized that I had different opinions about inclusion. The secret stories I lived bumped against both my sacred stories (i.e., stories that IPE approach would be the *best* practice in physical educational settings) and their own lived stories, the “counter” stories. *Counterstories* refer to “real lived and relational experiences” (Clapton, 2003, p. 545) with, and of, those who are “invisible, silent, composed, and lived on the margins” (Huber et al., 2013, p. 236). Until I heard from them, these counterstories of people with impairments were silent within my sacred stories of IPE: they were invisible in my formal education and the scholarly texts I was reading (Bredahl, 2008; DePauw, 1997). As a result, I had been taking for granted that my sacred stories were the “right” way of understanding disability and engaging in APA practice.

Once I shared my cover story with the other members, the conflict between our stories became highly visible. I felt uncomfortable as Ho-Jin challenged my own perceptions and assumptions about IPE (that was, I believed, based on good intention toward people with impairments) as ableistic views. They might also have felt tension as I challenged their opinions about IPE, from the *expert* point of view, suggesting that they were not considering its importance. As we all felt close to each other, the conflict became emotionally awkward for everyone.

The experience, however, was not all negative. Ho-Jin's remark prompted me to carefully consider his lived experiences, and those of the others. It led me to shift my research interests and ultimately to change my research direction (from studying how to promote IPE to exploring what meaningfulness IPE would have for people with impairments). I made these changes because I acknowledged that I could be the "problem," and did not want to be. As a result, I commenced a series of studies examining the experience of IPE from the perspectives of people with impairments (Yi, 2005; Yi & Kim, 2005). I began to consider their counterstories as fundamental sources of my own knowledge and understanding (Clandinin, 2013) and as a way of inviting "new interpretations and conclusions" (Lindemann Nelson, 1995, p. 23). This shift enabled me to begin understanding gaps amongst the taken-for-granted institutional grand narratives of IPE, my own limiting ideas of IPE, and the lived IPE experiences of people with impairments (Gilbert & Sliep, 2009; Munger & Mertens, 2011; Oliver, 1992; Oliver & Barnes, 2010).

For some of the members who were involved in the conversation, the moment also opened up to the possibility of change. They became the key informants of my future research activity. They continued to let me into their worlds, and they took it upon themselves to engage in dialogue with me. Furthermore, some of them who "never went back to PE class" later participated in inclusive physical activity undergraduate course offered at my department.

According to Clandinin et al. (2006), one function of counterstories is to "shift the taken-for-granted institutional narratives" (Clandinin et al., 2006, p. 171). As such, these stories "hold tremendous potential for educative reverberations" (Huber et al., 2013, p. 229) and offer "both alternative understandings and a more appropriate ethical platform from which to engage in crucial discussions" (Clapton, 2003, p. 540). However, I now recognize that counterstories of

people with impairments in APA are “still waiting to be told and studied” (Huber et al., 2013, p. 222). As such, I am aware of my responsibility to listen carefully to the voices of people with impairments in my APA scholarly practice so as not to be a “problem” for them.

My Story, Part 9: A Surprising Reaction

"Hey, Mr. Educator!"

I greeted Joon-Hong entering a dim sum restaurant, one of our favorite hangouts. We had not met for three years, since the time we both served in the Korean Army. After I had settled into my new life as a graduate student, I phoned him, as I really missed our getting together. Both of our lives had changed course after the completion of our military service. He had become a physical education teacher at a local junior high school, and I had become a Master's student in the field of APA. Having our favorite steamed dumplings and deep-fried seafood, we spent a lot of time talking about the good old days.

We also talked about our new lives as a teacher and a graduate student. He was particularly excited to talk about his teaching experiences. He seemed to enjoy them very much. Listening to his stories, I became curious about how students with impairments had been participating in his physical education classes. I asked him about it.

His answer was disappointing: "I've never taught them yet. . . . Typically, I have one or two disabled kids in each class, but they just stay in their classroom. If they come out, they are usually sitting somewhere and. . . just watching."

His answer resonated with what the members of disAbility had said at our gathering. I recalled their dreadful experiences in IPE, which had served as a reason for

them to avoid participating in physical education. I assumed that Joon-Hong's students with impairments would have had similar past experiences that contributed to their absence in his class.

I was interested in how he felt about this issue, to gain a teacher's perspective on IPE.

"Don't you think they should be in your class together with other students?" I asked him, expecting him to say yes. I anticipated that he would at least be willing to provide inclusion opportunities for his students with impairments, even if they turned down the opportunity. I thought that including all students in his class was his responsibility.

But he did not think so; in fact, he was pessimistic about the possibilities of inclusion. "These kids know they cannot do something 'physically' in PE. . . . I guess that's why they don't want to participate." Thinking for a while, he continued, "If it's impossible for them, why should they be in PE?"

I tried to look for a simple yet compelling way of arguing with his idea, but he continued to talk. "To be honest, I like them staying there. I would be worried, if they took part."

I asked him why. He pointed out that he was concerned about his lack of experience and readiness, and then he added, "I don't want to have to deal with them. . . . I wouldn't know what to do with them in my class!"

I decided to stop talking about it. His ideas about IPE disappointed and annoyed me; they were completely at odds with mine. However, I did not want to argue as we were

meeting for the first time in three years. I also thought that I needed time to reflect carefully on his opinions in order to find gentle ways of persuading him.

Later that night, as I reflected both on this episode and on the meeting at the pub with the members of disAbility, it occurred to me that both teachers and people with impairments perceived IPE negatively. Notwithstanding my firm beliefs about the approach (and what I had learned about it), it had been underestimated in real-world situations. Why did members of both those important stakeholder groups seem so resistant? Could IPE be designed in a way that addressed their concerns and provided positive and reliable outcomes?

My meetings with my friends thus became a motivation for my new research project. I was fascinated to examine whether IPE could be positively implemented within Korean educational contexts. Thus, I began a study aimed at promoting an inclusive approach in a PE class using action research.

Four months of intervention went well, and the findings of the study were significantly positive. The analysis of interview data highlighted all of the "good" aspects of IPE, and the results of pre-post tests indicated enhanced psychomotor, affective, and cognitive learning outcomes. I was particularly proud of these findings, because I was able to conclude that my strong beliefs in IPE were not wrong. After submitting the manuscript to a research journal, I gave Joon-Hong a call and told him that IPE was the best practice.

In so doing, I wanted to reassure myself, as I had been wondering whether inclusion really was an idealistic but impractical approach for both teachers and people with

impairments. Furthermore, I wanted Joon-Hong to recognize that IPE could be successfully implemented in his teaching practice. Finally, I hoped he would start trying to include his students who did not take part in his class.

As such, I offered to help him if he needed supports in including them. Despite my excitement, however, he replied, "Well, I'll try. . . . But, I'm not sure if they want to join in my class." His offhanded answer suggested that he was maintaining his pessimistic view. He did not seem to be as interested or committed as I was.

Reflection: Being attentive to social responsibilities. Eight years after the completion of the action research, I was preparing my PhD candidacy exam. I particularly focused on thinking about my own disability construction and its implications for my APA practice. Studying for the exam, I had a chance for revisiting my previously completed research projects in order to think about the societal significance of each study. Finally, I began to review the action research that I had shared with Joon-Hong. Carefully reviewing the study, I recognized that the intervention plans, in most cases, included “imposed prescriptions” (Clandinin & Connelly, 1996, p. 25) of IPE on the basis of the medical model perspective.

For example, a supporting document that I provided to a teacher-researcher on the first day began with the potential behavioral “problems” of the participating student with developmental impairments (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). Furthermore, my suggestions were mainly about how to prevent and correct those problems (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). I became concerned about the hidden ramifications of the predominance of the medical perspective within the study (Bredahl, 2008; Smith, 2009; Withers, 2013). I wondered whether the participating researcher might have believed that the medically-

oriented way of pursuing IPE *was* the best practice due to my limiting introduction of the approach. I also worried about students with and without impairments who might participate in his classes. The students with impairments might undervalue their own identity by perceiving themselves as the “problem” through the teacher’s medically-oriented instructions; or the students without disability might develop limiting ideas about their peers of impairments as the “problem.”

Preparing my exam, I was also developing my teaching materials for an intersession course (Introduction to the Movement Activities of Children). It was as the first time I taught as a primary instructor during my PhD program. Putting together the lecture slides for a learning module on inclusive physical activity, I noticed that the assigned textbook was written predominantly from a medical perspective. For example, the corresponding chapter of the module began with definitions and characteristics of various impairments, and typical “problems” associated with them (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). The chapter also highlighted some of what the authors called the “best” pedagogical strategies to “cope” with those problems (e.g., “behaviour prevention and management techniques” and “instructional strategies to promote appropriate behaviours for more challenging behaviours” [Francis, Johnston, Lloyd, Robinson, & Sheehan, 2011, p. 31-32]). I realized that the professional knowledge that I was assigned to teach was founded upon the medical model of disability, which views it in terms of individual deficits (Clandinin & Connelly, 1996; Goodwin & Rossow-Kimball, 2012).

Most of the students registered in the course were in the Elementary Education program. For some of them, the course was the only opportunity to learn about physical education prior to graduation. Thus, the course was an important professional knowledge landscape for them

(Clandinin & Connelly, 1996). I realized that I was responsible for their future sacred stories. My teaching thus became a socially responsible pedagogical practice (Goodley & Moore, 2000; Clandinin, 2013; Clandinin & Caine, 2012).

I was particularly worried that my students might regard their future students with impairments as having “problems.” This concern prompted me to look for other ways of teaching, seeking to identify “a different ethic” that would allow my students to live and tell “a different [sacred] story” in their prospective teaching (King, 2003, p. 164). I hoped to give them a chance to be attentive to different ways of understanding disability, which would create opportunities for ethically framed APA practice.

Preparing for the intersession course, I felt that I was “in a tension-filled midst” (Clandinin, Murphy, Huber, & Murray Orr, 2010, p. 81), as I realized that my stories as a novice APA instructor bumped against each other. My sacred story (i.e., the story that I needed to teach based on the assigned textbook) conflicted with my secret stories (i.e., the story about my awareness of the “harm” of prioritizing a certain way of understanding disability). Thus, looking for my cover story (i.e., the story of deciding what to teach in my class) was an ethical project for me (Goodwin & Rossow-Kimball, 2012). I finally told my cover story in my class: I taught the module based on the assigned textbook, and I also taught other perspectives of approaching inclusive physical activity. This search for my cover story, therefore, became my counterstory against the dominant institutional narratives.

Goodwin and Rossow-Kimball (2012) note that “making visible stories of instructors and practitioners can bring tensions and synergies in experiences to light” (p. 304). By composing the counterstory, I realized the importance of being attentive to social responsibilities within my pedagogical and scholarly practices in the field of APA. As a result, I will be continually

attentive and reflexive on my own process of composing stories as a way of “shaping more responsive and responsible living in the future” (Huber et al., 2013, p. 219) within my APA practice.

Reliving in the Midst of Tension: Being Reflexive, Relational, and Transformative

My stories and reflections highlighted how my own assumptions and perceptions about disability and ability shaped and constituted my own APA practice. They also illustrated how these ideas were expressed and enacted within the practice. Composing them, I realized the importance of being attentive to reflexivity, counterstories, and social responsibilities for my ethically framed APA professional and scholarly practice in the future.

The notion of *future-oriented ontology* involves “recognition of the way present experience is constituted in part by anticipations of the future” (Rosiek, 2013, p. 696). According to Colapietro (2011), “[t]he most effective. . . way to make the future different from the past is. . . to remake the present. . . . The most compelling reason to imagine the future is to reimagine and, thereby, to mobilize the resources requisite for remaking the present” (p. 161). Anticipating the future of my ethically framed APA practice, I thus began to attend to the remaking of my present disability construction.

Clandinin (2013) suggests that *thinking with stories* is a way of remaking the present. Thinking with stories refers to being attentive toward one’s own stories, the stories of others, and “all the narratives in which we are embedded as well as what begins to emerge in our shared lived and told stories” (p. 30). This notion prompted me to think carefully with sacred, secret, cover, and counter stories in examining my own disability construction.

By reflecting these stories, I began to think critically about the ways in which my own professional knowledge was shaped and constituted within and against the grand narratives of

disability. Furthermore, by contemplating what constitutes ethical stories, I began to search for more socially responsible *personal practical knowledge* in regard to my own disability construction. Connelly and Clandinin (1988) define this knowledge as follows:

Personal practical knowledge is in . . . past experience, in . . . present mind and body, and in . . . future plans and actions. Personal practical knowledge is found in . . . practice. It is . . . a particular way of reconstructing the past and the intensions of the future to deal with the exigencies of a present situation. (p. 25)

In this process of critical reflection, I became particularly attentive to counterstories of people with impairments as a way of shaping my ethically framed personal practical knowledge in relation to their own meanings of disability (Clapton, 2003; Gilbert & Sliep, 2009; Munger & Mertens, 2011; Oliver, 1992; Oliver & Barnes, 2010). According to Clandinin (2013), “our stories are always in relation, always composed in between, in those spaces between time and place and generations and places” (p. 30). Furthermore, I also began to focus on composing my own counterstories—that is, “stories in which my life and dominant cultural, institutional and social narratives could be otherwise” (Clandinin et al., 2010, p. 88). By making both of the counterstories visible, I became passionate about transforming “concealed social narratives” of disability, “with major ethical consequences” (Morris, 2002, p. 204). This involved identifying how my own stories and others’ stories bumped against each other and how I came to compose my own reliving stories within and against those stories.

Reliving my own disability construction in this way involved *living in a tension-filled midst*, including tensions between ideas of mine and others’ in relation to understanding disability and APA practice (Clandinin et al., 2010; Huber, Huber, & Clandinin, 2004). The

term, however, refers to understanding “tensions in a more relational way, that is, tensions that live between people, events, or things, and are a way of creating a between space, a space which can exist in educative ways” (Clandinin et al., 2010, p. 82). My reliving in a tension-filled midst will involve opening up ethically framed future possibilities for disability construction and APA practice in reflexive, relational, and transformative ways (Clandinin, 2013; Rosiek, 2013). As Clandinin and Caine (2012) note, “Our retold and relived stories are composed in the tensions of telling, living, and retelling, tensions that hold the fabric of our lives together, that allow us to recompose and restory our experiences in new ways” (p. 176).

Chapter 6: Ending Tentatively with New Beginnings

As narrative inquirers we enter into the research in the midst. . . . Recognizing this means that there will never be a final story, that each story and experience begs for a new story to be told, for the experience to be retold and also relived. When we, as researchers, understand this, we also bring a commitment to understanding lives in motion, a commitment to seeing, and representing lives always in making. (Clandinin & Caine, 2012, p. 176)

This journey began when I recognized my own ideas about disability and ability. Throughout this journey, I have reiterated the ways in which I came to understand the diverse meanings of these terms and engaged in thinking about the future reliving of my own disability construction. Just as I “began in the midst,” I now “end in the midst” (Clandinin & Connelly, 2000, p. 187). In coming to a tentative ending, I reflect backward to understand the meanings of this journey and think forward to identify other possible new beginnings.

Meanings of My Dissertation Research Journey

Clandinin (2013) provided a way of contemplating the meanings of narrative inquiry: attending to the “So what?” and “Who cares?” questions by asking “personally. . . why this narrative inquiry matters to us as individuals; practically. . . what difference this research might make to practice; and socially or theoretically. . . what difference this research might make to theoretical understandings or to making situations more socially just” (Clandinin, 2013, p. 35). In this section, I consider each of these three kinds of implications in detail.

Personal meanings. This journey mattered to me, because I wanted to change my own *stories to live by*—that is, stories lived and told in relation to my own identity, that are shaped by,

enacted within, and entangled with my relational, temporal, and continuous life contexts (Clandinin & Connelly, 1998; Connelly & Clandinin, 1999). In my journey, I have been continually attentive to the question, “How are my own stories evolving?” Accordingly, I have tried to challenge any fixed or predetermined notions of who I am and who I should be in my disability construction and in my APA practice (Cottle, 2002; DePauw, 2000; Huber et al., 2013; Standal, 2008; Stephens, 2011; Thomas, 2012). I have focused on my own stories in order to “live right” and “replace myself” in the sense that Morris (2002) describes: “The story is working on you now. You keep thinking about it. That story is changing you now, making you want to live right. That story is making you want to replace yourself” (p. 197).

My journey also prompted me to attend to social responsibilities (Clandinin, 2013; Clandinin & Caine, 2012). By attending to my own living, telling, retelling, and reliving stories, I was able to recognize the lived quality of disability construction. As a result, I began to reconceptualize meanings of disability according to my own stories lived and told in relation to my own disability construction. According to Huber et al. (2013), stories are persistent through time, and are thereby enduring in nature. Throughout this journey, I thus tried to think carefully about the responsibility and obligations that come with my own stories (Huber et al., 2013); as Clandinin (2013) suggests, “If we change the stories we live by. . .changing who we are. . .we might change. . .our own lives and those who live in relation with us” (p. 23). In sum, my dissertation research was an ongoing reflexive and reflective journey aimed at my own socially responsible ethical becoming (Clandinin & Caine, 2012).

Through this process, I thus changed my own stories to live by. Accordingly, I now realize that my own identity as an APA graduate student is not merely the one who lives out theory-driven professional knowledge. I am instead a reflexive, relational, and transformative

pre-service APA academic professional who is continually seeking socially responsible ways of thinking about disability and engaging in practice.

Practical meanings. The purpose of this journey was to explore “possibilities for reliving, for new directions and new ways of doing things” (Clandinin & Connelly, 2000, p. 189). Therefore, I sought to offer experiential and empirical knowledge of disability construction, opening a space for future dialogue around its ethical implications for APA practice, by sharing my own stories and reflections (Freeman, 2007). According to Polkinghorne (2010), this is a fundamental strategy of narrative inquiry, which offers “readers a vicarious experience. . . . From this the readers’ experiential background is enlarged, their repertoire of possible action is increased, and the judgments about what might be done in their practice in similar situations is sharpened” (p. 396). Sparkes (1999) also argues that, “In the telling, listening, and reading of stories, the opportunity arises to share experiences about our own lives and the lives of others” (p. 19).

Furthermore, this inquiry opened spaces for future dialogues amongst diverse perspectives and experiences regarding ethically framed disability construction and APA practice (Clandinin, 2013; Clandinin & Cave, 2008; Clandinin, Cave, & Cave, 2011; Clandinin, Pushor, & Murray Orr, 2007; Downey & Clandinin, 2010). Coles (1989) writes,

We have to pay the closest attention to what we say. What [others] say tells us what to think about what hurts them; and what we say tells us what is happening to us—what we are thinking, and what may be wrong with us. . . . Their story, yours, mine—it’s what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them. (p. 30)

Throughout this journey, I thus tried to attend to stories, as a way of promoting dialogue. I made visible the counterstories of people with impairments, which were often invisible in APA related literature (DePauw, 1997). I also shared my own sacred, secret, and cover stories—that is, stories of how I came to retell and relive my own disability construction and APA practice within and against grand narratives related to disability. My stories, then, served as the counterstories of an APA graduate student who wanted to inspire other APA professionals to revisit taken-for-granted narratives of APA (e.g., prioritizing certain ways of understanding disability, privileging experts' professional knowledge).

According to Huber et al. (2013) counterstories are “stories that hold tremendous potential for educative reverberations” (Huber et al., 2013, p. 229). As such, I expected that my journey would open up future discussions regarding what constitutes ethical ways of understanding disability and engaging in APA practice.

Social meanings. My autobiographical narrative inquiry, undertaking research into my own lived experience, was among the first in the field of APA to use an autobiographical methodology (e.g., Howe, 2008; Kuttai, 2009). I illustrated how diverse meanings of disability entangled with ongoing and transactional relationships amongst people, times, and places within the personal and social contexts of my life. I also shed light on how my own assumptions and perceptions about disability expressed and enacted within my own APA practice. By retelling my own stories and reflections, I tried to highlight lived experiences as fundamental sources and sites of, and validations for studying one's own disability construction (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007). My journey thus revealed another way of engaging with methodological knowledge in the field of APA.

I tried to compose my stories and reflections to be “interesting, thought provoking, and

evocative” (Markula & Denison, 2005, p. 168). In doing so, I hoped to encourage readers to participate in generating new disciplinary knowledge in socially interactive and relational ways (Coutler & Smith, 2009). Sarris (1993) notes,

In understanding another person and culture you must simultaneously understand yourself. The process is ongoing, an endeavor not aimed at a final and transparent understanding of the Other or of the self, but of continued communication, at an ever-widening understanding of both. (p. 6)

Throughout this journey, I realized that understanding the meanings of disability and understanding the processes of coming to understand the meanings according to grand narratives of disability was not the only way. Instead of merely arguing about how disability should be understood, I thus imagined a new method of knowledge generation guided by *relational ethics* (Bergum & Dossetor, 2005; Clandinin, 2013; Lahman, Geist, Rodriguez, Graglia, & DeRoche, 2011), as another way of engaging with disciplinary knowledge in our field.

Relational ethics are founded in ethics of care (Noddings, 1984) and are . . . a commitment to relationships, that is, to live in collaborative ways, allows us to re-compose and negotiate stories. Relational ethics call us to social responsibilities regarding how we live in relation with others and with our worlds. (Clandinin, 2013, p. 30)

My Story, Part 10: A Challenging Session

"No, stand on the pads! You need to stand on the pads. . . . Then, swing your bat like. . . . No, no, no. . . . Stand on the pads!"

One of my students was struggling to teach a boy named Jamie with whom she had been partnered. I was teaching the lab section of a senior-level course, Physical Activity for Individuals with Developmental Impairments. The lab was designed to provide firsthand pedagogic experiences to students who were in the final year of their undergraduate program. They were responsible for planning and teaching weekly one-on-one sessions aimed at the acquisition of fundamental movement skills (e.g., locomotive, balance, and manipulative skills).

The student was teaching Jamie a manipulative skill involving hitting a baseball off of a tee. In my view, Jamie did not seem to have enough balance to stand on the "pads" (rubber floor mats). Furthermore, he kept trying to wander around or sit down on the ground. He also did not seem to understand the meaning of my student's instructions.

After a while, the student physically prompted Jamie's swing action, holding him from behind. Several supported attempts were made, and she asked Jamie to do this on his own.

"Jamie, it's simple. Stand on the pads, hold your bat tight, and take a big swing! That's it. It's your turn, Jamie. . . ." She stepped back. However, Jamie wandered away immediately.

"No, no, no, Jamie. Stand on the pads. . . . You need to stand on the pads first. . . ." she shouted at him.

The same scene played out several times: the student shouted at Jamie, and Jamie wandered off. She looked upset about Jamie's "uncontrollable behaviors," seemingly lacking

the confidence to give up some control by speaking loudly to Jamie. She also looked frustrated that her carefully planned activity wasn't working, perhaps because she felt pressure to adhere to her lesson plan, so that he would be able to perform the skill in particular ways through her instruction.

Jamie also looked irritated, perhaps because he had felt the exclusion and suppression of his voice during the activity. He finally sat down facing a wall after wandering around for a moment. He crossed his arms and tilted his head. He frowned, closing his lips tightly.

"Jamie, let's try again! I will help you." The student tried to encourage him, but he did not respond—did not even make eye contact.

The student looked at me and mouthed that she needed help. I intervened in her session. I sat down with Jamie.

"Jamie, do you need a break?" I asked him quietly.

"No!" he replied firmly.

I tried to understand what had made him upset. "Do you want to try without the pads?"

"No!" he stayed still, looking away from me.

"Jamie, if you make three strikes with your bat, you will get to choose your favorite activity. Do you want to go back with her and try again?" I tried motivating him and also kept looking for what he would like to do at that moment.

"No!" he answered sharply.

After a while, he refused to answer any of my questions. I looked at the student and asked quietly if she had prepared alternative ways of doing the activity.

"No," she said. "I don't think this activity is going to work for him today. . . . I'll just skip it." She then hurried back to the play area and began setting up her next planned activity. I wished, however, that she had asked him about why he did not want to participate and what he would like to do next. I wanted her to realize that Jamie's "experience" was underappreciated in her teaching practice.

I sat down beside Jamie. I did not talk to him; I wanted him to have some time to settle down. I also needed time to think about how to communicate with him to alleviate his displeasure.

When my student came back after completing the set-up, I was still pondering the problem.

"Come on, Jamie. Let's go. . . . We will try some catching!"

Jamie refused, staying still. She kept asking him to follow her. Finally, to her relief, Jamie responded to her: He stood up and followed her. But he was still frowning.

I also stood up and moved to another play area where other partnered groups in the class were doing their activities. Observing other groups, I couldn't stop thinking about Jamie's session.

I worried about Jamie: "What if he got emotionally hurt? His feelings, his moods, and his opinions were not carefully considered. Instead, he seemed to be considered as a 'problem' within the context of his session."

I also worried about the student: "How would she later feel if she acknowledged that her session did not fully involve 'interaction,' but focused exclusively on 'instruction'—that is, telling how something should be done? What if she later recognized that she prioritized her 'planned' activity over Jamie's educational interests and needs? Consequently, what if she realized that the 'real problem' was her, as I had recognized in my past APA practices?"

Furthermore, I felt responsible for this difficult educational moment both for Jamie and the student. I asked myself, "What roles did I as a lab instructor play in this ethical moment?" I began to consider that my lack of experience and capacity as an educator for pre-service professionals, the lack of time and space for my students to reflect critically on their own teaching practice within the structure of the lab, and the lack of time for interacting with them, all contributed to these counterproductive outcomes of my lab. I felt vulnerable.

Finally, Jamie's session ended. I met with the student to debrief about her lesson plan and delivery. I asked how she felt about the session.

"I think he seemed to have a bad day," she replied disappointedly.

"Do you think he clearly understood what he was doing in the striking activity?" I asked cautiously as I did not want her to feel I was criticizing her teaching.

"I'm not sure. . . ."

"I was also wondering if he could understand why he had to stand on the pad," I asked. "If not, would that be meaningful for Jamie?"

"Um. . .I don't know, but that's how we make striking action properly. If he doesn't know how to, he won't be able to play baseball in the future. I just wanted him to learn some baseball skills. . . ." She replied defensively. I stopped asking and provided my comments on her session. I recommended that she reflect carefully on the meaningfulness of learning outcomes for the next session, from Jamie's point of view.

Preparing the next week's lab session, I also began to consider what I could do to prevent this kind of difficult educational moment both for my students and for the participants during the rest of the term.

Reflection: New beginnings. Thinking critically about the student's pedagogic practice, I recognized a number of ethical issues. First, she did not carefully consider what Jamie might be able to do, but prioritized a particular way of approaching a fundamental movement skill (Davis, 1995; Shogan, 1998, 2003). The goal of her planned activity was thus to "achieve the standards established for the task" (Shogan, 2003, p. 65). By failing to meet these standards, Jamie became a student with a deficiency within the context of the activity. Second, my student overlooked Jamie's experience. For Jamie, the session involved experiencing failure (e.g., being unable to balance on the rubber mats) without even being aware of what he was doing (i.e., not fully understanding the concepts of performing a striking skill in specific ways). The meaningfulness of Jamie's experience within the activity was underrated. Third, she was not fully mindful of Jamie's choices. According to Morphy and Goodwin (2012), *meaningful choices* involve perceiving and acting on a range of alternatives, and having a chance to seek them out. However, Jamie was merely told what to do; his own preference was not taken into consideration (Davis & Strand, 2007). Fourth, when she physically prompted the striking action for Jamie, she did not provide *consensual help* (Goodwin, 2001)—that is, she did not make Jamie's acceptance of help

consensual by asking him whether he would require support. Her help was based instead on her own expertise (Davis, 2004; Shogan, 1998; Skrtic, 1995).

Reflecting on these issues, I wondered whether the session created and intensified Jamie's experience of disability and contributed to his negative perceptions of himself, his physical education classes, and teachers. This brought to mind moments within my own life contexts: moments when I worried about being the "real problem" by contributing to other people's experiences of disability. Prioritizing a specific way of performing soccer skills, as I have shared, I excluded a boy with a mobility impairment from my own soccer team. Emphasizing my own opinions about IPE, I overlooked the lived experiences of people with impairments within IPE contexts. Providing help without asking a member of the Steadward Centre for Personal and Physical Achievement, I took my knowledge and expertise for granted.

These incidents occurred when I did not recognize the potential consequences of privileging my own opinions (Macbeth, 2010; Northway, 2000). Likewise, my student did not carefully consider her own ideas or the ramifications of prioritizing them over Jamie's experiences. Accordingly, she contributed to his experiences of disability unwittingly and counterproductively through her pedagogic practice. The session was therefore a snapshot of the kinds of risks inherent in APA practice that are shaped by practitioners' lack of reflexivity and critical thinking. As an APA PhD student actively involved in research, teaching, and service delivery, I wondered again whether I thought enough about my own contributions to disability construction and their potential implications for my professional and scholarly practices in APA.

Reflecting on the session, I also realized that the medical model of disability helped to shape my student's teaching practice (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). Relying on her own expertise and knowledge, she

planned and delivered an activity aimed at achieving normalization (i.e., performing the striking skill in the predetermined and standardized way with the corrective supports from her, the *expert*) (Shogan, 1998, 2003). Furthermore, Jamie's counterstories (e.g., the stories of his lacking voice and choice) were silent and silenced, while my student's sacred stories, based in the medical perspective, were dominant (Clandinin & Connelly, 1996; Bredahl, 2008; DePauw, 1997). As a result, I was concerned that she might develop limiting assumptions and perceptions about disability, regarding Jamie's failure to stand on the mats as his own individual problem, restriction, and lack of ability, due to a defect in or failure of his cognitive and physical development (Barnes & Mercer, 2010; Lawrence & Jette, 1996; Peters, 1995, 1996; Verbrugge & Jette, 1994). I came to realize that there was a lack of "space" for my student to reflect on her own sacred stories and Jamie's counterstories. As the instructor of her lab session, I was also concerned whether I worked hard enough to create this pedagogical space for her critical reflection (or whether I was even aware of the importance of this space).

In sum, the session highlighted the potential consequences of a lack of *watchfully waiting* in APA practice. Goodwin and Rossow-Kimball (2012) explain the concept of *watchful waiting* by citing Hanford (1993), who suggests that

To determine the ethical questions before us, rather than *doing* as is implied in *don't just stand there, do something* perhaps we should consider the merits of the opposite, *don't just do something, stand there*. . . . Watchful waiting replaces the natural inclination to intervene and may contravene the power-over another scenario that often unfolds in professional practice settings. Stepping back from professional practice that is based in virtuous character of the practitioner or the desire to provide care may bring the comportment of a relational ethic forward for consideration. (p. 303-304)

Reflecting on these ideas helped me to realize the importance of pedagogical spaces for thinking reflexively about one's own understandings of disability and for contemplating ethical responsibilities of one's own APA practice, in order that ethically framed future transformations in the APA practice may occur (Clandinin & Cave, 2008; Clandinin, Cave, & Cave, 2011; Downey & Clandinin, 2010). As such, my tentative ending of this journey prompted me to engage in new beginnings, seeking ways of creating the "watchful waiting" spaces for APA professionals and pre-service practitioners (Goodwin & Rossow-Kimball, 2012, p. 303). I imagined the spaces would become places where members of both groups could engage in retelling and reliving of their own professional identity development "in new and more attentive ways" (Huber et al., 2013, p. 221).

Accordingly, I began to ask questions that may provide the ideas for future research:

- How does professional identity development among APA professionals contribute to ethical and caring practice that promotes the health and wellbeing of people with impairments?
- How do students in APA-related programs constitute and shape their professional identities?
- What role do the APA educators play in creating pedagogical spaces where reflexive and ethically framed professional identities can be shaped?
- What challenges do the APA professionals face in maintaining ethical identities in professional practice?

Living and Reliving as a Narrative Inquirer

Living as a narrative inquirer, I have learned another way of attending to my own life. This is a reliving of my life reflexively and reflectively as a way of contemplating my own

ethical becoming. It is also a reliving while engaging in ethical and socially responsible relationships amongst people, times, and places within the personal and social contexts of my life. Finally, it is a transformative reliving, a remaking of the present while anticipating socially just future. As a result, I become wakeful to the purposes of my life.

Thinking and living narratively is “to focus on experience and to follow where it leads” (Clandinin & Connelly, 2000, p. 188). As my dissertation journey leads me to the new beginnings, I will continue to engage in experience of mine and others, in the sense that Clandinin and Caine (2012) describe: “Of course, exit, for narrative inquirers, is never a final exit as we continue to carry long-term relational responsibilities” (Clandinin & Caine, 2012, p. 170).

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