University of Alberta

A Narrative Inquiry into the Lives of Older Adults Labelled with Intellectual Disabilities: The Significance of Place As a Means to Story Retirement

by

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Dedication

To
my Grandpa Rudy
and
my daughter,
Wilder Grace…

Always embracing W*hat I Knew First*…

Abstract

This narrative inquiry engaged the author in the storied lives of three older gentlemen labelled with intellectual disabilities (the *inquirers*) as they lived out a story of retirement in their community in a mid-sized city in Western Canada. The author walked alongside the inquirers for nearly a year in search of coherence in their shared experiences. Although the grand narrative suggests that these gentlemen are likely to experience a lonely, isolated, and inactive retirement, it is with confidence and pride that they live a *competing story* in which they are engaged with their community; they enjoy spending time with new friends, participating in new activities, and venturing into new territory.

Seemingly, *place* proved to be of most significance to the inquirers as they lived out their stories of retirement. However, their storied past drives their current and future retirement prospects as they search to relive moments which provide meaning, structure, and familiarity, specifically seeking out opportunities to serve others in their community at church and the local senior centre, for example. In light of their success, the author suggests that perhaps a lack of structured retirement programming can actually *enhance* opportunities for growth as older adults labelled with intellectual disabilities are pushed to live a self-determined retirement as they seek out meaningful opportunities for success.

Throughout the paper, the author reflects on her own experiences on the professional knowledge landscape as she questions her positioning as a researcher, professor, student, support person, advocate, and friend. During her time walking alongside the inquirers in the three-dimensional space, she became awakened to/was reminded of/experienced tensions in relation to the grand narrative surrounding her own life and that of her inquirers. She relives/retells personal stories in an attempt to find coherence and live in an educative way amongst the tensions.

Acknowledgements

Of most importance, thank you to *the inquirers* for allowing me to walk alongside them on this journey. You gave me a great deal to think about... I have been awakened to the consequences of my engagement with others; 'necessarily troubled' by my influence on others' storied lives. Thank you for allowing me to live through you. Our time together caused me to reflect and recognize the potential to re-story myself. I adore you, my friends.

To my supervisor, *Dr. Donna Goodwin*, who has allowed me to walk alongside her in pedagogy, research, and friendship for the last 15 years, I say *thank you*. I am a better researcher, teacher, and woman because of you. It has been a privilege to learn from your mentorship.

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To *Dr. Ulrich Teucher*, the external examiner from the University of Saskatchewan, your considerate review and subsequent comments regarding this dissertation have been encouraging; you have left me feeling like a *writer*. Thank you for taking the time to provide rich, descriptive, thought-provoking remarks regarding the journey at hand.

To my enigmatic friend, *Dr. John McGee*, who I so dearly miss, you taught me two things: (1) the value of melancholy (*"You cannot know happiness until you have lived in sorrow..."*), and (2) the importance of being 'present in the moment' so as to embrace the diversity of gifts that others may offer. I think of you often as your encouraging words continue to guide me on my journey.

I appreciate the support of *my parents and grandparents* who always encouraged me. Thank you mom and dad for providing your unconditional love and support and for teaching me the importance of commitment and work ethic.

I live by the advice of my grandmother who often reminded me, ‘Don’t worry, things have a way of working out.’ (Grandma, you were right.) Grandpa, thank you inviting me to spend time with you in the sun-filled cab of the grain truck on warm harvest afternoons; those days with you are my favorite memories of the farm.

To my husband Ian... There was not a moment when you ever discouraged me, complained about my absence from our home, or protested when I interrupted our lives with a move here or a move there to pursue my education. More than once in your life you have *waited* for me... I am so thankful for your patience and persistence.

And finally, to little Miss *Wilder Grace*, the surprise of my life... In you I can see strong mindedness, independence, and tenacity in the midst of a flavorful sense humor, a kind heart, and a gentle soul. Thank you for *being*. You will be special, ‘Goose’. And I suspect you will be my greatest teacher of all...

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Chapter 1

A Narrative Beginning

On a warm August afternoon, I find myself standing in the middle of a small-town Saskatchewan cemetery, wondering how I should respond to the excitement elicited from the two older gentlemen – 64 year old twin brothers both labelled with intellectual disability- who have brought me here. Their excitement is not something I anticipated, as we have come to visit the graves of their mother and father. I look around and notice the variety of headstones throughout the grounds. Some graves are marked only with metal crosses, seemingly undignified as a Sharpie has been used to scribe a family name on a piece of metal, while others are marked with grand pieces of very expensive stonework. As I walk, I notice a fresh grave in the distance and I think of the family who is mourning the loss of a loved one. Suddenly, I'm somewhat startled at what I see before my feet as the earth has seemingly swallowed up the large concrete slab which was laid upon an old grave decades ago. It appears as though the earth is literally crumbling in on itself. Then, I realize I am quite likely standing on top of someone's final resting place and I question the tact of my positioning. I quickly step aside. Before I scan the vast prairie landscape, I look to be certain that I am no longer standing on 'someone'. Then, I take a moment to enjoy the peaceful surroundings. The cemetery I am standing in lies just outside the village of Earl Grey, a small farming community in Saskatchewan.

I don't need to see the history book to know that Earl Grey is an old community. The birthdates on the graves go as far back as the late 1800s. I am surprised at the number of children buried here, particularly as I notice that one family lost four children over a 5 year period, all in their infancy. I am left to wonder about the story of this family and what determined the fate of these infants as none of them survived over the age of one. I am troubled by this. However, I move on and look for Doug and Don to take me to the headstone that says "Poth".

Trepidation washes over me as I follow in the footsteps of the two sons who are seeking out the headstone "with flowers and wheat". "Our mom liked to garden and grow flowers. Dad was a farmer so we put grain on his side," Doug tells me. "There it is!" Don points ahead, "There it is! The one with the hands!" Their pace quickens, and I follow suit, wondering what they mean by '*the one with the hands*'. As I approach, I see the 'hands' are made of porcelain, set in a position of prayer. Upon arriving at the headstone I see that there is an engraving of a rose above their mother's name, and a wheat sheaf above their father's name. As Don labors to slowly read the inscription on the headstone out loud, he is grinning from ear to ear and shaking his arms in excitement. When I ask "Who brought the hands for mom?" both Doug and Don are very proud to tell me that they purchased the ornament themselves. I am surprised to see that the hands are still a pearly white and seem to have survived the unpredictable and inclement weather of the prairies. Don encourages me to touch the headstone and run my fingers over their parents' names, the wheat, and the rose. It is important to him that I *feel* the final resting place of their parents. I no sooner touch the marble and Doug suggests we move on. I wonder if he is uncomfortable with how 'close' I have come to his family. Doug suggests we carry on and wander the grounds to find their grandparents. I agree, and step away from his parents' graves...

Preliminary Thoughts

The short story I just shared with you is only one of many that evolved as I embarked upon a year long journey with the inquirers… my friends David, Doug, and Don[1]… to learn more about their experiences of retirement. Throughout my time with them I have tried to make sense of this experience... this story... and many other experiences and stories we shared. I have situated the stories the inquirers told me, the stories we shared, and the stories we both relived within a framework that helped us to understand the relational aspect of our stories and our lives: the framework of *narrative inquiry*. It was so hard to know where to begin, for there was a great deal of 'unpacking'. However, because "there are two starting points for narrative inquiry: beginning with living stories or beginning with telling stories" (Clandinin, 2013, p. 35), I followed the advice of the well-respected writers and mentors in my life who have always advised me to 'just write'.

I hope this dissertation (which I will refer to as a *journey* or *inquiry*, hereafter) will enlighten you to many ideas. Academically, this paper will tell you [more] about narrative inquiry, my experience using narrative inquiry as a methodology and theoretical framework, and my thoughts regarding the retirement experiences of community-dwelling older adults labelled with intellectual disabilities. Personally, I will share stories of experience with you… stories about me, the inquirers, and how we came together to awaken ourselves to the possibilities and consequences of relational-being… of "relational living alongside" (Clandinin, 2013, p. 23) one and other.

Through my writing, it is my intention for you to understand the personal, practical, and social justification for this inquiry (Clandinin, 2013). My *personal* justification can be understood from the stories of my own life experiences and the tensions I have/continue to live; the *practical*

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[1] Pseudonyms have *not* been used for the inquirers. I will explain why later.

justification may be realized as you read through the storied history of services that we have provided to people labelled with intellectual disabilities; and the *social* justification may be realized as you come to know the inquirers and their ability to lead/live an active retirement.

At this time, it is necessary for me to share with you my thoughts on the definition and labelling of people with intellectual disabilities. Over the past sixty years, in the field of disability, the definition of intellectual disability has changed significantly. The American Association on Intellectual and Developmental Disability (AAIDD) contends to provide the most current and authoritative information on defining, classifying, and diagnosing intellectual disability (2010). They define intellectual disability to be characterized by "significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills" (AAIDD, 2010, p. 6), beginning before the age of 18.

However, for this inquiry, the inquirer's 'disabilities' are considered within the framework of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (2002). The ICF defines disability according to the level of functioning of an individual within a particular context; environmental factors that may affect one's ability to function within particular settings are examined. An ecologically based description that takes into account how the environment can exacerbate or enhance one's functioning replaces a medical-model, deficits-focused definition in which personal characteristics are emphasized. Disability is not emphasized in the ICF; health and function are at the forefront.

Thus, intellectual disability is not simply a condition that someone has, nor is it a condition that solely indicates an individual is lacking in a particular area of human development. Rather, it is a state of functioning that an individual experiences within particular environments. The level of functioning the person will experience is an indication of the 'fit' between one's abilities and immediate environment and is considered to be based on a continuum. Level of functioning is not thought to be a static state. Within one's environment, the ability to function may be increased with the presence of contextual factors such as services, supports, technology, policies, and social attitudes. According to the ICF, with proper supports, the disability no longer exists.

Now, I will explain why I use the term older adults '*labelled* with intellectual disabilities' rather than older adults '*with* intellectual disabilities'. The purpose of this wording is threefold. First, to reflect the paradigmatic shift in disability services from the expert-driven medical model of the early 20th century to the more current ecological and social construction model of today in which we recognize that policy, attitude, and architectural structure can impose or exacerbate the experience of disability. Second, to assist the author in revealing her personal belief that any demonstration of a limitation in metacognition or adaptive behavior by the gentlemen involved in this inquiry could be attributed to context. Specifically, at certain points in their lives, the inquirers were placed in structured, 'expert'-driven environments (i.e., institutions, sheltered workshops) due to their label of intellectual disability. These environments, in which activity was defined by rote tasks, failed to provide much opportunity for development. The gentlemen may have become products of their environment (Pringle, 2007). Finally, I use the term *labelled* to highlight that disability is not simply a condition one either has or does not have. Withers (2012) writes that "disability is in constant flux and people move in and out of the category depending upon the context...using the categories of disabled and non-disabled works to uphold the problematic and false binary and the systems that permit their creation" (p. 7).

To begin, let us reflect on what it means to be a narrative inquirer and re-engage our thinking in the theoretical framework that was used to guide this inquiry, and ultimately, complete this journey.

What is Narrative Inquiry?

"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."

(Coles, 1989, p. 30)

Clandinin and Connelly (2000) write:

> Narrative inquiry is a way of understanding experience. It is a collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in this same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people's lives, both individual and social. (p. 20)

"Narrative inquiry begins and ends with a respect for ordinary lived experience" (Clandinin, 2013, p. 18). The role of the narrative inquirer, and ultimately my role in this journey, was to "describe… lives, collect and tell stories of them, and write narratives of experience" (p. 2). Narrative inquiry is more than telling stories however. Narrative inquirers must *think narratively*. "Narrative thinking is a part of the phenomenon of narrative" (Clandinin & Connelly, 2000, p. 18). Thinking narratively means to think within a three-dimensional space (*temporally, socially and personally,* and *place*)*:*

> …temporality [is] along one dimension, the personal and the social along a second dimension, and place along a third… any particular inquiry is defined by this three-dimensional space: studies have temporal dimensions and address temporal matters; they focus on the personal and the social in a balance appropriate to the inquiry; and they occur in specific places or sequences of places. (Clandinin & Connelly, 2000, p. 50)

Temporality, sociality, and place are the “three commonplaces of narrative inquiry” (Connelly & Clandinin, 2006, p. 479). A narrative inquiry explores a time influenced by societal conditions within a particular place and the interactions between ourselves and others. A narrative inquiry involves the “simultaneous exploration of all three commonplaces” (p. 479).

Throughout the inquiry, the researcher is also always looking in four directions *(inward, outward, forward, and backwards)*. The researcher moves *inward* to reflect on internal conditions such as feelings, hopes, and moral disposition; *outward* to recognize the influence the environment has on experiences, impressions, and life; and *backward and forward* along a temporal dimension reflecting on the past, present, and future (Clandinin & Connelly, 2000). It is necessary “to ask questions pointing each way” (Clandinin & Connelly, 2000, p. 50).

Relational Awareness

Bateson (2000) writes that “lives follow different rhythms in different times and places, and fit together in different ways…” (p. 243). Narrative inquiry is *relational* (Clandinin & Connelly, 2000) meaning that the inquirer relates to the subject matter. I came to this *research puzzle* (Clandinin & Connelly, 2000) of retirement and the stories lived by people labelled with intellectual disabilities by unpacking stories in a ‘relational space’. The stories were reflections of experiences I’ve shared with people I’ve known in particular places during particular times. They were the building blocks for my curiosity and ultimately, this inquiry.

My ‘puzzling’ began as I reflected on experiences with people I have cared *for* and *about*. Specifically, I reflected on my personal interactions with people labelled with intellectual disabilities. I listened to and quietly observed their storied lives in many places including schools, group homes, sheltered workshops, and community centers. I witnessed stories of growth as individuals progressed towards greater independence and transitioned to community based, inclusive settings. Other stories revealed the effects of a progressive disability or the aging process that placed people in environments of intense supports and structure.

I knew I carried these stories with me, as I would frequently unpack them in contexts of coursework I had taken and taught, as well as in contexts of support when my role was that of an advocate and friend. In those times, I was unaware of why I still carried those stories and why I only unpacked them at certain times. It was not until I realized that stories are important to me because I view "individuals as living storied lives on storied landscapes" (Clandinin & Connelly, 2000, p. 24). Clandinin and Connelly helped me make sense of the importance of stories, as they suggested that "… people by nature lead storied lives and tell stories of those lives" (p. 2). Unpacking stories and reliving their associated tensions has helped me to experience them in an educative way (Clandinin, Murphy, Huber, & Murray Orr, 2010).

Of course, it is the relational aspect of narrative, as well, that draws me to this method of research. This journey that I embarked on revealed many stories… those of my inquirers[2], those of myself, and the stories we lived together. My role in all of this was not only to "describe [such] lives, collect and tell stories of them, and write narratives of experience" (p. 2), but to also understand them in a *relational* way.

The Professional Knowledge Landscape

I came to stories of experience and caring for/about others as a young woman in search of opportunities to develop my career. I suppose my arrival into these three-dimensional spaces coincided with my stepping onto the "professional knowledge landscape" (Clandinin & Connelly, 1995, p. 4).

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[2] The term 'inquirers' is being used in place of research participants to reflect the reciprocal, co-composing nature of narrative inquiry. I will explain more later.

The professional knowledge landscape is the context in which theory and practice merge (Clandinin & Connelly, 1996). Through these experiences working alongside others, I came to learn several things about the profession of supporting people with disabilities. Just as Clandinin and Connelly observed within the context of teaching, the professional knowledge landscape taught me: (a) what is thought to be effective, good practice; (b) what professionals in the field know; (c) what knowledge is necessary for the field; and (d) who is 'authorized' to create and share new knowledge with others. Essentially, it is my time spent on this landscape that shapes the *stories I tell myself about who I am*, the *stories I tell others about myself*, and the *stories I tell others about who they are*.

The professional knowledge landscape "has a sense of expansiveness and the possibility of being filled with diverse people, things, and events in different relationships" (Clandinin & Connelly, 1995, p. 4). Within the landscape, there is dynamic interplay between these constructs, and between *professional* and *practical* knowledge. The *professional knowledge* is comprised of the stories and information that is shared by other professionals (e.g., policy makers, administrators, supervisors) and the *practical knowledge* is comprised of stories created by those who support people with disabilities. To further explain these concepts, I will borrow an example from Clandinin and Connelly (1996) and the world of teaching.

Clandinin and Connelly (1996) observed that in the world of teaching, there are several occasions throughout each day that teachers move back and forth from the *professional knowledge landscape* - a place described as being "filled with other peoples' visions of what is right for children" (p. 25) - and the *practical knowledge landscape* - a place behind closed doors where teachers spend time with their students. The professional knowledge landscape is "littered with imposed prescriptions" as a result of a "theory-driven view of practice" (p. 25). The professional knowledge landscape is a *sacred story* that tells us how to 'be' and how to 'do'. In my experience, I suppose the sacred story told me how to think about, feel for, and support people with disabilities.

The practical knowledge landscape, again in reference to the profession of teaching, is the space that teachers can occupy “safely, generally free from scrutiny, where [they] are free to live stories of practice” (Clandinin & Connelly, 1996, p. 25). These stories, described by Clandinin and Connelly, are *secret stories* and are seldom shared with others outside of the practical knowledge landscape (i.e., they are most often shared with other teachers in spaces and places of practice). My secret stories were shared with others I worked with and lived by the people I supported.

Now, if one is aware of or anticipates dissension between the sacred story and the secret story, one can live and tell a *cover story.* Referring back to Clandinin & Connelly’s (1996) example in education, when teachers move out of their classrooms onto the professional landscape, they “portray themselves as experts, certain characters whose [teacher] stories fit within the acceptable range of the story of school being lived in the school” (p. 25). These cover stories allow those who have a marginalized teacher story to continue to live, work, and function in the context of their profession. In my case, as you will see, I had to be certain that my words and actions, or cover story, reflected the sacred story when I was in the presence of certain others.

The “epistemological dilemma” (Clandinin & Connelly, 1996, p. 24) that I would find myself in resulted from the discord between my professional knowledge and my practical knowledge. Specifically, the sacred story I was told about how to best support people (i.e., the professional knowledge I learned under the direction of my supervisors, executive director, agency and government policies) and the secret story I was living (i.e., the practices I engaged in that, at times, bumped against the sacred story), were disharmonious and left me feeling uneasy. However, regardless of my secret story, I had to be sure to portray a cover story in which my words and actions told a story that ‘fit’ with what was going on in the context I was working in at the time.

Throughout this paper, I will unpack stories of sacredness, stories of secrecy, and stories used for ‘cover’. The stories I will share are those I have previously and recently lived/reflected on during my time walking alongside professionals and the inquirers. As stories are recalled, relived, and recounted, you will see how I moved in all four directions to reflect. The stories I have already lived led me to anticipated stories of the future. You will see how the professional knowledge landscape and the influences of place, people, and time (i.e., the three-dimensional space) have (and will continue to) contributed to my physical, relational, emotional, and professional ‘knowing’, or epistemology. All of this will be revealed within the context of my research puzzle, as I attempt to develop and share my understanding of retirement as it is experienced by older adults labelled with intellectual disabilities. Before I share these stories with you, I will share some tensions I have previously experienced walking in the ‘parade’ of disability support services (Clandinin & Connelly, 1998). This, I hope, will give you an idea of how my puzzling came to be.

Stepping into the Parade

Just as any landscape, the professional knowledge landscape changes. Clandinin and Connelly (1998) use the metaphor of a *parade* to describe the changing landscape:

> Each participant in the landscape, in the parade, has a particular place and a particular set of stories being lived out at any particular time. Our influence in the landscape in the parade, is uncertain. We cannot easily anticipate how our presence, our innovations, our stories, will influence other stories. The parade proceeds whether we wish it to or not. (p. 161)

It is also important to note that the landscape of my "nonprofessional everyday life also changes epistemologically and morally over time" (p. 29). My professional narrative and my everyday narrative are interwoven, thus influencing the person, professional, and emerging academic I am today. "Change apparently is not a parade that can be watched as it passes" (Geertz, 1995, p. 4). It is important to remember that just as narratives and lives change, so do the landscapes upon which they are lived.

Throughout my experiences working in the field of disability, I have come to learn that there are, in fact, a diverse group of individuals who walk in the parade alongside a person labelled with a disability. The parade is comprised of family members, friends, vocational support workers, day program support staff, group home staff, recreational programmers, social workers, bus drivers, cab drivers, physicians, psychologists, psychiatrists, and numerous others. When I was 20 years old, I entered the parade of 'disability supports'. I was hired as a summer student to write a policy manual for the participants of an activity centre; I wrote about their rights and responsibilities. The manual included simple policies like, "*You have the right to ask for help at work*", "*You do not have to eat anything you do not like*", and "*You should be at work on time*". I truly believe my experiences that summer created the foundation for my professional philosophy: People with disabilities have the right to be treated just like anyone else. This includes the right to choice and the belief that they have the competence and ability to meet responsibilities at home, at school, and in the community.

Throughout my time in the parade, I was often advised not to develop friendships with 'the clients' (i.e., the people I supported). I was told that, "*Clear boundaries of 'supervisor' and 'client' must be established.*" This strategy was thought to be best practice as there was high staff turnover due to low wages and long shifts. It was thought that if employees developed friendships with the 'clients', it would be devastating to them as staff left to seek new opportunities with other agencies. In other words, it would be difficult and hurtful to the people we supported if we left their parade for someone else's.

I can recall one morning when I was sitting in a staff meeting at a group home. The executive director of the agency indicated that some staff were becoming "too friendly" with some of the "clients". "*They're going to start to think that you guys are their friends. And you know damn well that once you leave here, you're not their friend!*" I thought her lecture was ridiculous and offensive; I was uneasy with her dictate. *Really? You want me to come here everyday and get Sharon out of bed, bathe her, feed her breakfast and lunch, administer medication, go for walks, take her swimming… All the while being very careful that I do not develop a friendship with her? Oh, sure, that will be easy. Some days, she's the only person I* ***want*** *to talk to around here!*

To my surprise, some of my colleagues were able to check their emotions and 'relational being' at the door. Not me; it was too difficult. I saw that the people we supported were affected by our presence. You could tell whom the 'clients' liked, and whom they did not. If they liked you, the day would run pretty smoothly, without incident. If they didn't like you, there was "obvious defiance" (this is a term I credit to my mother, as she frequently used this when referring to me throughout my teenage years). The 'clients' would argue or disagree with staff members or flat out refuse to engage in activities. Some would refuse medications, or in some cases, even refuse to eat.

A "Tension-Filled Midst"…

My observations and experiences in the parade helped me develop an awareness of the relational aspect of lives and how the presence of others affects the stories we live in the three dimensional space. The uneasiness I felt walking in the parade, living a cover story, was like being in a "tension-filled midst" (Clandinin et al., 2010, p. 82). In narrative inquiry, tensions are understood in a relational way, "…tensions live between people, events, or things, and are a way of creating a between space, a space which can exist in educative ways" (p. 82). I sometimes felt that my heart and mind were fighting against the actions of my body… actions that were 'conditioned' into me by others on the professional knowledge landscape. I can recall one afternoon while I was working with a young man who had been labelled as 'severely autistic'. He did not use conventional words to speak in a conventional way; only gestures, eye movements, self-injurious behaviours, and vocalizations.

Raymond. My first meeting with Raymond in the Autism Centre's Christmas Program was uneventful, yet I was left feeling uneasy and reluctant to work with him. He did not communicate verbally, wandered endlessly, and picked at his arms relentlessly. Although my job was to "follow his program plan to the letter" I soon realized that he didn't have much of a plan and my purpose in his life for that week was to make sure he did not wander out of the building, for he rarely participated in the scheduled activities of each day. Raymond had an incredibly difficult time staying still or being in the same space with large groups. Thus, as he wandered, I wandered. We spent little to no time with others throughout the first morning, as I was told that Raymond needed "to get a feel for the place before being with others". The 'place' was a small, community recreation centre. As the clock ticked closer to noon, I was excited at the thought of nourishing myself; I was sure I had already dropped 2 or 3 pounds that first morning simply by following Raymond around the centre.

When lunchtime arrived, I was told by my supervisor that one of the goals of Raymond's 'program plan' was to learn to sit during mealtimes. Two of my supervisors directed Raymond and me into a separate room away from the others who were eating. The four of us entered the room, and the door was shut behind us. In the room sat a small table and chair. On the back of the chair was a weighted nylon vest. These vests are typically used to meet the sensory needs of children with autism or those with sensory processing dysfunction. In this particular case, I was told that the vest was used on Raymond to "tire him out" so he would sit during lunch. The vest was placed on Raymond's body, much to his dislike. Then, the supervisors began repeating the same instruction over and over, pointing at the chair.

"Sit down, Raymond. Raymond, sit down. Sit down, Raymond. Raymond, sit down." The zombie-like chant continued for several minutes. Then, a new instruction was introduced.

"Sit down, Raymond. Then eat sandwich. Sit down, Raymond. Then eat sandwich. Sit down, Raymond. Then eat sandwich." These instructions were accompanied by a simple demonstration of moving one's hand from the table to one's mouth.

This didn't work either. You could tell that Raymond was getting more agitated as he began to vocalize and pace the room faster and faster. Then, as Raymond passed by the chair, one of the supervisors pulled Raymond down onto the seat and pushed on his shoulders so he was forced to sit down. The other supervisor pressed Raymond's thighs to the seat. His head rapidly swiveled back and forth on his neck, his eyes darted around the room, and he screamed out.

The supervisor yelled, ***"Put the sandwich in his mouth, Brenda! Hurry up!"***

I couldn't believe what was happening! In that moment, I had to make a choice: Disobey my supervisors and potentially eliminate any opportunities for future employment or invade someone else's space, rights, dignity, and personal freedom? I wasn't experienced enough, nor confident enough, to speak up and share a voice with/for

Raymond. I wanted to say, "***Hey, that's wrong!***" But then I wondered... maybe what they are doing to Raymond is right?!? So, I did what I was told. I pushed a piece of a bologna sandwich through Raymond's pursed lips. Raymond writhed in discomfort. I was tense with fear. I'm sure we both fought back tears.

Half an hour later, Raymond finished his sandwich. Then, he was free to leave the chair. That evening, as I reflected on the day's events, I cried. You know that feeling you have when you are so sad that it feels like your heart is crying, too? I cried so hard, my heart ached. My whole being was sad for Raymond. And, I was disappointed in myself. I dreaded the days to follow as I questioned my ability and interest to pursue a career in the field.

From time to time, I am struck by the necessity I feel to unpack stories, particularly the one I just shared with you as it is wrought with discomfort and emotion. Perhaps it is a way for me to relieve the experience in an 'educative way', for me to understand the tensions which surrounded the experience. Although it has been years since I have lived my life in those spaces (e.g., group homes, sheltered workshops, community programs, etc.) I find I often reflect on the stories I have lived, recount the stories I have been told, and retell the stories I have seen others live. I believe that unpacking these stories helps me to make sense of the morals, values, and principles that I live and work by. Often, I share my stories of experience with the undergraduate students I teach in adapted physical activity. I think it's my way of awakening my students to possible tensions they may bump up against on the professional knowledge landscape.

Chapter 2

The Grand Narrative

"We have been shaped by individual history
and the histories of our communities."

(Bateson, 2000, p. 227)

The grand narrative is an important element in understanding narrative inquiry. The grand narrative, as described by Clandinin and Connelly (2000), is a story that is created and sustained within the larger cultural context of our lives. It is a common way of thinking and believing as to what is normal or right. Thus, the grand narrative is a story that is shared by many people. It is influential in defining who we are. The following pages will provide examples of a grand narrative, specifically how it can relate to the 'typical' population as well as those labelled with intellectual disabilities.

Education is an example of a grand narrative. For most of us, we enter the school system as a young child. In order for us to be successful, we must meet standardized indicators of achievement before we are allowed to move progressively from one grade to another. In the event that we fail to meet the markers of achievement, we do not move into subsequent grades and are left behind. This can create challenges for the student, the parents, and the teachers as their lives are changed and filled with tensions when their storied landscapes shift (Clandinin et al., 2010).

I suggest another example of a grand narrative is the story of *marriage and family*. When I wrote the proposal for my dissertation two years ago, I wrote:

> As a married but childless woman in my mid-thirties, I can tell you that there are many people in my life who are perplexed as to why my husband and I do not have children yet. It is assumed that because I am a woman, I must be pining for a child. At times, the advice I receive from aunts, uncles, and child-'full' friends is intended to alarm me, *"You know you're not getting any younger! You better hurry up or you won't be 'any good' anymore*". Any 'good' anymore? What the heck does that mean?! One of the most memorable comments I recall was shouted to my husband and I as we departed for a summer road trip last year. As we were pulling out of the driveway, my mother-in-law yelled, *"Have fun! Get pregnant while you're gone!*" I remember when the well wishes were, "Drive safe" or "Here's some extra money for gas". As you can see, the grand narrative creates a perception of what is 'normal' or 'right' for someone.

Oh, how things have changed! Now that 40 is closer than 30, I am, to my genuine surprise, 'childful', as my husband and I now have a daughter, born September 1, 2012. Now, as I try to negotiate my way into/around/out of the grand narrative of 'motherhood' and what it means to be a 'mother', I am somewhat inspired to write on this topic. However, the journey I am sharing with you now is about the experience of retirement of older adults labelled with intellectual disabilities, not my experience of meandering through the tension-filled midst of the motherhood narrative. I digress…

Disability Paradigms

"… there are lives…upon which others' lives are written and lived and told, and without which these other lives simply would not be."

(Neumman, 1997, p. 102)

The grand narrative for people who have been labelled with intellectual disabilities can best be understood within a paradigmatic framework. There are five paradigms that reflect our understanding, practices, and assumptions of service provision for people with disabilities over the last century (Gabel & Peters, 2004; Polloway, Smith, Patton, & Smith, 1996; Saleebey, 2009). Essentially, these paradigms (i.e., facility-based, services-based, supports-based, empowerment, and resistance) reflect the grand narrative and the storied history of people who have been labelled with intellectual disabilities. You will see how the three-dimensional space influenced the storied lives of these individuals. I believe that viewing the life experiences of people with disabilities through a paradigmatic lens is an effective way to see just how influential social milieu, culture, moral disposition, and associated attitudes, feelings, and hopes can affect one's storied life in a particular place at a particular time.

In my writing, as I attempt to remove labels from the people I care for and about, I will refer to them simply as 'individuals' or 'older adults', whenever possible. Later, the stories I share will reveal how the paradigms continue to influence the lived experiences of the inquirers.

Facility-Based Paradigm

The facility-based paradigm extended from the early to middle 1900's and resulted in large institutional settings and residential programs for people who were considered to have subaverage intellectual functioning (Polloway et al., 1996). The goal of this period of service provision was to bring individuals who required special services together into one setting. The assumption was that the needs of this particular population could best be met if they were grouped together in the same environment (DiGiovanni, 1978; Polloway et al., 1996). The individuals residing in these facilities were permitted few personal possessions, family members were discouraged from visiting, there was little or no privacy, and schedules were strictly set and adhered to (Pringle, 1997). In essence, all aspects of the individual's life were subject to surveillance and scrutiny. Although well intentioned at its inception, overcrowding, poor staffing, involuntary sterilization, poor treatment and misconceptions about the impact of people described as disabled on society resulted in calls for deinstitutionalization (Pringle, 1997).

Services-Based Paradigm

The services-paradigm of the 1960s followed. Rather than bringing people to the services or institution, the services were brought to the people (Polloway et al., 1996). The goal of this paradigm was to prepare individuals for integration into the community through skill upgrading and educational programming. Special education classes were taught in regular schools and training programs within sheltered workshops were established. Group homes were established as a means by which people could progress towards more independent living. It was assumed that within these specially contained environments, individuals would learn the skills and behaviors required to succeed outside of their self-contained setting. Unfortunately, many of the participants never left these self-contained programs. Students remained in special classes and transitional workshops became permanent places of employment. Although no longer isolated in large facilities, individuals became permanent residents of group homes with little or no choice of living arrangements (Stainback & Stainback, 1996).

Supports-Based Paradigm

The supports-based paradigm reflects, in large part, the current service delivery ideology. It focuses on inclusion, or full participation in all aspects of life. For individuals to be successful in an inclusive setting, supports are required to achieve and maintain success. Supporters of this paradigm assume that with proper and adequate support, individuals will experience successful learning, work-related achievements, and positive encounters with community members (Polloway et al., 1996). Concerns surrounding the efficacy of this paradigm include cost effectiveness, availability of trained professionals, and the degree to which instructional models are supportive of people who are immersed in inclusive contexts. These concerns have caused some to look towards the importance of personal agency by people with disabilities in determining their own goals, desires, and aspirations.

Empowerment

The next paradigm that continues to grow in communities is that of personal empowerment. Empowerment, as Bandura (1998) suggests, is not simply a state that can be granted to someone. Personal empowerment is gained through a *process* in which one develops self-efficacy, self-esteem, a sense of personal control, a sense of belonging, and self-determination (Polloway et al., 1996). Rappaport (1981) suggests that empowerment can be used to enhance the possibility of people gaining control of their own lives. Arai (1997) further explains empowerment. "Empowerment is defined as an individual *process* by which one secures increased *control* over his/her life, and positive changes in the *capacities* or abilities of the individual occur in conjunction with *supportive* change within the community" (p. 4).

Empowerment is not complete without the contribution provided through community support. In other words, for one to be truly empowered a responsive environment that recognizes, acknowledges, and supports self-determination must exist.

Wehmeyer and Sands (1996) suggest that for behavior to be considered self-determined, and individual must (a) *act autonomously* (i.e., make decisions without coercion), (b) *self-regulate* (i.e., evaluate one's environment and options for response for coping within the environment and decide how to act, respond, and change plans as necessary), (c) initiate the behaviour in a *psychologically empowering* manner (i.e., believe personal control is possible over circumstances that are personally important and possess the skills to reach the desired outcomes if the skills are executed), and (d) act in a *self-realizing* manner (i.e., use the knowledge of oneself and ones strengths and weaknesses to reach a desired outcome). Wehmeyer and Sands believe the following skills are essential for self-determined behavior: choice making, decision making, problem solving, goal setting and attainment, self-observation, evaluation and reinforcement, internal locus of control, positive attributions of efficacy and outcome expectancy, self-awareness and self-knowledge. Thus, environments that are supportive of the development of these skills are ones in which self-determination, and ultimately empowerment, is possible.

Resistance

Another paradigm is that of *resistance* which recognizes the presence of power in social relations and that this power manifests itself through the policies, support practices, inequities, and lack of accessibility experienced by people with disabilities (Connor & Gabel, 2013; Gabel & Peters, 2004; Peters, Gabel, & Symeonidou, 2009). Resistance theory is not entirely new however, as Gabel and Peters (2004) suggest that previous paradigms have shared a foundation of resistance. Specifically, previous paradigms "are grounded in resistance aimed at social processes that oppress disabled people" (p. 592). The resistance paradigm is reflective of Foucauldian-theory and takes into account relations based on power. We are asked to analyze the paradigms, theories and ideas previously used to interpret disability and "bump up against traditions" in order to trouble our assumptions and see new ways of knowing as we live alongside people with disabilities (p. 593). This exemplifies the 'bumping against' that occurs in narrative, specifically in reference to Lindemann Nelson's (1995) notion of the *counterstory*. The counterstory is a form of narrative in which the morality of the teller can be redefined by "undermining a dominant story, undoing it and retelling it in such a way as to invite new interpretations and conclusions" (p. 23). Resistance theory may aid in the understanding of the influence on - and potential change to - the grand narrative and the storied lives of retirement for older adults with disabilities.

Later, I will discuss the possibility of a new paradigmatic horizon, the 'strengths perspective' (Saleebey, 2009) which, I suggest, would be an appropriate and exciting new way to situate the lives and stories of people with disabilities.

A Step (Nudge? Push?) Towards Retirement: Carl's Story

Before I tell you the stories of retirement that are in the literature, and the stories the inquirers revealed to me, I will share with you another *narrative beginning*. A co-worker shared this story with me. It is about an older adult labelled with an intellectual disability and his experience taking a 'step' towards retirement…

It was 8:55 a.m. Monday morning. Carl sat quietly in the break room at the woodshop where he worked each day. It was a room Carl knew well. He had worked there for nearly three decades and the combined smell of dust and coffee was very familiar to him. Since his move from the institution into community living, he spent every working day building pallets, painting ringette sticks, and cutting ground stakes for local businesses. The work was repetitive and monotonous, but I can only wonder if it was activity that Carl preferred to the life in the institution.

On that morning in the break room, Carl patiently awaited the arrival of three people from his ‘parade’: his community support worker, Heather; his social worker, Wendy; and the woodshop supervisor, Bill. They gathered together once a year to review and revise Carl’s ‘PPP’ (Personal Program Plan). A PPP was designed for every employee at the woodshop to monitor achievements, challenges, and future aspirations over the course of 12 months.

At five minutes after nine, Carl’s social worker Wendy arrived for the meeting. “Good morning, Carl. How are you today?”

“Not very good,” Carl replied. “Cal was up all night getting sick. I’m tired today.”

‘Cal’ was Carl’s best friend, a cat who lived with him for the past 13 years in his small, one bedroom apartment. Carl named the cat himself, and no one knows why he chose a name so close to his own.

About 5 minutes later, Carl’s community support worker walked into the coffee room.

“Heather, Cal’s sick. He needs to go to the doctor,” said Carl.

“And good morning to you, too, Carl.”

“Yah, Heather. He’s sick. He needs to go to the doctor.”

Just then, the woodshop supervisor walked in. He sat at the table. “Good morning, everyone. Hi Carl”. Just then Wendy looked at her watch and opened her file. This signaled the start of the meeting. Before anyone spoke, Bill, Wendy, and Heather exchanged hesitant glances.

"Carl," began Heather. "You've been working here for a long time, haven't you?"

"Yep", said Carl. "I work hard".

"You sure do, Carl. You've worked really hard for many, many years," said Bill.

"Do you ever wonder what it might be like to not have to work? To be able to do what you want everyday?" asked Wendy.

"But I already do what I want everyday," explained Carl.

"Carl, do you know what *retirement* means? Have you ever heard that word before?" asked Wendy. Heather and Bill sat back in their chairs. Carl looked puzzled.

"It... it means you quit work." he replied.

"Right!" replied Wendy with a lift in her voice. "It means that you get to sleep in everyday, you get to do what you want everyday... and you don't have to come to work!" Carl sat quietly, not sure why they were talking about retirement and what it had to do with him.

"I like to work" said Carl. "I get to see the boys everyday. My friends."

"Carl," Wendy began. "You have worked very hard for many years. You've worked here for almost 30 years. That's a long time for anyone to work. And you know what? There are young men who need a job here. Just like when you were a young man moving from..."

"Don't say that name!" Carl shouted. Anyone who knew Carl knew better than to speak the name of the city he lived in while he was institutionalized. Carl forbade it. No one knew of Carl's stories from the institution. Perhaps even Carl did not know all the stories anymore, for they may have been pushed into the greatest depths of his forgotten memories, hoping they would not resurface for an eternity.

"Right, sorry, Carl." Wendy apologized. "But when you moved out on your own, you needed a job so you could afford your apartment, so you could buy groceries. So you could take care of Cal. Well, there are many young men graduating from school right now who need a job at the woodshop. There just isn't enough room for everyone. Some people have to retire to make room for new workers. It's time for the older gentlemen who have worked here for a long time to retire. Older gentlemen like you." It was obvious that Wendy was trying to have Carl believe this would be a positive change in his life and that he would be helping someone else in need. Her voice was so sweet as she tried to sugarcoat every word that it almost made Heather and Bill sick to their stomachs.

Then, there was silence. Wendy paused as she hoped that someone else in the room would continue the explanation of retirement and Carl's future at the woodshop. She looked to Bill and Heather for help. Everyone sat quietly in the awkward silence that filled the room. Heather recalled all the times she had been asked to do Wendy's dirty work. As far as Heather was concerned, Wendy only knew Carl from a file. She didn't know Carl's life they way Heather did. Wendy only knew Carl when he was in crisis.

Frustrated by the lack of support in the room from her colleagues, Wendy blurted out, "Carl, you get to retire on Friday!"

Carl slammed his open hands on the tabletop. "What? You mean I gotta stay at home?"

"No, you don't *have* to stay at home. You *get* to stay at home! You can do anything you want! Isn't that nice?" said Wendy.

"But what am I gonna do?" asked Carl.

Heather spoke up. "Carl, I'll help you figure out what you will do during your retirement. Don't worry. You can spend more time with me. We'll go to movies, we'll go for coffee, we'll go grocery shopping and banking..."

"But I don't like any of that stuff!" Carl shouted. "I like to work! My friends are here!"

Bill quickly responded. "You can come visit anytime, Carl. You know when coffee breaks are, and lunch..."

Wendy interrupted. "And the best part, Carl, is that you get to have a party on Friday! All your friends will come to the woodshop and we'll have a retirement party for you during coffee break. We'll have cake and coffee! Won't that be nice?"

"Yah, yah," replied Carl. He sat with his hands on the table, his eyes fixed on the floor, his spirit drained from his body.

Wendy looked at her watch. "Okay, Carl, I have to go to another meeting. Someone else has an emergency this morning and I have to help. But Bill and Heather will stay and answer questions for you, okay? I'll see you on Friday and we'll have another meeting next week to talk about your retirement. How does that sound?"

There was no response.

"Carl, I asked you a question..."

"Fine." Carl replied. His eyes didn't move from the floor.

"Good, I'll see you on Friday. Don't worry, Carl. Everything will be great. You'll love being retired!" Wendy walked out the door. Bill, Heather, and Carl sat quietly, each not knowing what to say to the other.

Finally, Heather asked, "Carl, how do you feel about this? About retirement?"

"But I like work, I like my friends. Who's gonna help Harry when he uses the saw? He cut himself one time, you know!"

"Someone else will have to help him, Carl. Or I'll help him," Bill said.

"Carl," began Heather, "you and I will spend more time together. We'll figure out what you would like to do during your retirement. I'll help you."

Carl sat quietly thinking to himself. Heather and Bill waited patiently as he mulled over what had just happened. Both Heather and Bill knew how difficult this life change would be for him. Carl took great pride in his work and respected and cared for his colleagues at the woodshop. Carl wasn't just another worker; he was someone who all the employees looked up to. And in Heather and Bill's eyes, Carl was a part of the history of the building and the program.

"Can I go back to work now" Carl asked.

"Sure, if you feel like it. Are you okay?" asked Bill.

"I've got sticks to paint," replied Carl. Carl quickly got up from his chair and left the room before Heather could say goodbye. He stepped out into the work area and paused, only for a moment. He didn't look up. He only stared at his feet. He crossed the floor to the paint area where six other men were working. He picked up a stick and went back to work. He didn't say a word.

Stories of Aging and Retiring as Someone Labelled with an Intellectual Disability

In the story I just shared with you, you can see that some people in the parade make decisions regarding retirement dates and plans for others. Sometimes these decisions are based on perceptions of the person's health, functioning, energy level, and interest in work (Heller, Miller, Hsieh, & Sterns 2000; Hodges & Luken, 2006). Or, decisions are made for administrative purposes and are based on funding, staff limitations, and the need for work placements of new participants which take priority over the preferences and opinions of older adults as they retire (Hodges & Luken, 2006; Sutton, Sterns, & Schwartz-Park, 1993).

Curious if there is mandatory retirement for 'clients' attending a sheltered workshop in my city, I asked my friend who works with older adults in a variety of vocational programs. She replied, "No, there is no mandatory retirement. They can stay till they are 100 years old as long as they are productive". *Productive??* I must say her response left me feeling uneasy. Within this context, the word *productive* has a negative connotation and is a subjective measurement of success that can greatly affect an older adult's life. And yet Carl seemed to have meaning in his life due to his productiveness – fulfilling his job related tasks, developing and maintaining friendships, and being a role model for his co-workers. Nevertheless, regardless of the reason, it appears that older adults are seldom consulted before a decision is made about their path for retirement (Heller, Miller, Hsieh, & Sterns 2000; Hodges & Luken, 2006).

Why are questions about the experience of retirement for older adults with intellectual disabilities coming to light now? There are many reasons. Advances in medical care, better living conditions, and opportunities for personal growth have allowed older adults labelled as intellectually disabled to live to an age of retirement (Government of Canada, 2004). While there has been a considerable amount of research exploring the health and well-being of individuals during their retirement years, many of the stories paint a bleak picture.

It has been suggested that older adults labelled with intellectual disabilities are at risk for living in isolation, segregation, and loneliness during this period of their lives (DiGiovanni, 1978; Glausier, Whorton, Knight, 1995; Hayden, Soulen, Schleien & Tabourne, 1996; Heller et al., 2000; Hodges & Luken, 2006; IASSID, 2002; Mahon & Martens, 1996; Rossow-Kimball & Goodwin, 2009, 2013; Salvatori, Tremblay & Tryssenaar, 2003; Stainback & Stainback, 1996). However, we also know that active lifestyles produce more pleasure and reduce loneliness, depression and anxiety of isolation (Iso-Ahola & Weissinger, 1984), and individuals involved in leisure activities during retirement experience greater life satisfaction (Mahon & Goatcher, 1999*)*. When I reviewed the stories in the literature, I wondered if the lives of the older adults in my community were reflective of the grand narrative: ***What are the stories of retirement for community dwelling older adults labelled with intellectual disabilities?***

Tensions and Awakenings: The Grand Narrative Got the Best of Me

As I walked into the senior centre on Toronto Street[3], I was nervous but excited about my new job. I was hired as the Program Coordinator for a new project called, 'Retirement for All'. The program was created to support older adults with intellectual disabilities as they left (voluntarily or not) sheltered workshops and community day programs. Retirement for All was created to address the gap in services and supports for individuals as they were removed from the familiarity of their vocational programs. Advocates, such as the local Association for Community Living, believed that a community-based seniors' centre would be an appropriate place for older adults with disabilities who were no longer 'eligible to work' (i.e., 'productive') to develop relationships and become more engaged with their peers. (You will soon learn that the inquirers in this journey are participants of the Retirement for All program. In fact, it was the imminent retirement of the inquirers that inspired the program in the first place!)

Organizers of the program were very proud to be a part of the Retirement for All venture, as it was touted the "first of its kind in Canada": a retirement program in which older adults with and without disabilities (i.e., 'mainstream older adults) spent time together participating in community-based recreation and leisure. I was hired to spend approximately 20 hours per week at the senior

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[3] Although the inquirers true names are revealed, pseudonyms have been used for street locations (i.e., Toronto Street), program names (i.e., Retirement for All), and facility names (i.e., 'senior centre') to protect the identity of others.

centre to act as a support for older adults who wanted to access the available leisure and recreation programming after they ended their placement in the sheltered workshop.

It wasn't long before the Supported Retirement participants and I developed a routine. Tuesday and Thursday mornings were spent floor curling, visiting on 'coffee row', or playing shuffleboard. Wednesday and Friday afternoons were spent at the dances. These afternoons were by far my most busy and interesting days at the centre. From 1-3 p.m., a live band would play songs from years gone by, while older adults from 55 to 95 years of age would waltz, foxtrot, and polka. Most often, the participants and I would sit and watch others dance. Our faces would hurt from smiling and laughing, as we were so impressed by the fancy footwork of a few gentlemen who seemed to leave their partners breathless from the incessant spinning and twirling! On occasion, participants from the Retirement for All program would approach one of the 'mainstream' older adults and ask him or her to dance. I would guess that two-thirds of the time, the invitation to dance was rejected. I quickly learned that the mainstream older adults were very particular about who they spent their time with, so much so that they would not sit with, talk to, or dance with others outside their own clique.

During my time as the Program Coordinator, I was eager to help the program participants make connections with the mainstream older adults. It was apparent that simply sharing the same space was not enough to facilitate the development of friendships; they had to take part in activities together that would increase opportunities for socialization. I believed that the dances provided the best opportunity for the program participants to demonstrate shared interests and abilities with the mainstream older adults as everyone was together and there was ample opportunity to socialize. I decided that my goal was to have the older adults perceive the program participants as approachable, sociable, and interesting enough to develop a relationship with them.

As I began to plan, I reflected on the history of the program and possible reasons for the failure for the two groups to come together. Essentially, I developed my ideas based on what I had seen in the past, specifically addressing what I thought was 'wrong' with the program. Something that always bothered me was that previous coordinators failed to provide age-appropriate activities to the participants. So, while coordinators before me would lay out coloring books and markers as an activity for program participants to pass the time during dances, I would put out dice, dominoes, and playing cards and try to teach the participants more age-appropriate activities. I thought these activities would help the mainstream older adults see opportunities to connect with program participants. After all, if I was going to follow the 'principles of inclusion' (i.e., focus on similarities, identify a common purpose or shared vision, share responsibilities, etc.) (Bullock & Mahon, 2000), I had to present activities that both groups of older adults would find interesting and meaningful (Smith, Austin, Kennedy, Lee, & Hutchison, 2005). I looked at it like this: If my grandparents came to the senior centre and saw a group of older adults playing cards, they would be more likely to sit with the card-playing group than the group of 60 year olds who are coloring pictures of Santa Claus and the Easter Bunny.

It wasn't long before I realized my idea was a flop. Removing the coloring books and markers left participants bored, unhappy, angry, and lost with the absence of familiar activities. Introducing new activities led to feelings of anxiety, inadequacy, or indifference. I was disappointed in myself, as I reflected on my decision to remove any kind of self-directed and personally meaningful activities from the participants. After all, I was in the process of completing my thesis and was writing extensively on the right to choice for people with disabilities. Days later, the coloring books and markers were back on the table during dances and I played solitaire and dominoes alone. Now, as I reflect on this story, I realize I let the grand narrative get the best of me.

As months passed, I found that I was quite bothered with how the mainstream older adults perceived the program participants. I was aware of the scowling faces and dirty looks directed towards some of the more vocal, gregarious participants. I heard others refer to them as “those people with the mental problems”. It was obvious that some older adults went out of their way to avoid program participants by looking at the floor when they walked by or they would flat out ignore them when a participant offered a friendly ‘Hello’.

Just as the tensions grew, so did the number of program participants. Almost every week I would hear of older adults who were in the transition stage of leaving their sheltered workshop and beginning the retirement phase of their lives. Often, they would spend three days a week at their ‘workshop’ and two days a week participating in the Retirement for All program. Eventually, when they completely retired from their vocational placement, they would attend the retirement program as often as possible. For some individuals, the senior centre became their new day program as there was a sense of continuity and safety for both the participants and group home staff who dropped them off each day. For others, typically those who were more independent, the senior centre was a place that they could access as they pleased. Some would drop-in for a quick game of billiards or a visit with those on ‘coffee row’. But dance days stayed just the same as this was always the most popular and well-liked activity.

Among the older adults who attended the centre were David, Doug, and Don. Once retired, they took part in many of the centre’s activities . David was there almost every day. I thought to myself, "Wow, this is great. I don't know what David would do without this program. He would likely just spend every day at home trying to decide what to do with himself. And Doug and Don are here early on Tuesday and Thursday mornings to play floor curling." I thought about encouraging Doug and Don to engage in more activities, assuming they needed the socialization and outings. Doug and Don were very involved in floor curling and did not take part in any other activities at the centre. David, without warning or explanation, began spending less and less time at the centre. He would only come to curling once a week and he completely quit coming to the dances. I was concerned and decided to find out what was causing his absence. I worried that something was wrong or perhaps I did something to upset him. Attempts to call him at home were unsuccessful. Weeks passed and then by chance I saw him downtown one afternoon. I quickly walked towards him, waving my arms wildly, and loudly repeating, "David! Hi! How are you?" I thought for certain he would be as elated to see me as I was to see him. I was wrong.

He turned his head, looked right into my eyes, and said... nothing. Actually, he looked at me like I was bothering him! He turned away and continued on with a conversation I had obviously interrupted. Ah! Only then did I notice the older gentleman standing beside him. So, I patiently, quietly, and respectfully waited my turn. After a few minutes, David said good-bye to his friend. He turned towards me with a smile and said, "What are you doing here, Brenda?" I asked if he had a few minutes to visit, and he agreed. We sat on a bench. I expressed my concern for him and asked why he had not been at the senior centre for a number of weeks. In two words, he matter-of-factly resolved the mystery of his absence.

"I'm busy!"

He's busy?!?! What could he possibly be doing, I thought?!

David explained that much of his time was spent talking with friends downtown, working at church Sunday mornings, and 'doing homework' (i.e., spending hours doing word-find puzzles). I asked if he was unhappy with activities at the centre or if someone – particularly myself – had done something to upset him. He vehemently said "No" and expressed that his friendship with me and the other program participants was important to him. He indicated he enjoyed the activities at the centre but he was just too busy with other things to come every day.

As I reflect on this story, and move in all four directions (inward, outward, back and forth), I have so many things I want to share with you. I am embarrassed to say that I was surprised at David's independence. I thought about all the times I drove him somewhere, always assuming he was incapable of traversing the city by himself. I felt… well… almost abandoned. I wondered, "Did he ever really need me? Will he ever need me again?'…"Was I just a "faceless, anonymous, average of the other 120 people who had come into his life" (J. McGee, personal communication, May 10, 2010). My reflecting on that experience revealed to me that I was 'living in an arrogant way' (Lugones, 1987) as I made assumptions about David, his life, and the significance I held in his parade. I assumed he needed to be 'programmed' to be happy, for that is what the professional knowledge landscape had told me. I was "taught to perceive arrogantly" (p. 4) by others with whom I shared the professional knowledge landscape.

Regardless, I was proud of him for having the confidence to do whatever he wanted and to talk to whomever he saw. But then I wondered, "what do people think as they see David walk past, unshaven, wearing his grungy jacket? Are the people outside of the senior centre more accepting of him?' I wondered if years of 'sheltered programming' had stifled his independence and only now did he feel free to exercise his autonomy. I thought about his age and wondered what would happen as he got older… how would he feel when his body and mind would no longer allow him to experience such freedom."

Living a Competing Story

From this point, I will begin to share retirement stories that were revealed to me as I walked alongside David, Doug, and Don. I believe they are living a *competing* story, a story outside of the grand narrative, which lives in dynamic but positive tension with the dominant story (Clandinin et al., 2010). They are not alone in this competing story. I have observed other older adults with intellectual disabilities become more engaged with their community after they retire. They actively pursue leisure, recreation, and 'work' outside of structured community programming and appear to be content with their retirement experience. There are those who meet at the mall every day to catch up on the news with and about others. There are those who spend their time wandering downtown visiting with the food vendors and the local employees who are getting some fresh air on their coffee and lunch breaks. There is the older woman who, carrying a handful of black garbage bags walks the entire 10 km stretch of Albert Street everyday - twice - in search of aluminum cans to be recycled at SARCAN where she can get from 3 to 7 cents per unit. She uses the money to purchase furnishings for her home, food for her cat, and craft items for her hobbies. It is the experiences of these individuals who lead me to wonder about my role as a professional, an advocate, and a friend, and what I should/not be doing/teaching to/about others as they live retirement.

Relationally-Inspired Puzzling

As I indicated earlier, I believe it is the relational aspect of narrative inquiry methodology that calls me to this research approach. As a researcher and writer, I feel that narrative inquiry has been such a wonderful gift as I am encouraged to reveal the inspirations for my puzzling. Most often, my puzzling originates from time I have spent with people who are close to me. That is why I invited my friends to be a part of this inquiry. It is the time I have spent with brothers Doug and Don, and my long-time friend David, who inspired me to engage in this journey and learn about their storied lives of retirement. Although these three men share a label of 'intellectual disability', it was important for me to hear the experiences of all three gentlemen because "people [do] not necessarily have the same story to tell, despite the historical similarities of their lives" (Gergen, 2004, p. 269). What interests me is that although their label may assume a shared history, the stories revealed to me indicated diverse experiences throughout their life. As I think narratively, I think how temporality, the social milieu, and place influenced the storied lives of my inquirers. The relational framework of narrative has encouraged me to think about how entering their lives (i.e., their respective parades) influenced their stories and my own positioning as an advocate, a support, and a friend. Clandinin (2013) writes that "… we, as inquirers, need to pay close attention to who we are in the inquiry and to understand that we, our selves, are part of the storied landscapes we are studying" (p. 30). Although I have positioned myself as an advocate, support worker, and friend to all the inquirers over the years, it is my most recent positioning as a researcher in their parade that has me thinking about the ethics of stories, writing, and their engagement with me in this context.

Chapter 3

Narrative Inquiry Ethics

"Relational ethics call us to social responsibilities
regarding how we live in relation with others and with our worlds."

(Clandinin, 2013, p. 30)

As with any research, narrative inquiry requires an appropriate ethical 'letter' of approval from a research ethics board (REB), however, as a narrative researcher, I am cognizant of the depth of ethical consideration required for this inquiry, and for those I will be involved with in the future. The consideration of ethics in narrative inquiry goes much further and deeper than what is acceptable in more 'traditional' research as we work alongside our inquirers. Gaining informed consent, informing research participants of their rights, ensuring benefits outweigh the risks, and having our diligent paperwork overseen by an external body is not enough to ensure the ethical treatment of our inquirers. Just as the inquiry itself is relational so are its ethical considerations (Clandinin & Connelly, 2000).

In narrative inquiry, ethics does not end once we are finished 'collecting' stories; there are moral codes that must be considered as stories are retold and relived. Ethics permeates the entire narrative inquiry. Narrative inquirers consider the responsibility one has in friendship to be the same responsibility we have in narrative inquiry. As we enter/walk alongside/considerately exit their storied lives in a relational way our intention is to demonstrate care, consideration, reciprocity, sharing, and kindness. Revealing these relational intentions can pose some challenges when narrative inquirers apply for ethical approval, particularly when many REBs request the researcher to identify any 'potential conflict(s) of interest', ‘power differential relationships’ or ‘pre-established relationships with research participants’ in ethics applications. A positivist, hierarchical research paradigm, which asks researchers to remain impartial and callous to one’s own research ‘puzzling’, continues to permeate ethics boards. Because it is likely that our inquirers are people that we have come to know through shared experiences, and because it is our time spent with them that has inspired our puzzling, it can be difficult for others to comprehend how our ‘bias’ is beneficial to our research agenda and not a problem to be resolved through objective sampling strategies or data collection methods.

The Morality of Ethics and Gentle Teaching Practice

In 2002, just after the 1998 launch of the initial Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*, Kellner (2002) wrote about ‘coping with guidelines from the Tri-Council’ and attempted to distinguish between the ‘letter’ (i.e., the ethics code) and ‘spirit’ (i.e., the morality) of ethical research. She indicated that “it is necessary to be aware of the distinction between ethics and morality as they have to do with research practice” (p. 33). She described that while codes of ethics must be met in order for research to occur (i.e., conducting fair research, gaining informed consent from participants, ensuring certain groups are not disproportionately burdened nor excluded from research, etc.), morality ensures that there is care, attention, sympathy and appreciation of those who participate in our research. Thus, ‘letter’ ethics does not ensure the moral caring of research participants; morality should be a sincere, distinctive characteristic demonstrated by – and embedded within – the researcher.

The principles of Gentle Teaching (McGee, 2009) proved useful in providing some guidance in the moral, ethical conduct of research while I was working alongside my inquirers. Traditionally found in the context of caregiving, Gentle Teaching asks caregivers to express gentleness, warmth, and unconditional love towards those who are the most disenfranchised from family and community life. Gentle Teaching asks people to develop companionship with others, and move beyond the typical hierarchical separateness that exists in caregiving (i.e., the caregiver is often seen as an authority figure in the person's life, similar to the traditional view of the researcher-participant relationship). McGee writes:

> A sense of companionship is much more than being 'nice' to someone or having rapport. It is much deeper. It is an emotional prerequisite in all human beings - having a warm circle of significant others in our life who help us feel safe, wanted, loved, and loving. These feelings are pillars in the foundation of companionship and our task is to set them deeply and generously in each person's heart. (p. 11)

The four pillars, the guiding principles of Gentle Teaching, help others to feel: (a) *safe*… comfortable, relaxed, fearless; there is no discussion of previous mistakes or reminders of 'dysfunction', (b) *loved*… certainty that the people who surround you want what is best for you; they will not hurt you; you will be safe, (c) *loving*… a desire to bring joy, happiness, comfort, and safety to others, and (d) *engaged*… ambition to spend time with others and to be an active participant in one's own life; to live in the absence of loneliness. [It is important to note that by 'love', I do not mean enamor, affection, nor adoration. Rather, 'love', in this context, refers to safety; love is "an extension of feeling safe" (McGee, 2009, p. 12). Some agencies who use Gentle Teaching philosophy have replaced the words 'loved' and 'loving' with 'valued' and 'valuing'.] As you can see, the philosophy of Gentle Teaching and the methodology of narrative inquiry share tenets of relational authenticity, reciprocity, integrity, and morals in the coming together of people and their stories.

Potential Research Concerns Associated with the Inquirers

Regardless of my conviction to ensure the moral and ethical care of the inquirers who joined me on this journey, there still exist a number of concerns when engaging people labelled with intellectual disabilities in a research context. Because the inquirers used their own frame of reference when sharing personal and meaningful stories, anecdotes, and artefacts from their world of retirement – and these stories were shared on their own terms - concerns of acquiescence (Heal & Sigelman, 1995; Matikka & Vesala, 1997), difficulty understanding abstract constructs (Antaki & Rapley, 1996; Morris, Niederbuhl, & Mahr, 1993; Sigelman, Budd, Winer, Schoenrock, & Martin, 1982), inability to recall personal experiences (Michel, Gordon, Ornstein, & Simpson, 2000), and challenges in communicating meaning about what they are thinking and feeling (Kernan & Sabsay, 1989) were diminished. However, regardless of the aforementioned issues, the most significant research concern associated with individuals with intellectual disabilities is engaging them in the informed consent process, an issue that continues to receive a lot of attention by the research community (Nind, 2009).

Ethically Engaging People Labelled with Intellectual Disability in Research

"As individuals who experience vulnerability, there are questions about how to ethically engage adults with [intellectual disabilities] in research" (McDonald & Kidney, 2012, p. 27). The primary concerns are related to their capacity to understand their role in research and the associated risks and benefits of their participation so that informed consent can be provided. According to McDonald and Kidney (2012), minimizing coercion, assessing capacity to consent, proxy consent (when necessary) lacking condescension, and the researcher's responsibility to promote understanding are key to ensuring the ethical engagement of adults with intellectual disabilities in research. The following sections briefly describe how I addressed concerns of coercion, ensuring informed consent, and encouraging comprehensions. Later, I will provide an in-depth description of how I invited the inquirers on this journey.

Minimizing coercion. The relational aspect of shared stories and experiences of retirement is what precipitated my interest in this research puzzle. Regardless of my belief that I was inviting my *friends* into this inquiry, it is quite likely that David, Doug, and Don may have felt that I was/continue to be an authority figure in their lives as my introduction into their respective parades was that of a paid person of support (e.g., I was David's independent living worker for a number of months; I was 'in charge' of the Retirement for All program at the senior centre when Doug and Don began attending floor curling). To minimize coercion, I (a) approached them in a relational way and spoke about our shared experiences at the senior centre and in the community in hopes that they would see me as a friend rather than an authority figure, (b) I situated them in a leadership role, asking them to 'teach me' about retirement, their experiences, and their community, and (c) offered them the opportunity to discuss their involvement in the inquiry in the presence of a self-chosen advocate (i.e., support worker, social worker, friend, family member, etc.). However, it should be noted that when offered this option, all inquirers chose not to contact an advocate, even when I offered to identify one for them.

Ensuring informed consent. Ethics review boards tend to view people labelled with intellectual disabilities as having decreased capacity and therefore they are unable to provide informed consent to participate in research (McDonald & Kidney, 2012). For this inquiry, the inquirers were asked to provide verbal informed consent. I determined their capacity to participate based on the manner in which they lived their lives; they demonstrated their capacity to make choices regarding many aspects of their lives (i.e., choosing what to do, where to go, purchasing groceries and clothing, preparing food, navigating public transportation). In laymen's terms, I explained that I would like to 'visit' with them at least twice per week at times and locations that were most convenient and comfortable for them (i.e., over coffee, via telephone, at the senior centre, etc.). I explained that I could meet them anywhere at any time of their choosing. They were also informed that if at any time they were uncomfortable with my presence, questioning, or reflecting, or if they did not feel like meeting me one day, they did not have to continue with our meetings or discussions and they could cancel any plans that we had made. If they chose, they could request that I no longer 'connect' with them, nor include their narratives in this inquiry. Specifically, I indicated that if they were 'too busy' or if they felt like they were 'seeing too much' of me, I would not be hurt or upset if they decided they did not want to spend any more time with me. At the end of the conversation, I asked each inquirer if he had any questions about me, my schoolwork, what we would be doing together, or if he had any concerns or anything 'bothering' him about the project. It should be noted that these questions were not only asked at the initial discussion of the project, but throughout the entire inquiry.

Encouraging comprehension. Promoting understanding of the research was necessary for the inquirers to provide informed consent. In an extensive literature review about how to engage people labelled with intellectual disabilities in research, McDonald and Kidney (2012) found that scholars have suggested a number of strategies to assist with this, including "tailoring approaches to fit individuals' strengths and weaknesses... presenting information in relationship to familiar situations and experiences and using simple, jargon-free language, symbols, concrete visual aids, and multi-format practical demonstrations, repeating information, providing information in person verbally with nonverbal communication signals, and allowing participants increased time to make decisions" (p. 35). For this inquiry, I shared my puzzling with the inquirers in a relational way, used terms that were familiar to them, and unpacked meaningful stories of previously shared experiences in places and spaces familiar to us both.

Throughout the inquiry, it was important to me that my inquirers were always aware of their rights. For example, when making plans to get together, I would often ask, "May I bring my camera along?" When we were out together, I would always ask permission to take photos. At the end of our outing, I always asked, "Is it okay if I write about what we did together today? What are some important things I should remember to include?" It was important that the facet of competency focused on the *ongoing consent process* throughout the inquiry, rather than on the competency of the inquirers themselves (Dye, Hendy, Hare, & Burton, 2004). In other words, was the way I went about assessing their ongoing consent, valid and effective? Finally, the continued reciprocal interest and engagement that the inquirers demonstrated during our outings was taken as consent (Boxall, 2010). Ongoing consent with the inquirers was confirmed throughout the inquiry by their willingness and agreement to (a) meet with me, (b) share their stories, (c) live their stories alongside me, (d) and create and share images of experience.

The Relational Ethics of Informed Consent

Thompson (2002) identified some challenging 'personal dimensions' that qualitative researchers may face when they work through the informed consent process. First, Thompson writes that participants may expect friendship from a researcher upon agreeing to being involved in the study. Friendship may be desired by the research participants due to the inconsistency and instability of social networks in their lives, the lack of expectation for success by 'the system' (i.e., caregivers, service providers, etc.), and internalized feelings of worthlessness as much of their time is spent with others whom they perceive to be just as 'worthless' (i.e., others with disabilities). Thompson suggests that when researchers have "extended engagements with participants with developmental disabilities [it can] pose very real emotional risks for them" (p. 99). People labelled with intellectual disabilities tend to place great value on any interactions they have with non-disabled people because it helps them to improve the negative self-image they carry of themselves. The fact that someone who they perceive to be 'better than themselves' is spending time with them enhances their feelings of self-worth.

I suppose for some researchers, it can be problematic when research participants desire a friendship with the researcher. However, a key aspect of narrative is to engage with the inquirers in a relational way; to establish a friendship and to share a part of ourselves with them. It is immoral of us to befriend someone for a short period of time in which the sole purpose is to capture their stories. I purport that it is unethical to jump in – and out – of the relationship in haste. It takes time to develop a level of comfort, trust, and friendship with the inquirers and negotiate our entry into their parade on their terms. It is even more important to negotiate our way out... we do not want them to feel as though we have suddenly walked away from the journey we began together.

Second, Thompson (2002) notes that participants with disabilities tend to share too much about their experiences. By making the participant feel comfortable, there is a risk that she or he may reveal previous incidents of abuse because they feel safe when talking to the researcher. Thompson is quick to recommend that when situations of abuse are disclosed, researchers should make an immediate referral to the proper professional to deal with the issue.

We owe more than just our simple 'presence' to those who walk alongside us on these journeys. They trust us with their stories and, ethically, I cannot take their story and share it with someone else without their permission. I can offer the option of help, and offer that perhaps they could talk to someone, but if they choose not to, I cannot change their minds.

Finally, Thompson submits that when feelings of ‘coziness’ arise, which tends to occur within the parameters of qualitative research, participants may discuss subjects that are off-topic to the research question, thus raising questions about the voluntariness of informed consent provided by the participant (i.e., did the participant actually have an understanding of what information they agreed to share?). In narrative inquiry, we continuously verify the consent of the inquirers. But what is most important is that we recognize that if our inquirers share stories outside of the research puzzling, it does not make their stories irrelevant. In fact, the researcher must reflect on how the story is situated within the three-dimensional space in order to understand how it resonates with other life experiences. *Because the story was told, it is important.*

“When we fail to include people with disabilities in the informed-consent processes... [this] exclusionary practice may be ‘reinscribing’ the very disabling regimes that we wish to dismantle in our research work” (Thompson, 2002, p. 96). Fisher (2003) wrote about ‘goodness-of-fit’ and informed consent from a relational ethics framework, suggesting that the consent competence of people with intellectual disabilities is a product of the relationship between the person (i.e., the participant or inquirer) and consent context; creating a space that feels comfortable, safe, and secure for the individual to understand and to freely agree to engage in the research.

Encouraging Other Researchers to Work Alongside People Labelled with Intellectual Disability

Unfortunately, the apparent complexities of working alongside people labelled with intellectual disabilities in a research context may deter academics from choosing to engage with them in scholarly work (Boxall, 2010). Moreover, researchers may find that the efforts employed to discourage the aforementioned challenges may not ‘pay off’ in the end, as the data may not be as rich nor as extensive as they may have liked.

Irrespective of the challenges, I feel I it is imperative to conduct research alongside people labelled with intellectual disabilities so their voices are heard; learning of their experiences, attitudes, beliefs, dreams, strengths, and needs can help to work towards practices and policies that encourage fair and dignified interactions (McDonald, Kidney, & Patka, 2013). Furthermore, being involved in research is important because research and researchers can (a) help improve their lives, (b) help others with disabilities, (c) encourage learning, growth, and preparation for new life experiences, and (d) facilitate opportunities to engage with others (McDonald, Kidney, & Patka, 2013). In looking backward and forward, perhaps it is best to focus on the benefits of participation and provide researchers with strategies to negotiate the intricacies of their involvement, rather than continue to question the validity of their contributions.

Chapter 4

Revealing the Inquirers

As I indicated earlier, I have chosen to use the *real names* of the inquirers whom I worked alongside side to complete this journey. Typically when a manuscript has been prepared and disseminated to an audience beyond the researcher, it is expected that pseudonyms be used when referring to research participants because it is "the researchers' perceived responsibility to protect respondents" (Wiles, Coffey, Robinson, & Heath, 2012, p. 46), particularly when visual images are used to represent their experiences. In spite of this, the inquirers and I made the decision to use their real first names and the names of the cities and towns they are associated with for several reasons: 1) just as it is the right of the inquirers to request that their identities be kept confidential, it is also their right "to be seen and heard and 'given voice'" (p. 44); 2) the inquirers "have expectations of being identified" (p. 45) to my 'school teachers' and are proud of their involvement in this project; 3) I believe that failure to reveal the contributions of 'stigmatized' individuals only leads to a continued stigmatization of the group (i.e., people labelled with intellectual disabilities) as a whole; 4) the expectation that the inquirers' identities would remain confidential lends itself to a paternalistic view of what the researcher believes is right or is 'in the best interests' for the participants; 5) allowing the inquirers to use their real names throughout this inquiry favors the relational aspect of narrative inquiry (Clandinin & Connelly, 2006) and the shift towards a more inclusive framework when working alongside people labelled with intellectual disabilities (Walmsley, 2001); and finally, the inquirers are proud of the places they have previously called/continue to call home (i.e., Early Grey, Regina). *Place* is important to them.

Inviting the Inquirers

As I briefly indicated earlier, when asking my friends to embark on this journey with me, I shared stories of personal experience and tensions I have been awakened to; narratives from my world to show them my research puzzle. Specifically, I talked to them about my awareness of their 'busy-ness' during their retirement and I wondered 'what it was like to be retired from the woodshop' (i.e., the Saskatchewan Abilities council, a sheltered workshop). "You don't seem to spend a lot of time at the senior centre at the retirement program" I noted. "Could I spend time with you in the community to learn more about what you do during the day?" I wanted to ensure that they felt comfortable with the idea of being involved in the project and spending time with me talking about their experiences. Next, I describe in more detail how David, Doug, and Don were invited on this journey with me.

David's Invitation to the Inquiry

Due to the nature of the relationship I have with David, it was very easy to talk with him about being included in the inquiry. I typically saw David every couple of weeks, and spoke on the phone with him at least once per week. He took great interest in my work at the university, often asking questions about "Where are the students now that summer is here?" or "Did you teach the students today?" David also knew that even though I was a 'teacher', I was still in school myself and often had 'homework' to do. Below is a recount of the conversation I had with David about participating in this inquiry:

Me: Because I have known you for so long, David, and

I have spent so much time with you since you left the woodshop, I’ve been thinking a lot about how your life has changed over the last few years. I’m wondering if you would be interested in teaching me more about what you do in your retirement...’

David interrupts: Don’t worry about it! Yeah. Let’s talk about that!

Me: Well, I want to tell you more about what we would be doing together if you chose to help me with this project I am doing for my teachers at school...

David interrupts: Don’t worry about it! Let’s do that! I’ll help you and your teachers!

Me: If you wanted to tell me more about...

David interrupts: Yeah! Let’s talk about my retirement!

Me: Ok, well I thought maybe we could share some stories...

David interrupts: Let’s go to school and work on it... To your office. We can do it on the computer!

Me: For sure we can go to my office! Can I spend some time with you in the community? Like maybe at the senior centre or...

David interrupts: Look, that’s not what I said! I never said that! I said let’s go to your office after we go to the senior centre and we can do the computer work that says what I did there...

Me: What if we went to other places where you spend time?

David, smiling: Where?

Me: I don’t know... what do you do in the community? How do you spend your time?

David: Maybe we can talk about those Roughriders!

Me: Sure we can!

David: And how I help at the church? The usher...

Me: Absolutely... I also I thought I could give you a camera to use, too. So when I'm not with you, you can take pictures of things you do, or things you see.

[Silence.]

Me: What do you think about using a camera?

[Silence.]

David, quietly: I don't know how to do that. I never had camera...

Me: What if I showed you how to use it?

David loudly: Yeah! I want you to show me!

Doug and Don's Invitation to the Inquiry

Prior to this inquiry, Doug, Don and I did not have the history of relationship or the frequency of contact that David and I shared. Thus, I felt the conversation with the two of them was almost *more* important than the one I had with David; I was a regular in David's life so I did not feel that it was out of the ordinary for me to ask to spend even more time with him because spending time together was something that we already did on a regular basis. Being in each other's presence was an expectation that we both held. But since leaving the Retirement for All program, my interactions with Doug and Don had been drastically reduced. I was concerned that by asking them to engage in this inquiry they would feel that my interest in their lives/well-being/experiences would not be genuine. I feared they would perceive I was only interested in spending time with them for my own return; they would reject my invitation because they might feel my desire to reawaken our friendship would be inauthentic or for a selfish reason. I knew that if they accepted the invitation to the inquiry, I would be sure to re-enter/exit their lives in a morally ethical way, but how could I ensure they perceived my behavior in that way?

On a Tuesday morning, I arrived at the senior centre early as I knew Doug and Don would be waiting for floor curling to begin. It had been a handful of months since I stepped foot into the centre. I walked into the auditorium and saw them sitting at a table having coffee. As I began to walk towards them, they both looked up at me. In that moment, I thought to myself, “Shit. What if they don’t recognize me? I haven’t seen them for months!” I smiled and said, “Hi Doug! Hi Don!” in hopes of jogging their memories. They exchanged a brief glance with each other... then they both stood up and smiled. I took no more than two steps closer and they both reached their arms towards me for an embrace. My heart leapt!

Now, imagine for a moment visiting with a friend whom you have not seen for a long while. What would you talk about? How would you begin your visit? Most likely you would ask questions to reacquaint yourselves. For instance, "How have you been? What’s new? How is so-and-so? How was Christmas or Easter or Thanksgiving?"(In my case, *‘Are you done your PhD yet*?’) Well, here is how my visit with Doug and Don played out:

“Guess what!” Don says, excitedly.
“I don’t know. What?” I respond.
“I have a hernia. I need an operation.”
“Oh wow! Are you ok?”

"Oh yes, I'm ok. I don't need an operation for a long time. But someday I will. The doctor told me."

"Ok," I say, not sure how to respond to his news. "Well, let me know if you need anything. Maybe I can help out or maybe Ian[4] can..."

"How is Ian[4]!" Doug's excitement has his question sounding more like a statement as he demands a response!

"He's good! He's busy with work..."

"How is that dog?" Don interrupted. "Wilson, right? He barked at us." Ah yes! Wilson! Don always brings up the time that he and Doug came to our house for supper – years ago – and our big dog, a Newfoundland-Chow Chow cross, barked incessantly at them both.

"Oh, he's good," I say. "He still barks at everyone. It's his way of saying 'I'm-happy-to-meet-you-but-don't-get-too-close-to-me-because-I-don't-really-know-who-you-are-or-what-you-are-doing-here!'"

"Guess what else!" says Doug.

"I have NO idea! What?"

"Someone died."

"Oh no. Who?"

"A floor curler. He died just before Christmas."

I think to myself, "It's April now... that seems like a long time ago... but it must be important to them if they are telling me about it."

"Oh, that's too bad. I'm sorry," I say, lightly rubbing Doug's shoulder.

"That's ok," says Don, "We didn't really know him."

Right after Don's comment, I decided that I would not ask them that morning about joining me on my journey. I felt that it was necessary for me to hear the important stories and happenings in

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[4] Ian is the author's husband.

their lives to determine if *I* felt they were an ‘appropriate fit’ for the inquiry, for I did not want to interfere too much with their lives. My reservations were not due to a perceived lack of ability on their part to participate, but rather a question I had about my fit into their lives; perhaps they were too busy with others to join my journey. We continued our visit as they shared more details about their lives. Before I left, I indicated I would come see them again the following Thursday.

Two days later, the brothers were standing in the foyer of the centre, waving at me through the window when I arrived; I could see them as I pulled into the parking lot. As I approached the entrance, Don pushed open the door and said, “Hi Brenda!” while Doug stepped around him to take my hand to lead me into the auditorium. We sat at a table and had coffee, visiting about the old days and the former participants who had attended the centre. The Retirement for All program had a consistent following, but sometimes participants discontinued their involvement due to a residential move, illness, or – unfortunately - death. I realized how significant the people at the centre were to Doug and Don as they voluntarily provided updates on people who were part of the floor curling group, the Retirement for All Program, and the staff at the centre. It made me wonder more and more about the *other* people in their lives… who existed outside the walls of the familiar auditorium, a place in which they spent much of their time?

Just as I did with David, I shared my relational puzzling with Doug and Don. I indicated that I was interested in learning more about their retirement as I had come to know that the two of them were very busy since they ‘left the woodshop’; I was curious as to what they did every day to keep ‘on the go’. I said that I was hoping I would be able to spend some time with them at the senior centre and in the community talking to them about retirement. I wanted to ‘learn more about what there is to do when someone leaves the woodshop’.

Don immediately agreed to my proposal and asked if I could meet with them the following day. Doug, on the other hand, seemed a bit hesitant and asked, “But what will we do? Where will we go?”

“We can do whatever you want,” I replied. “We can go wherever you usually go. You can just tell me or show me what you usually do. Like... do you go downtown?”

“Yes,” replied Doug.

“Well, if you feel like having company one day, maybe I could meet you downtown. Or I could ride the bus downtown with you. You could teach me how to take the bus... And you could show me around downtown. Or we could just have coffee somewhere.”

Doug thought for a moment. “We could go to Smitty’s...” he suggested.

“For sure!” I said.

Time to begin floor curling was drawing near. I suggested the men think about it over the weekend and we could talk more the following week. They agreed and I told them I would see them again Tuesday at the senior centre.

Over the weekend, I thought a lot about Doug and Don and their potential involvement in this inquiry. I wondered if I had presented them with enough information in a way that they could truly understand what/why/how I intended to spend time with them. I reflected on the thoughts I shared with them and hoped that my proposal was perceived to be genuine and respectful.

Upon my arrival to the senior centre the following Tuesday morning, I wondered how much Doug and Don would remember about our conversation from the previous week. I wondered how I would gauge what information they had retained and how would I assess and respond to potential questions they would have for me.

As I pulled into the parking lot at the senior centre, I saw Doug and Don waving at me through the foyer window. I was relieved to see they were expecting me. As I walked towards the door, I thought about how to re-engage them in the conversation about the inquiry, as I wanted to ensure that the invitation felt genuine... that my request to spend time with them was genuine. I remember thinking, "Don't be too hard on yourself, Brenda. It's ok if it takes one, two, three times inviting them to the inquiry. And if they say 'no', that's ok, too, because you can talk to others who might be interested in taking part in this project. Just don't come across as too eager with Doug and Don. You don't want to scare them off...."

I approached the front entrance, Don swung open the door, and Doug looked me straight in the eye and said:

"Good morning, Brenda. Can you come to Smitty's with us today? We'd like to show you where we have lunch. And maybe you could come see our garden sometime?"

"I sure can, Doug. I would love to!"

Being Wakeful in 'the Midst'

It is important to note that the stories, the experiences, nor the lives of my inquirers began just at the moment I chose to enter into their worlds. Just as I was and continue to be 'in the midst' of my storied life, my inquirers were/are in the midst of theirs "located somewhere along the dimensions of time, place, the personal, and the social" (Clandinin & Connelly, 2000, p. 63). As the lead inquirer, I had to ensure that I moved beyond "the traditional role of researcher as expert knower… and become an engaged, involved coparticipant in the community of study" (Schulz, 1997, p. 84). It was necessary to be mindful of this as one of the hats I wore previously when walking in their parade(s) was that of a 'supervisor' or 'boss.' During our time in this inquiry, the relationship I had with the inquirers held us as equals; there was no hierarchical separateness. This encouraged trust, openness, and caring, which offered richness to our dialogue and, ultimately, the inquiry. I wanted the inquirers to feel that they had a voice and that they were cared for.

As many narrative inquirers are required to do, I had to *negotiate*: the relationships, purpose(s), transitions, and ways to be useful with my inquirers (Clandinin & Connelly, 2000). I had to awaken myself to the *many* 'hats' that I would need to wear throughout this walk; I anticipated I would be a friend while I was a researcher; I would be an advocate while I was a teacher. I was required to maintain constant awareness of how my presence in my inquirers' lives affected their stories. For Doug and Don, I wondered how my consistent presence in their lives would affect our *relationship* or their independence and self-determined 'schedules'; I wondered if it was fair to David that I requested to spend even more time with him than usual, in contexts that were not typical for the two of us to spend time in. I wondered if the inquirers would feel that my interest in their storied lives felt *purposeful* and *authentic*. Did I explain my reason for spending time with them as clearly as I could have? I wondered how I could ensure my *transition* into their storied lives would not disrupt the normalcy of their days and how my shift out of those daily life experiences could be fair and would not rupture our ongoing relationship. Finally, I knew it was necessary for me to be *useful* to my inquirers and find ways that would help them to relive and retell or 'recollect' (Crites, 1986) the stories that were important to them; I wanted them to enjoy their time with me on this journey.

Chapter 5

Creating the Field Texts:
Reflections of Past and Current Experiences

“We have all accumulated stories in our lives.
Each of us has a history of stories.
And no one’s stories are quite like anyone else’s.”

(Coles, 1989, p. 11)

Composing Stories: Walking Alongside the Inquirers

To begin, I had to enter the parade, walk alongside the inquirers, and awaken myself to the three-dimensional space and recognize “how the kinds of field texts are attentive to … temporality, sociality, and place” (Clandinin, Pushor, & Murray Orr, 2007, p. 27). I listened to the stories expressed by the inquirers, shared my own, and awakened myself to the relational connections. I carefully listened and watched for the stories that were *unpacked* (the stories they shared with me), *retold* (the stories they revealed to me more than once, perhaps for different reasons), and *reperformed* (the stories, events, activities they lived and engaged in repeatedly throughout our time together) in their world(s). Yet it is not only the ‘story’ I was listening and watching for, it was also the “responses to questions, gossip, idle chitchat” (Sarris, 1993, p. 4) that complemented this narrative. I paid close attention to the anecdotes the inquirers shared about their retirement. Anecdotes served the purpose of this inquiry well, as they were “an encapsulated crucial event – often unforgettable – that provide[d] a variety of possibilities for research direction” (Ely, 2007, p. 585). Ely describes anecdotes as:

> …stories [that] stand out like beacons. They may be brief or long, happy or unhappy. They may center on oneself as researcher, or participants, or context. They may nudge our awareness until we pay attention, or they may scream for it. What they have in common, however, is that they carry a nugget of meaning – often crucial to insight. (p. 584)

Conversation was the best way to hear their stories as "conversations create a space for both participants and researchers to be composed and heard" (Clandinin, 2013, p. 45).

As we know, the nature of narrative inquiry requires ongoing consent from our inquirers. With their ongoing verbal permission, I participated in daily happenings and special events in their lives. I connected with David, Doug and Don at least twice per week in two ways (a) face-to-face, and/or (b) via telephone when they were unable to meet with me in person. Through writing and audio-recordings of my thoughts, impressions, feelings, and reflections of personal experience, I made detailed notes of the conversations and occurrences I shared with them. With their permission, I also took photos and made video-recordings of our time together. Just as I do with a friend or family member, I respected their time, comfort, feelings, privacy, and trust.

Months ago when I began thinking about the stories of my inquirers, I realized that due to their active lifestyle, they would be living and telling stories even when I was not with them. I thought it would be a good idea to provide them with easy to use audio-cassette recorders so they could document their lives when I was not with them. If and when they chose, they could record their thoughts, feelings, perceptions, and stories of personal experience. Essentially, they would have the opportunity to keep an 'audio-diary'.

When asked if they would like a tape-recorder to 'talk about' what they did in between the times I saw them, all three replied, 'Nah. That's ok.' Neither David, Doug, nor Don were interested in recording their stories in this manner. I am not sure if they declined this opportunity because they were unfamiliar with using the technology, or if they felt it would be an inconvenience. Regardless, I found that the best way for me to stay informed of their lives was to ensure that I remained in contact with them *frequently* and *consistently*, meaning that they knew when to expect me. For example, I asked Doug and Don when the best time would be for me visit them each week. Don said, "I don't know. We're out a lot." I suggested that I meet them every Tuesday and Thursday morning at the senior centre before floor curling. They agreed. So every Tuesday and Thursday morning I would arrive between 8:30-8:45 AM and have coffee with them for 45-60 minutes. We could catch up on what they had done/were planning to do in recent days. During our meetings we also made time to discuss where and when we could get together for a longer visit. Often, we planned to meet for lunch downtown once a week or visit while wandering around the farmer's market on Saturdays. Sometimes, they invited me to attend special events in the community (i.e., The Farm Progress Show) or go for a drive in the country.

Meeting with David consistently was not nearly as easy, as the activities he regularly attended did not afford visiting. He attended church on Sundays where he volunteered as an usher; his arrival to weekly floor curling at a smaller affiliated senior centre never allowed enough time for a visit. However, I did have ample opportunity to visit with David at Saskatchewan Roughrider home games where he volunteered with my husband and I. In addition to these outings, David gradually became more and more comfortable calling me on my cellular phone when he wanted to visit and tell me about something he did or was planning to do, sometimes calling twice per week. (It is noteworthy to mention that neither Doug nor Don called me, even when I encouraged them to call just to say 'Hi.')

Composing Images of Past Lives and Current Experiences

As I indicated earlier, I asked the inquirers permission to take photos on our journey. Images (i.e., photos and video) helped to create coherence (Marmon Silko, 1996), thicken ways of seeing the story (Bach, 2001), and provided a means for reminiscence and communication (Boxall, 2010). Photographs and video were useful to the inquirers and myself to identify what was important in the three-dimensional space. The images captured a moment in time (temporality) and provided a springboard for us to explore the dimensions of that time (looking to the past, present, and future). It was my hope that they would feel comfortable and confident to create and capture images that were of importance to them. I anticipated that their self-created images, along with the pictures I produced, would enlighten all of us to a story of retirement that would not otherwise be revealed through conversation.

I offered the use of digital cameras to the inquirers. Although 35 mm disposable cameras are still available, inexpensive to purchase and easy to use, I have found that they are not ideal for use in research by people labelled with intellectual disabilities. In my master's thesis, I asked women labelled with intellectual disabilities to take photos of their leisure experiences using disposable cameras. Although the photos revealed that they had an understanding of the parameters surrounding their leisure (i.e., they took photos of activities, objects, and people related to their leisure experiences) many of the photos were blurry, dark, and rendered useless for both photo-elicited conversations and for placement within the thesis itself. Also, the cost of developing the photos became quite expensive, particularly because very few of the photos turned out. With advances in digital photography, I decided I would seek out a practical, user-friendly, relatively inexpensive digital camera for the inquirers to use. Digital cameras provide researchers and their participants the luxury of taking limitless photos (of course, this is dependent on the capacity of the storage device inserted into the camera). And because the photos are accessible for immediate review feedback regarding image quality and accurate representation of the subject matter is instantaneous (Phelan & Kinsella, 2011). Digital cameras also produce sharper images than a one-time-use disposable camera and provide diverse opportunities to record interviews and research sites (Murthy, 2008).

You may recall David's reluctance to use a camera. When the idea was initially presented to him I assured him that I would teach him and help him when he required assistance. "We could even go buy it together." I suggested. He agreed. It was important for me to find a camera that was going to be accessible for his use. Researchers have suggested that when using electronic technologies, people labeled with intellectual disabilities prefer to use items with universally designed features. For example, large easy to see displays, large buttons with pictures instead of words, and large screens (Carey et al., 2005).

Together, David and I went to the electronics section at Wal-Mart and looked at the selection of cameras available to us. The camera that I felt met the criteria of 'accessibility' was the Kodak Playsport. The face was very 'clean' and did not have an excess of buttons. The screen was 2 square inches and was easy to view in camera mode and picture replay mode, and it could easily be held in one's hand without accidentally pushing a button that would make the experience frustrating (e.g., accidentally turning the camera off or switching modes while trying to take a photo). In fact, I found this particular camera to be so user-friendly that I have used it for other research projects in which I have engaged children and youth labelled with intellectual disabilities!

It is important to note that David, albeit slowly, did embrace the idea of taking photos. After I explained to him the 'rules' of using the camera (i.e., "Don't take close up pictures of people unless they say it's ok…, don't lend or show the camera to anyone unless you know you can trust them..., if you lose the camera or it breaks or someone takes it, it's ok. It's just a camera and we can always buy a new one...”), he was excited to get out and take some photos. We practiced taking pictures in his house, in my office, and outside. I suggested that he take the camera with him anytime he went out and so he could take pictures of anything he thought looked interesting. In subsequent weeks when I would check in with him face-to-face or on the phone and he would tell me about going to floor curling or a Pats hockey game, I would always ask, “Did you take your camera with you?” he would always reply, “No.” And of course I would always cheerily follow with, “No?! How come?” His response: “I don’t know.” I could tell by the tone of his voice that he did not want me to continue questioning him.

However, anytime David came out with me, I did notice that he always brought the camera along and he was eager to use it. The camera was either slung around his neck by the lanyard I attached to it or he kept it stashed in his jacket pocket. When he was with me, he would frequently ask, “Should I take a picture?” particularly at times when we found ourselves in a ‘moment of interest’ (e.g., a new city bus driving past us or a squirrel running down the sidewalk). I would say, “Do you want to take a picture?” Then, without a word, he would take the camera out of his pocket, turn it on, and without prompting or reminders on how to use it, he would successfully take a photo – while grinning ear to ear! He would then confidently and correctly press the ‘Review’ button, turn the display towards me, and proudly show off his self-created image.

Sometimes after taking a photo, David would ask me if he should keep the picture or erase it, but he only seemed to ask when the photo was obviously poor quality (e.g., blurry, the bright sun washed out the subject matter, someone walked in front of the camera while he was taking the picture). It was obvious that he had an understanding of how to use the technology and was engaged in the feedback loop of learning how to use the camera to create quality images. However, he seemed to be most comfortable using it when the option of having someone to help him was available. When using technology, this is a common desire of others labelled with intellectual disabilities (Carey, Friedman, & Nelson Bryen, 2005). They prefer to use technology in the presence of those who can provide assistance.

Now, having Doug and Don use a camera was an entirely different story. When offered the same opportunity to take photos of things they did when I was not with them, they politely declined the opportunity to use a camera. When asked why they did not want to take photos/use a camera, they replied, “We have a camera at our house.” “This is great!” I thought to myself, “They can use their own camera!” When asked if they would like to use *their* camera to take photos, they – again – politely declined. I even offered to pay for the developing of the pictures, to help them make a photo album, or to show them how to use the camera if they needed some assistance, and they still said “No thanks”. When asked if they had any photos they would like to share with me, they politely said “No” and we left it at that. I respected their privacy and did not push the issue. Thus, the only photos I have of Doug and Don’s experiences are the photos I took myself, with their permission.

Reliving the Stories Through Imagery

I felt it would be most appropriate to provide the inquirers with copies of the images that were created. I printed the photos from my computer linked to a high quality colour printer. The images, four photos per page, were large, vibrant, and rich; ideal for viewing. I slid the pages into clear page protectors and inserted them into a 3-ring binder. This way the inquirers could touch the photos and literally point out objects and people of significance. While preparing the respective photo package for each inquirer, I realized other benefits of using the digital camera. First, having the photos on my computer provided the option of diversity when presenting the images to the inquirers. Second, the photos were naturally organized by date/location/activity/person on my computer, as iPhoto intuitively knows how to categorize images which are uploaded into the program.

Discussing the images. I met with David and Doug and Don to visit about their respective images. We sat and relived our experiences through the photos. I asked questions within the three-dimensional space (the 'who', the 'where', the 'when' of the image) and posed questions pointing in all directions (i.e., I asked questions about inward feelings, the outward environment, and the past, present, and future. For example, 'What did you think; How did you feel; How has this changed; Do you think this will this stay the same?'). I found it helpful for them to talk about their 'favorite' photos and to point out which photos they felt comfortable sharing with others.

In addition to reviewing the photos together and asking the dimensional and directional queries, I also found it helpful to invite the inquirers to share their favorite stories and photos with others. Today, and throughout my engagement and writing of this inquiry, I have been a faculty member of Kinesiology and Health Studies at the University of Regina. Every semester, I take the opportunity to talk to students about the retirement 'dilemma' as it relates to older adults labelled with intellectual disabilities. Often, my colleagues invite me to speak in their classes as well.

Over the last number of years, I have always invited David to come with me to these lectures. We use PowerPoint to share pictures of the Retirement for All program activities that David and other participants engage in. During the collection of field texts, my colleague invited David and me to come and speak to her class. I decided to take this opportunity to freshen up our presentation and I asked David which pictures from our inquiry he would like to share with the students during his lecture. This was a great way for David to identify some of his favorite photos, and for me to ask the dimensional and directional questions about the images. We sat together and flipped through the pages of photos, recollecting the experiences we had shared together on this journey. He chose several photos, but a majority of the photos were images of our time spent at football games. I inserted the photos into the PowerPoint slides and we delivered our presentation to nearly 60 students! Later, David reported with a smile, "I wasn't even nervous! Usually I'm like that [holding up his hands and shaking them as though he was trembling]! But not this time." Perhaps this is because he was more familiar with the images that were in the presentation, for he was the one who created them and chose which ones to reveal to the class.

Observing how well the presentation went with David, I decided to invite Doug and Don into my 3rd year adapted physical activity class to talk about their retirement. I found that following the same process I facilitated with David to be incredibly helpful (i.e., "Choose your favorite photos to share with the students..."). A majority of the photos they chose to share were taken on the days we visited their farm. During the presentation, they spoke with such heart and conviction about how important the farm was to them. They even went so far as to tell the students, "Ok, now pay attention... Never – EVER - stick your hand in an auger. You know what will happen? **RIP**!!! Your shoulder comes right off! And then you know what you've got? Only one arm; NOT TWO." (Although the students and myself found this safety reminder to be humorous, I could tell that Doug and Don were very, *very* serious.) Listening to Doug and Don tell others about the significance of *place* in their lives helped me to make sense of their retirement experiences; you will soon understand, too.

Negotiating an Ethical Exit...

Although I continue to live in a relational way with my inquirers, there was a point in this journey when I had to choose to live in a 'less intense way' as I moved from field texts ('data') to research texts ('results'). Prior to beginning the transition from field texts to research texts, I had to consider my exit from the field. I had spent months talking with my inquirers and sharing/living/reliving stories; some were shared over morning coffee or during a car ride downtown while others were revealed during a garden walk or with the vast prairie landscape beneath our feet. Regardless, the time came for me to "move away from the close contact, the daily conversations, the frequent meetings and working alongside... to begin to focus more directly on the reading and rereading of field texts... to compose research texts" (Clandinin & Connelly, 2000, p. 129) The 'exit' from David's parade was essentially nonexistent nor possible; we continued to see each other on a regular basis due to our volunteer commitment in the community. The only difference was that I did not continue to document our meetings nor collect his photos. My time spent with Doug and Don, however, was reduced significantly - and at a rapid pace.

...With Doug and Don

At the time of my exit from the field, it was mid-May and I was almost 6 months pregnant and preparing to attend a conference overseas. Just as I did for previous trips away from the city, I told both Doug and Don that I would be away for a few days and I would reconnect with them once I returned. Unfortunately, when I returned from my two-week trip to Europe, I arrived at the senior centre on a Tuesday morning to find a 'CLOSED FOR RENOVATIONS' sign on the door. Instead of being greeted by Doug and Don's smiling faces, I was disappointed to learn that the centre was closed for two weeks in order to refinish the dance floor in the auditorium. Although I made efforts to contact the brothers (e.g., telephone calls to their home, a wander through the downtown mall during a couple of noon hours), I did not reconnect with them until late June. When I did, it was by chance that I saw them at the farmer's market downtown on a Wednesday morning. Now, obviously pregnant, we had a lengthy visit about the baby and how I was doing; they talked about feeding the baby, smelly diapers, and how Ian "won't get much sleep because of the crying!" I asked them about their garden, time spent at the Farm Progress Show the week earlier, and how floor curling was going. It felt as though we were able to pick up our conversation where we left off weeks earlier; sharing thoughts, feelings, and genuine interest about the experiences in each other's lives.

"Well, should we get together for lunch sometime?" I asked. "What are you doing next week?"

"You're having a baby!" Doug replied.

"An..n.n..n...n...d.d.d...? So...?..." I began, not sure how to respond to his statement of the obvious.

"You need to rest!" said Don.

"Oh...?" I thought to myself, 'What an odd, yet annoying, traditional-paternalistic view of a pregnant woman he holds. He sounds like Ian's Aunt Bonnie: "*Don't you want to lie down and have a rest, dear? You should be napping everyday. I did when I was pregnant.*"'

"You should rest. It's hot. And it's hottest at noon. We don't want you to get sick." Doug explained.

"I'll be okay. We can go somewhere air conditioned... Or we can have supper somewhere..." I began.

"It's okay. Can we have lunch after you have the baby?" asked Don.

"But not in the winter time when it's cold. The baby will get sick. You need to keep the baby warm," Doug advised.

I began to wonder if their reasoning was a clever way to avoid spending time with me. But then I remembered years ago when they told me about their niece having a baby. When I asked when they were going to meet their new great nephew, they said, “Not for a long time. Carol just had the baby and she needs to rest. We need to leave her alone so she can take care of the baby.” I knew Carol lived in Saskatoon, the same city where their brother lived. I thought it would be of great convenience for Doug and Don to travel to Saskatoon to see their brother and spend time with their newest nephew. I assumed they would have to wait 3-4 weeks. However, when the brothers finally met their nephew the following Christmas, he was 11 months old.

Now I felt guilty for the organic surge of frustration and defensiveness that washed over me moments earlier. Perhaps their protests were due to genuine concern for my well-being as a pregnant woman. I wondered if the story they carried with them about women ‘in my delicate condition’ was shared with them in/by another generation; a time when newborns were not to be exposed to outside elements for two weeks after their birth and how ‘refrigerator mothers’ caused autism. Regardless, I agreed to meet with them after the baby was born. They advised me to rest for the remaining weeks of my pregnancy, and then they politely excused themselves from our conversation so they could catch the bus to Safeway. I did not see them again until after my daughter, Wilder Grace was born. I did not bring Wilder with me. She was nearly a year of age when they finally met her.

…With David

At this point in our lives, I continue to see David on a regular basis. We continue to volunteer at the football games and he still calls once a week to see how Ian, Wilder, and I are doing. If there are special events in the city he asks if we are going, wondering if he can catch a ride. He also loves to see our little girl, Wilder Grace. She is so loved by David... I think his heart doubles in size every time he sees her. He cares for her so deeply and is so taken with her that he cries at her smallest achievements. When she smiles at him he quietly says through his verklempt voice, "You smiled at me! Do you love me? I think so. I love you, too, baby girl."

Creating the Research Texts

"Don't ask me what it means, the story.
Life will teach you about it, the way it teaches you about life."

(Sarris, 1993, p. 5)

The three dimensional space has a great influence on where, when, how, and why stories are told and reperformed. Because of this, stories are open to multiple interpretations (Bateson, 2000). As stories are recalled and retold, they are being shared from a "new perspective, out of a new background, as part of a new narrative" (Kerby, 1991, p. 30). As I moved from field texts to research texts, and throughout the inquiry, I was looking for "important, binding ideas and insights about what it all mean[s] to me, what [I] have learned, and what this might mean to others" (Ely, 2007, p. 595). As a narrative inquirer, I had to understand that my role was/is not to interpret the story, but to help myself/ the inquirers/the reader make sense of it. I am not interested nor qualified to *confirm* the stories of the inquirers. Rather, it is simply my presence, that *thickens* the narrative (Bruner, 2004). My writing should honor their stories and experiences and reflect that my inquirers were of great importance to me (Gergen, 2004).

Moving from Field Texts to Research Texts

Fieldtexts were used to record thoughts gathered during the moments spent with the inquirers and afterthoughts of our time together, while *interim research texts* represent a sort of 'thinking out loud' that I engaged in as I became awakened to how all the puzzle pieces might fit together. Before completing the final research texts, which follow this section, I first had to take the interim texts back to the inquirers for reviewing and reflection.

Due to literacy challenges, I did not feel comfortable creating a contrived situation in which I would 'read' my writing to them. I found that recalling the stories through imagery (i.e., during the creation of presentations for class lectures) was beneficial. Each inquirer chose which stories/images were important and I began to understand the significance of the stories retold (revealed more than once) and reperformed (engaged in repeatedly). When they were selecting/discussing their photos, I spoke of my experiences within the three-dimensional space (e.g., 'I remember when we took that photo... We were... I was thinking... I felt like..., etc.). I re-engaged in this dialogue with the inquirers after the class presentations when students had asked their own questions about the photos and the stories. To me, this was a more natural, authentic, and thoughtful engagement with my inquirers.

After coming to realize the significance of particular stories in their lives, the narrative accounts shared by each inquirer were laid beside one and other and understood within the three-dimensional space. I paid attention to the events, time, and space within which the stories were told. I asked "*What similarities are there? What resonates across stories? What tensions do they share?'*" I was aware of emerging narrative threads that enlightened me to the experiences of retirement. I worked to engage in narrative thinking; to consider the three-dimensional space, and write of the "temporal unfolding of people, places and things…, the personal and social aspects of [the] inquirer's and participants' lives, and the places in the inquiry" (Connelly & Clandinin, 2006, p. 485).

Prior to submitting the complete draft of my documented journey to my committee, I sat down with the inquirers once again and showed them the work that we had created together. "All of this writing is what I was thinking and feeling when I spent time with you... and it also includes some of the stories you told me and the photos that you shared. Would you like to look at it? Here's the story about the day we went to the cemetery... I told my teacher that I was feeling nervous as we walked around the grounds. I was also feeling sad about how much you must miss your parents and the farm.... But I was happy that you invited me to see them and your old house… I thought a lot about my Grandpa…" and so on... and so on.

As I shared my writing with them, I encouraged them to offer their thoughts and interpretations of the story before I offered the narrative to a greater audience (i.e., "Don, what do you think about this? What are you feeling? What would you like to add/change/take out? What more should we write, together?"). By viewing my inquirers labelled with intellectual disabilities as 'co-producers' of knowledge, it provided them with a stronger voice to share their experiences. It was my hope that as I disclosed my relational narrative/awareness to the inquirers, they would see how this inquiry might inspire their own questions about their lives. In addition, I shared my own relational-thinking and experiences… about my time spent with them at the senior centre, downtown, on the farm, at football games, etcetera.

The Power of *Place*

I will never ever forget the day Jean Clandinin read a book to our narrative inquiry graduate class titled 'What You Know First'. This book is about a young girl and her family who are moving from their prairie home to a place near the ocean. The young girl's father assures her that she will never forget the prairies, but just to make sure she remembers, she takes a number of items with her including a little bag of prairie dirt and a twig from the cottonwood tree. As Dr. Clandinin read the story and spoke about how the young girl will always remember 'how soft the cow's ears are when you touch them' and how the young girl "cannot take the sky", I cried. *Uncontrollably*. (This is why I'm certain Dr. Clandinin will never forget this day, either!) The words took me home, back to the place on the Canadian prairies where I grew up. It wasn't until that moment in that class that I realized how much *place* meant to me. I realized how much I missed the endless fields of wheat and how if you look far enough you can see where the stalks of grain touch the sky… and then, carefully, you can follow the sky right back to where you are standing. I recall, as a young child, engaging in that activity over and over again as a way to help the seemingly endless summer pass by. On that February day in Dr. Clandinin's class, I was awakened – perhaps startled is a better descriptor – when I realized the significance of 'place' in my life. (Thank you, Jean, for helping me to remember and embrace 'what I knew first'.)

During my time with the inquirers, it was not long until I realized that, for them, unpacking stories in the dimension of *place* worked well. Place seemed to help them jog their memories of stories once lived, and to act as a springboard to elicit conversations of their current lives. I wondered if this is because place is more-so static and 'concrete' than the ever-changing dimensions of temporality and the social milieu, as place does not necessarily always or accurately reflect these social and cultural changes. Regardless of the reasoning, *place* was a good starting point in which to situate my thinking and inquire into the stories of the inquirers as a way to reflect on experience. In the following section, you will see that *place* was the starting point for all of us to begin to unpack our stories.

Chapter 6

My Time with the Inquirers

In this section, I will share with you stories that were either lived/told/performed by myself *with* the inquirers and the stories that were recalled *by* the inquirers, as I walked alongside. You will read stories about childhood, community engagement, and friendship; stories of sorrow and memories wished to be forgotten; and stories about plans and hopes for the future. I have organized this writing under the names of my inquirers: Doug & Don, and David. To begin each section, I will write about how I came to know each inquirer and then I will recount the stories they shared/lived with me. Just as I have done throughout the first section of this paper, the **typewriter text** has been used to represent the stories. You will also find photos throughout this section; I have included them to help tell the story of our experiences together and to enhance the narrative itself.

I hope that the writing and the imagery will allow you to "world travel" (Lugones, 1987) into the lives of my inquirers and myself. It is important to note that in narrative inquiry "final research texts do not have final answers, because narrative inquirers do not come with questions" (Clandinin, 2013, p. 51). Rather, the research texts are "intended to engage [you] to rethink and reimagine the ways in which [you] practice and the ways in which [you] relate to others" (p. 31). Finally, you will read some of my 'thinking out loud' as I try to make sense and find coherence between/amongst our lives.

Doug & Don

Coming to Know the Inquirers

Do you recall the story I shared with you about my time with Doug and Don at the Earl Grey Cemetery? The story of how we got to the cemetery on that August afternoon began long ago, as our lived story began when I met them at the Senior Citizen's Centre when I was hired as the Coordinator of the 'Retirement for All' program. You may remember that my role in that context was to facilitate inclusion among older adults with and without intellectual disabilities in a shared community-based recreation and leisure program. Again, the idea behind the program was to eliminate the perpetual segregation of people labeled with disabilities in the community and to provide them with opportunities (or at least the option) to experience retirement in ways that their 'non-disabled' peers might. Doug and Don had just retired from a sheltered workshop and were beginning to explore opportunities for activities in the community.

While they waited for floor curling to begin on Tuesday and Thursday mornings, I would have coffee with them. I looked forward to this time with them as it was the only time it was just the three of us. They would tell me stories of the people they used to work with and the products they made at the workshop. We talked about their parents, whom they still lived with in a small house in the city, and about their brother who lived in Saskatoon about 2-1/2 hours away. Since first meeting them, I became privy to a number of significant events which influenced the trajectory of their storied lives.

Several years ago now, their elderly mother passed away leaving the father to care for the two sons in the family home. However, during my time at the senior centre, it became apparent through conversations with Doug and Don that it was the two of them who were looking after their father. Just months after the passing of their mother, their father moved in to a long-term care facility as he was very ill. Suddenly, the two men were living on their own in the house they had shared with their parents for the past 40 years. I recall them telling me about how they had “ripped out the carpets for new ones” and “painted the walls” and “bought new furniture”. Perhaps what was most astonishing was that the two men decided *they no longer needed to share a bedroom*. Don moved into the master bedroom and out of the bedroom he had shared with his brother for over 40 years. For the first time in their lives, the men slept in the privacy of their own, separate rooms.

A few years later, their father passed away in the care home. It was no surprise to me, as their frequent reports regarding their Sunday visits to their father’s bedside indicated he was not well. Many times they reported that their father “was sleeping again” when they went to visit and they regaled when “he ate supper last night!” Despite the loss of their parents, they remained active at home and in the community, perhaps even more so as they found they had more time to explore new opportunities and adventures.

Arriving at the Senior Centre

Having left the meaningful employment they engaged in at the woodshop for over 30 years, I believe Doug and Don found themselves in search of something to which to contribute during their retirement. They were introduced to several activities at the centre, including the Wednesday and Friday afternoon dances, Thursday morning shuffleboard, and Friday morning drop-in billiards. But it was the Tuesday and Thursday floor curling in which they took the most interest, perhaps because this activity provided them with the greatest opportunity for ‘work’. Soon after they began attending the centre nearly 15 years ago, they would arrive early on Tuesday and Thursday mornings, often waiting for someone to unlock the door at 8 AM so they could have coffee before floor curling. One morning, the leader of the floor curling group asked them if they could help to set up the rinks. It wasn't long before floor curling set-up became their job and it was solely their responsibility every Tuesday and Thursday morning.

In order to see what floor curling set-up entailed, I arrived early one morning to document – and help with - this work. Below is my verbatim fieldtext of my observations and experience; thinking and reflecting 'out loud' as I recorded my thoughts on my iPhone when I left the building:

Holy shit! I just spent the last hour with Doug and Don at the senior centre setting up this frickin' floor curling. I usually forget how old they are, but today it all came back to me as I watched two 70 year old men do some serious, serious heavy lifting, stressful bending, and a LOT of walking back and forth and back and forth to that equipment storage room. Ok, so what did I see? I saw them carry out two rolls of indoor carpet and roll them out to create curling lanes. Roll them out to the other side of the auditorium. I saw them move stacks of chairs to each end of the rinks so players could sit while they watch between throwing their own rocks. I saw them move around floor curling sticks. I think the worst of it was watching them move the curling rocks. So, the rocks aren't heavy, they're just made of wood but someone – probably a retired fellow who is good with tools – made a carrying case… not a case… a carrying box from solid wood to store and cart the curling rocks around and it's so frickin' heavy I couldn't even lift it. And I think I'm pretty strong but I guess not as strong as a 70 year old man!

Anyways, now I'll talk about what I saw in their eyes and on their faces doing that heavy lifting… I saw pride. They were so proud of showing me where everything was in the storage room and how they knew where to get things from and where to put them back. They were proud to tell me how to set up floor curling and how Cecil always says "You did a good job, today!" I get the sense that they believe that if they weren't there to do the work, then floor curling wouldn't happen. Like, the entire program or activity would not exist. And I kind of feel like it's true. They were so excited to show their boss the work they had done this morning!


2

Stepping Back in Time: Travels to the Farm

Ever since I have known Doug and Don, the farm has held a special place in their hearts. They often shared stories of farming "the home quarter," sharing memories of driving the one-ton Ford, shoveling grain on a hot summer day, and the story of the dog Jip who had an unfortunate meeting with a skunk one evening. Even after the family moved from rural Earl Grey to the city in the early 1960s, Martin, their father, continued to farm during the day while he spent nights cleaning floors at the SaskPower building downtown. Both Doug and Don frequently mentioned that their father "worked hard" and that "the work was hard on him."

Knowing how important the farm and rural life were to Doug and Don, it was important for me to step into the pages of this story with them. I wanted to see the place that held such significance in their lives. As a 'farm girl' myself, I was hoping they would share their memories with me, as I hoped to relive some of my youthful memories with them. When asked if they would be interested in showing me around the now abandoned home quarter, they enthusiastically agreed. They were also quick to mention that I had "never been to the farm" and I didn't know where it was!

"You don't know where it is! We'll have to show you!" They both said with smiles on their faces. Don was especially excited.

"Should I bring a map?" I asked. "Which direction will I drive out of the city?" I asked this in all seriousness. I had not a clue where Earl Grey was.

Doug seemed offended by my question. "No! You don't need a map. *We know* where we're going!"

To be honest, I was still a bit hesitant. I knew they didn't get out to the farm often. I wondered how long it had been since they were there and if they could really remember how to find their way on the gravel roads outside of the city. As a farm kid, I grew up driving on the backroads of

Saskatchewan and even I got lost coming home a couple of times simply because I got caught driving the same grid over and over again! (In my defense, it was dark and it was hard to see the tree with the crook in the branch that signified my next turn should be a half-mile down the road…) However, I soon learned that just because I did not have confidence in myself to navigate the rural roads of Saskatchewan, I should not have projected this onto the brothers. The following story is my narration of the unfolding events as we left the familiarity of the big city to experience a country adventure...

We're driving north out of the city on Highway 6. I literally have no idea where I am going, however, Doug and Don are confident that they will get me safely to the farm. As we drive down the highway through the Qu'Appelle Valley, I know that we are going to turn on a gravel road at some point, and I find myself slightly softening my foot on the gas pedal as we approach grid roads that intersect the highway. I wonder if the brothers will give me enough notice so I can slow the car down to take the corner safely, or will I have to slam on the breaks or turn around on an approach to retrace my path to get back to the correct turn. I feel terrible for not giving them enough credit, or not having enough confidence in their ability to safely and accurately navigate my way to our destination, but we're visiting so much... It's happened to me before... you forget to tell your driver where to turn and you end up backtracking. Finally, Doug says from the backseat "Turn at that next corner on your left." I'm relieved. As we turn off the highway onto a grid road, I look upon the vast prairie landscape in front of me. Although slightly nervous about what lies on the road ahead, I realize how familiar the space looks. I don't know where I am... yet at the same time I do... I take comfort in the familiarity of the surroundings, as the sloughs, bluffs of trees, and crops remind me of home. Although I live in a prairie city, it feels good to be ‘in’ the prairies again.

As we drive, Doug and Don are sure to watch for bumps and potholes in the highway, which can be found at least every 500 feet. The road we are on is definitely one of the less traveled as it appears to be overdue for maintenance. The grass is high in the ditches and I wonder if any farmers will come to bail it to claim it as their own. In amongst the bluffs of trees, I see farmyards. Some appear to have been abandoned years ago, while others are obviously still inhabited as the homes and yards are well-maintained. Regardless of their condition, Doug and Don know who had been living on each home quarter at one time or another.

“That’s where the Smith’s used to farm. And there’s the Barrett Farm....” They seem to know the land like the back of their hands. As we navigate another turn at a fork in the road, they exclaim, “There it is! THERE’S THE FARM!” All I can see are bluff of trees.

“Where?!” I ask.

“THERE!” replies Doug, tapping on the window.

“Ohhhh....!”. Still, I have no idea and quickly scan the countryside that lays before me.

“The one with the old buildings!”

Then, I see it.

We drive another half mile down the road and I’m soon instructed to turn right onto a short prairie trail.

“Stop!” says Don. “There might be glass somewhere on the path. We’ll just walk from here.”

We get out of the car and step into the 'silence' that is the prairie... the sounds of crickets chirping, the breeze blowing through the tall prairie grass, and the gentle rustling of the birch tree leaves. It's just the right kind of silence. The warm sun is beating down on my face. For me, it feels good to be 'home' again; it is peaceful. I imagine the same for Doug and Don.

I scan the landscape. The slough just north of the old farmhouse is surrounded by trees...

If I look hard enough, I can see a couple of old cars hidden amongst the brush...

The small farmhouse stands empty, while other buildings still shelter a few tools, machinery, and I would assume, a number of rodents.

We wander for about an hour, exploring areas where it is safe to do so. Doug and Don have many stories to tell, about neighbors helping neighbors, the hard work they put into the land, and the care that mother put into the house.


EARL R GREY
EARL R GREY

For me, Doug and Don's recollections of farm living, and being able to physically experience the land that is so important to them helped me to remember and reconnect with the 'place' that is important to me, too. Their home felt like my home, as my eyes moved across the landscape in view of the old wooden granaries, the wheat field, and the fence posts bordering the land. I have memories of traveling familiar looking roads, sitting beside my grandfather in the grain truck as we moved from field to field during harvest. I remember walking through the alfalfa fields with the livestock entertaining them with my renditions of numerous Top 40 hits and crafting 'welcome' and 'goodbye' songs to the geese flying above as they arrived from or departed for the south in spring and fall. I wondered if Doug and Don shared their stories of their land with me because they knew I would appreciate the experience and their memories, being a farm girl myself. Or, could it be that I was the only one with whom they were comfortable sharing their memories? During our time together at their farm, I remember thinking…

Here we are standing on the farm where they once played, worked, and lived. They haven't lived here for over 40 years, yet they still have such as strong connection to this place. They could tell a story for every day of the year for every building out here, I bet! They must have wonderful memories of their time here.

Being with Doug and Don moves me think about my brother and myself 40 years from now. He will be 80 years old; I will be 76. Will we miss our home, our farm in such a way that we will desire to make the long, tiresome drive to see everything again? Our parents can't even get us to go there now while they are still living in the house we grew up in! As a child, everything seemed so grand and auspicious. Now, our once spacious and 'modern' home is crowded with 'stuff' and in dire need of repair; the bales where we freely climbed and played are now dangerous and dirty; and the hayloft in the barn where I spent time fantasizing about having my first kiss is dark and dank.

I am intrigued with my continued love affair with the prairies. Although I have little desire to return to visit the farm and home where I grew up, I find myself longing for the spaciousness and wilderness that the prairies can offer. Sometimes I find myself fantasizing about living on an acreage, far from the city lights. I wonder if I do this as a way to remind myself that there is potential to re-write stories - *my story* – of the farm. Although I do carry pleasant memories, I can honestly say that most of the stories I carry with me about farm life harbor shades of sadness and frustration. Memories of my perpetually impatient father, often drunk, cursing and yelling at the cows to "Stop fucking knocking over the hay feeders!"; my mother, often on the verge of an apparent nervous breakdown, but with vehement work ethic furiously peeling potatoes every morning at 11:30 a.m. to ensure dinner would be on the table at 12 o'clock sharp; my brother, taking off on the trike every afternoon with a shotgun and gopher traps to torture whatever living creature happened to unfortunately cross his path.

And me... sick to my stomach all summer as I anxiously wondered what the town kids were doing/saying/ without/about me over the two months that I would not see them; getting off the school bus to see the managers from the John Deere dealership console my father as tears ran down his face while he negotiated the price on a much needed new piece of machinery; chasing the chickens in the box stall trying (and not trying at the same time) to catch just one, so it could meet its fate and join us for dinner that evening; carrying six, yellow and fluffy ducklings to the burning barrel because they did not survive the trek in the small, crowded box when it left the hatchery 3 days earlier. Ugh... there is nothing more black and white... nothing more about life and death, than a life on the farm.

Perhaps *what I knew first* and *what Doug and Don knew first* were different. Or, perhaps they were just better able to embrace it; or accept it, at the very least. Regardless, my experience on the farm taught me to appreciate farm living and everything it encompasses, from the wind stirring the motionless trees to the breaths taken by the creatures that surround us. Regardless, I think I found some peace within myself and about my family's livelihood on the farm with Doug and Don, that day. It helped me to see/re-live my story of 'what they/I knew first' with greater appreciation and a fresh perspective.

The Garden

On a warm Wednesday morning in July, I arrive at Doug and Don's home in the city. There they are standing at the end of the driveway, obviously waiting for me, as Don points at my car as it turns down the street. Doug begins to wave. As I slowly pull into the driveway, they move towards the car. I roll down the window and say, "Good morning! I'm looking forward to breakfast!" I get out of the car and we exchange hugs and proceed towards the house. Today, we planned to have breakfast together at Humpty's at 10 AM, however, I know they have both been up since 6 o'clock and had their porridge and toast already. This is more of a brunch for them. I, on the other hand, am starving. Regardless, nourishment can wait as I am eager to see their home and garden area.

As I stand in their driveway, I look curiously at their house. I often wonder if time has stood still within those walls, as I know they have lived in that home for dozens upon dozens of years, sharing one bedroom until the death of their mother and the subsequent move of their father into a care home. To this day, I still find it astonishing that the men were over 60 years old before they had their own bedrooms; I marvel at their stories of tearing out carpet, moving furniture, and buying new linens once it was just the two of them in the home. As I follow them to the backdoor of the house, which is the main door they use, I anxiously wait to be invited inside. Rather, to my surprise, we walk right past the backdoor and into the yard and garden area. I know that gardening is important to them, as this was a favorite activity of their mother's. For now the house can wait, as I am curious to see the efforts they have put into the garden of which they so frequently speak.

They point out the rose bush beside the house, one that had been moved from farm to the city. There is a wagon wheel leaning against the house, also brought to the city as a memento from their time living in a rural area. We stop by the crabapple tree to look at the bountiful crop of young apples still developing amongst the leaves. I ask, “What will you do with these apples?” They seem to ignore me as we turn away from the crabapple tree towards the garden.

I am curious to see their garden, as they have spent much of the spring waiting for the earth to dry enough so they could plant their crop of peas, carrots, beets, lettuce, corn, and beans. I recall several Thursday mornings, when asked, “What are your plans this weekend?” they would respond, “Oh, we are trying to plant the corn…” or “peas…” or “beans…” and the following Tuesday they would report to me, with a look of disgust on their faces, “It was too wet to do anything!” I knew the garden was important to them, and they took great pride in continuing this activity once carried out by their mother. I scan the yard for the garden area… I continue to scan…. and I ask, “So, the garden is…?”

“It’s right here,” Doug replies, stretching his arm out behind him to direct my attention. I am surprised at what I see…

The ‘garden’ is overcrowded with weeds, bushes, and other native Saskatchewan foliage. In fact, it’s difficult to find the *vegetable* garden, as it appears that the brothers only planted seeds where there was some space to work. Too, I see a large flatbed trailer that a neighbor has parked in their backyard which only diminishes the potential garden area even more.

I had imagined Doug and Don’ garden similar to the garden we had planted on the farm, with perfectly straight rows that seemed to go on forever (particularly in the potato patch). They would be marked by weathered wooden stakes at each end and small seed bags filled with dirt indicating what was planted where. I wonder to myself if their garden has turned out the way they had hoped, or the way it did when it was their mother's responsibility. I don't ask, as I don't want to embarrass them or appear like I am assessing their ability.

"Look here! Here's some corn!" says Don, eagerly pointed to the ground.

"Yes, there it is!" I smile, all the while thinking, "And here is some crabgrass that is going to choke it out."

Regardless of what I think, they are obviously proud of their work and are excited to point out their pockets of horticultural success. We tiptoe through the garden, around patches of weeds and grass, to seek out other sprouts of life poking up above the earth.

Finally, we turn back towards the house. "Ah... alright! Here we go!" I think for sure I get to see their house now. And so we walk towards the back door, stepping over the overgrown foliage in the backyard, and we...continue... walking....?!?! I ask, “Do you need anything in the house before we go?” hoping for a glimpse inside.

“Nope.”

“...Are you sure?”

“Yep.”

“...O...K....”

We continue walking past the door, down the sidewalk, towards my car. I just can’t bring myself to ask to see their house, as I feel it would be rude. I wouldn’t ask this of any other person... and there’s nothing I hate more than a ‘pop-in’ at my house, especially when I haven’t cleaned or organized the clutter for a few days. I have the sense that, for whatever reason, I’m not welcome in their home, or at the very least they don’t want me to see inside. Perhaps their personal space is very sacred and private to them. I will respect their wishes and proceed with our breakfast plans.

We all get in the car, but not before Doug and Don negotiate who will sit in the front seat and who will sit in the back. They ultimately decide that Doug will sit in the front on the way there; Don will sit in the front on the way back home, a fair negotiation.

As I reflect on my time in the garden, I think of my reaction(s) and how I fit into Doug and Don’s lives. I think about my positioning as a researcher and how I saw their garden as good ‘data’. I wondered if their garden (or lack thereof) would be considered a success or failure; would it be an indication of skill development or regression? Does it demonstrate their knowledge or naivety of independent living? As an advocate, I suppose one might ask similar questions to determine what kind of assessment or creative program support they would require to determine their prospects to continue to live independently.

It is times such as these when I realize how strong the grand narrative's chronicles exist within me: If people labelled with intellectual disabilities are taught *what is right* and are shown how to do things *correctly*, they will appear 'normal' which will lead to social invisibility and ultimately a better chance for inclusion. For example, the professional knowledge I carry with me tells me to teach them that a garden should be a carefully marked out plot of land that is meticulously cared for with no noxious weeds nearby to invade it. Suddenly, I realize that years of institutionalization has not only affected people with disabilities, but *it has affected me as well*. We so often speak of the effects of institutionalization on people with disabilities, but often fail to address how institutionalization has continued to carry itself forward in paradigmatic thinking in how we support/address/teach others.

The Homesteader Restaurant

Today, I think I'm more anxious than Doug and Don, as we have planned to visit a place they have not been since their father's funeral. But, they want to take me to lunch in Southey, a small community north of Regina to show me where they had dinner after their father's service two years ago. It's a simple drive to Southey, just head north on Hwy 6, follow the dotted yellow line, and you'll get there in about 30 minutes. The Homesteader Restaurant is right on the highway. We arrive just in time for an 11 o'clock lunch.

The Homesteader looks like a typical small-town Saskatchewan restaurant. The carpet is old and dated. The paths of wear resemble the driving grids of the rural roads as they crisscross one another between the tables. The walls have dark wood paneled wainscoting and each table is adorned with a small glass vase containing either an artificial flower or wheat sheaf. One table hosts what appears to be the usual morning coffee gang, as I see a group of older gentlemen wearing coveralls and dusty, worn ball caps. They all turn and give us ‘the look’. If you’re from a small town, you know ‘the look’; it’s the ‘hey, you’re-not-from-around-these-parts’ gaze as they are obviously assessing your potential for belongingness. Regardless, the brothers choose a booth at the back of the restaurant and we seat ourselves.

The waitress brings us some menus and asks what we’d like to drink. The two gentlemen order coffee while I order an iced tea. She leaves, and the brothers immediately turn to the back of the menu looking for the meal options for ‘seniors’. I know that Don is looking for one word: *liver*. Doug chooses a Saskatchewan diner classic: a Denver sandwich with fries and gravy. It sounds good to me; I order the same. As we wait for our food, the brothers tell me about their father’s funeral. Albeit brief, what they share is not about the service at the church or gravesite, but rather the dining experience they shared with family and friends in private room at this very restaurant. The menu consisted of roast beef with potatoes, buns, and gravy. Dainties, another Saskatchewan classic, were served for dessert. The tables were set up so that they could have a long serving area like a “smorg” and “everyone could help themselves and have seconds if they wanted to”. I told them “that sounds delicious.” “Oh, it was! It was very good!” they reply. I imagine that this restaurant was a favorite of their father’s; perhaps a family favorite over the years.

I think about the time that I have spent with Doug and Don and I reflect on the amount of their sharing about their mother and father. I feel that the stories and experiences they have shared with me are a gift; they have invited me in to a very private and personal aspect of their lives. Rarely do I share my memories of people I have lost, the memories I have of my grandfather in particular. I think back to the last days of his life in December 2001 and January 2002…

"*Why the fuck would I want to go see my Grandpa today?"* I cry to Ian, with tears rolling down my face. "I just saw him last week and he wasn't good then... why would I want to see him laying motionless in a nursing home bed now?!"

In that moment, I can't believe how fast Grandpa went downhill after his lung cancer diagnosis. I was so angry with him a year ago for choosing not to get treatment; I wondered how he could make the choice to leave his family behind. Just 6 months ago, I remember calling him from the top of Big Mountain in Whitefish, Montana, to tell him that Ian and I did, indeed, get married.

"Well, congratulations! That's great! Did you have a good day?"

"I did, Grandpa! I'm sorry you couldn't be here. Uncle Ron took a lot of pictures and I can't wait for you to see them!"

"Me either, sweetheart! I sure love you!"

"I love you, too, Grandpa! See you next week!"

I assumed that he couldn't make the trip to Whitefish because it would be too long for him, not realizing that the 'fatigue' he complained about was the cancer sucking the life out of him.

Last week, December 25 [2001], I saw my grandfather for the last time. Ian and I had spent Christmas with my parents and we were on our way to Rockglen to have supper with his family. We stopped to see Grandpa on the way. As soon as I walked into my grandparents' small apartment in the care home, I realized something was terribly wrong. Grandpa wasn't sitting in his recliner; he wasn't the first thing I saw when I opened their door. Grandma told me, "He's in bed. Go ahead and see him..."

I slowly walked into their room and there he was, lying with his back towards the door. I said, "Hi, Grandpa" and he replied, "Hi, sweetheart... come lay with me. I'm tired today." I laid beside him and put my hands on his back. I was surprised at how prominent his ribs were through his t-shirt. It wasn't until that moment that I realized how sick, and how close to death, he really was.

Ian visited with Grandma in the living room while they watched television. His presence must have been a good distraction for her. For two hours, I laid with Grandpa. Much of my time with Grandpa was spent in a comfortable silence. Even though I knew this was likely the end... our last time together... there was a great sense of peace between us. I quietly cried behind him, carefully taking in breaths so as not to let him know what I was doing. Finally, it was time for Ian and I to go.

"I have to go, Grandpa. We need to get to Ian's before it's dark."

"How long is the drive?"

"About 4 hours..."

Silence.

"Well, you better go, sweetheart."

He rolled over; I could tell it took a great deal of energy for him to face me...

"I sure do love you. You're such a good granddaughter. You always told your Grandma and I how much you loved us. None of our other grandkids have ever told us that. But every time you see us ... or you talk to us... you always say, 'I love you'.

"I *do* love you, Grandpa."

"I want to tell you something else..."

"Yes...?" my lips were quivering... I didn't want him to see me cry.

He took my hand and squeezed it tight. "Ian's a good man."

"I know, Grandpa. I know how lucky I am."

He continued... "And you don't let anyone else tell you when you should have kids. You have them when you want to. You do what's important to you first."

"Ok, Grandpa." I was surprised by this advice. I wondered if he had regrets about having children early in his life. Perhaps it was his way of encouraging me to continue my schooling for I had just began working on my Master's at the University of Saskatchewan. No one else in my family had completed any university.

"You take care of yourself. I love you."

"I love you..."

And with that, I left the room. I gave Grandma a hug. I couldn't say goodbye. I didn't want Grandpa to hear me crying. I walked out the door and Ian said goodbye for both of us. We got into the truck and drove off. I cried the entire way to Rockglen, so sick to my stomach that I couldn't eat.

Grandpa died two weeks later. On the day that I couldn't bring myself to go visit him... the day I screamed at Ian that I 'didn't want to go'... the day before my grandfather's death, I sent a card with my aunt to give to him. In the card I told him how much I loved him, how courageous I thought he was, and how much he meant to me. On the day of the funeral, as he lay in the casket, the card was placed in his right hand. That was 11 years ago. Every day I take a moment to think of his face and try to remember the sound of his voice and how he would close his eyes and throw his head back when he would laugh. I'll always remember watching the Flintstones with him during noon hour lunches at their house, playing card games like 'Go Fish', and riding in the grain truck in the summer. I'll never forget the smell of that grain truck.

I'm no longer angry with him for 'choosing' to leave his family. In fact, I am at peace when I think about how he chose to live out the final weeks of his life. He once said, 'the treatment is worse that the disease'; it must have taken great courage for him to face death the way he did. I like to think that it was comforting for him to face death and to be able to say goodbye to those he loved in his own way.

At his funeral, my father and uncle chose to play Frank Sinatra's *My Way* during the service.

It is obvious that Doug and Don harbor pleasant memories of the final 'places' and 'coming together' of their family members. It is interesting to note that in the apparent absence of any consistently present support network, the two brothers have seemingly done well dealing with the loss of their parents. The literature suggests that when people labelled with intellectual disability experience grief, they are likely to experience other significant losses as well, including the loss of individuality and loss of 'capacity', especially when there are significant changes within the context in which they live (Dodd, Dowling, & Hollins, 2005). Those dealing with familial bereavement tend to be at greater risk for developing psychopathology (Dodd, Guerin, McEvoy, Buckley, Tyrrell, & Hillery, 2008). Read, Nte, Corcoran, & Stephens (2013) reported that the social context in which the death and the grieving takes place is of great importance to the bereavement process for people labelled with intellectual disabilities. The fellowship and coming-together of the community that Doug and Don were able to experience upon the death of each parent was seemingly beneficial, as they are able to comfortably and joyously share memories of that time with others.

'Downtown'

As I navigate the icy highway between White City and Regina, I reflect on the time I have spent with Doug and Don. It's been a busy few weeks and I have not been as diligent going to visit them at the senior centre in the mornings. They have my phone number, so I assume they will call when they need me. I was able to stop in at the centre this past Thursday morning to see them and make plans to meet for breakfast today. Once again, when I arrived at the senior centre on Thursday, they were waving through the window as I walked up to the entrance. They were quick to give me an update on what is happening in their lives. They "made borscht and three different kinds of salad" last Saturday; their brother "cancelled his trip to Mexico because he's having surgery"; and "the Cup of Diamonds floor curling tournament is on March 14th". Oh, and "Doug had a problem with his heart last week on Friday morning" so Don called 9-1-1.

"What?"

I did hear Doug correctly. He said he has been feeling dizzy lately and did not feel well last Friday. He told me that he "told Don to call the ambulance." Everything seemed to be ok, but he has an appointment in March to see his doctor. Don is going for a check-up, too. I'm so glad they have each other and can watch out for each other in times of need, but at some point, at their age, something's got to give. The real question is *when* – not will – but *when* will be the time when Don cannot help Doug? Or what if Don needs help and Doug is not strong enough or able to provide assistance? Although they know a lot of people, they really only have each other. What are the chances the guy they know from their bus route will be around to lend a helping hand?

I arrive downtown Regina in good time, despite the ice and snow. I am pleasantly surprised at the plethora of parking right outside of the mall doors, as Smitty's is just inside. I don't have too far to walk in this winter weather. The mall doors are open early, and I expect to see Doug and Don sitting on the benches outside of Smitty's as I walk in. They aren't there. The next logical place to look is inside the restaurant. I walk into Smitty's and catch Don's waving arm out of the corner of my eye. He is standing up in the back of the restaurant. I walk to the table and see the two men seated across from each other. I remember that this is the same booth we sat in during a lunch in November. I wonder if they ask to sit there, or do the servers just know to seat them there.... And if so, why? I don't believe they sit in the same booth every time by chance; there's at least 30 empty tables in here.

I feel it necessary to mention that I am on time. "I thought I was going to be late because the highway was icy coming in from White City, but I made it! I'm a minute early!" The time is 7:59 AM. There is no comment from either of them.

I sit in the booth, sandwiched between the wall and Don. Doug sits on the other side, directly across from his brother. He looks tired. His face is pale and lacks the bright-eyed and bushy-tailed-ness I see in Don's eyes, posture, and gait. I watch him as he talks; his words seem labored; his right eyelid tries to close at times, and he sighs.

They've already picked out what they want to order. After I peruse the menu, I decide on the same menu item they have both chosen, the 'Wake-Up Breakfast' comprised of 2 eggs, 2 slices of bacon, 2 sausages, 2 pancakes, and a small orange juice. It seems like a lot of food, but it's a good price. Doug and Don order a side of toast instead of pancakes, and two slices of tomato. We visit while we wait for our meals. We talk about the old days on the farm, the days spent at the woodshop, and the upcoming floor curling tournament. It's the usual conversation we have, but none of us seems to tire of it.

The food arrives, and Doug notices right away that there is no peanut butter for his toast. He asks, and the waitress runs to get two small packages. We eat in silence, but it is comfortable silence. Someone once told me that when you can sit comfortably with someone in silence, then that is an indication of a true friendship. I wonder if it is as comfortable for them as it is for me. I remember to ask, "Do you always sit here? In this booth?"

"Yep," says Don.

"Do you pick this booth or does the lady bring you here?" I ask.

"We like this booth. We can hang our coats up," replies Doug. I look behind him and I do see their jackets hung on the wall.

I only get through half of my meal and decide it is too much. Don has finished his meal completely. Doug is still eating. Don leaves the booth to go to the washroom and he has no sooner left the table and Doug says, "He eats so fast! He doesn't need to do that! I don't know why he does that! He should SLOW DOWN!" I am surprised at Doug's need to vent, but I like it. It seems to have brought some vigor to his existence. Don returns from the washroom, Doug finishes his meal, we pay the bill, and leave.

They invite me to walk with them through the mall so Don can say 'hi' to his girlfriend who works at a small footwear store. He tells me that he stops in everyday to see her. I've never been so curious about someone in my life as I am about this woman. Don is always talking about a girlfriend he has. Unfortunately, he tends to have his heart broken because the gal ends up "cheating" on him, or she "finds another job," or she "moves away". It's too bad, as Don is a generous and attentive companion as he often tells me how he showers his lady friends with frequent visits, cards, and gifts.

As we approach the store, my paradigmatic thinking has me assuming his girlfriend also has a disability; I think it's nice that she has a 'real job'. Literally a hole-in-the-wall, the small store can only house two or three customers at a time as boxes of inventory are stacked to the ceiling. I see a young woman in her mid-twenties standing behind a cluttered counter. Don leaves Doug and I standing outside the store as he quickly goes to greet the shopkeeper; he is smiling from ear to ear. Although she's already noticed him, he waves frantically as if he is trying to grab her attention. I have never seen him so excited. She smiles politely, and looks past Don's shoulder to see who is waiting for him outside the store. She says hello to Doug then looks at me and smiles awkwardly. I wonder if she is confused, surprised, unsure, perhaps shy. I smile, hoping to make both of us feel more comfortable. I'm immediately reminded to take note of my mannerisms to ensure I am not 'checking her out'… well, not obviously, anyway. Don tells her that we just had breakfast at Smitty's together. I feel the need to introduce myself; she does the same. '*Melissa*.' There is an awkward pause. I try to fill in the uncomfortable silence.

"So… Does Don come by and say hi often?"

"Oh yes," she says. "Everyday." She pauses. "How do you know Don and Doug?" she curiously asks.

"From the senior centre," I reply. "I've known them for a long time."

"And she used to live down the street from us!" Don says.

“Are you busy today?” I ask.

“It’s not too bad,” she replies.

Silence. We all just stand there looking at each other, expressionless. Except Don, he is still beaming from ear to ear.

“Well,” she begins, “I better get back to work. Thanks for stopping again… will I see you tomorrow?”

“Yep, I’ll be back,” Don says smiling, shaking his arms in excitement.

With that, we left the store. I consider how normal this interaction appeared to be for Doug and Don, and even for the ‘girlfriend’. I try to comprehend how one might negotiate the relationship with Don once one finds out that she ‘is the chosen one’. I want to ask so many questions… How did you meet? How long have you been ‘dating’? How did you decide that she is your girlfriend? Is she aware of this? I decide my questioning may spoil the moment.

As we continue our walk through the mall, many people say ‘hi’, wave, or smile and nod at the brothers. Many, *many* people. Then I notice that the same people give me a once-over look as if to say, ‘Who are *you* and what are you doing with *those guys*?!’ As people pass by, Doug and Don return the smile and say ‘Hi’. They sometimes stop to chat about the weather or talk about which brother paid for lunch on which day this week. There are a few businesses in the mall where the brothers stop to talk if they see a particular employee. It is interesting that these particular people, regardless of their age, seem to know a lot about Doug and Don. Things like where they worked, who their parents were, and that they curl at the senior centre. I am left to wonder how these people got to know the brothers and these details of their lives…

David

Coming to Know the Inquirer

David and I have a long and storied history together. I met David nearly 15 years ago when I was a Supportive Independent Living Program (SILP) Worker. SILP programs provide limited support to individuals living in their own apartments or rented homes so they can live as independently as possible. Some tasks of a SILP worker might include helping an individual budget, purchase, and transport groceries, pick up checks from The Department of Social Services, or even apply and advocate for specialized funding from social programs. In fact, I can remember working with a number of SILP 'clients' who received extra grocery money because they were on a 'special diet'. Typically, an individual would be allotted approximately $20 per week for groceries. However, upon receiving a doctor's note indicating the need for a 'special diet', individuals could receive an extra $10 per week from Social services. Although dependent on the physician, it was typically quite easy to get a doctor's note for the individual; I was advised by my mentors to indicate that 'So-and-So has difficulty going to the bathroom. I think if she/he could afford more fresh fruits and vegetables containing fiber, So-and-So might feel better. Could you write a prescription for that?' I never understood why the government would not just bump up the food allowance an extra $10 per week for everyone as the exorbitant amount of paperwork and human resources necessary to process such paperwork surely cost the government more in the long run.

The SILP program I worked in was housed in the basement of an agency called Residential Services whose main mandate was to provide respite care to individuals with disabilities. The Residential Services building, which looked like a typical bungalow from the outside, provided a temporary stay in a group home type environment for individuals if their family members were unable to provide care for them due to a vacation, a family event, or if they just needed a break. The home was able to provide respite for up to 8 individuals upstairs while the basement housed offices for the executive director, the administrative assistant, cubicles for the SILP workers, and a board room for meetings. Although I learned a great deal working in the context of the respite home for nearly three years, I was looking to gain more experience in an advocacy role supporting people in the community. I was excited to have the opportunity to move from the respite home where I provided front-line support to the SILP position where I would be spending time in the community learning new skills, connecting with other professionals, and working within the parameters of a flexible schedule. It helped that the pay was much higher, too. I recall the first day I entered the building *not* from the front door of the respite home, but rather from the back door to access the basement offices. I carried a binder-briefcase with me; a hard-shelled three-ring binder, which I carefully organized the night before with loose leaf, page separators, and pens and pencils. When I zipped the binder closed, two small handles allowed me to carry the binder like a briefcase. I thought the purchase was very clever as I could carry my filing cabinet with me throughout the day and make ‘client progress notes’ as I met with the individuals on my ‘caseload’. I was elated when the executive director commented that I looked “very professional” for she was someone I looked up to.

I had spoken with other SILP workers about the caseload I was taking over for Heather as she went on maternity leave. As we went through the list, David’s name came up.

“Oh, he’s a tough one”, someone said.

“Yea, he seems pretty nice, but he can be kind of gruff sometimes. And he stinks. He doesn’t wash his clothes very often.”

“If you have any trouble with him, let us know and we’ll talk to him” said Al, a SILP worker veteran. “Don’t let him push you around.” I was left wondering what to expect for my first meeting with David that week.

My co-workers told me that David lived in a basement apartment in a run-down building in the core of the city. I was instructed to stay in my government issued vehicle (another perk of working in the program) and honk the horn when I pulled up to the front door of his building. David would hear the horn and come out to meet me. As I pulled up to the building on a Wednesday afternoon, I looked towards the basement suites wondering which apartment was his. I hadn't even parked the car when I noticed a poorly hung and tattered blind swinging from side to side in a window. I honked the horn and anxiously waited, unsure of whom would walk out the front door of the building. Soon, I saw a small-framed man with a slight slouch in his back step out onto the front step. He wore a ball cap with lots of 'flare' (i.e., pins and buttons from a variety of sports teams, community based organizations, etc.), he had a scruffy beard and moustache, and his glasses looked to be too big for his small face. It didn't look like he weighed more than 100 pounds. He shuffled his feet slightly as he walked towards the car. He looked at me quickly then turned away, almost in a bashful manner. I made sure to smile with enthusiasm. He opened the door, sat down, and looked at me.

"You my new worker?"

"I sure am! Is that ok with you? My name is Brenda!" I replied with a smile.

"What are we doin' today?"

"What would you like to do? What do you *need* to do?" I asked.

"I need some groceries."

And with that, we drove away. That morning, the drive to Extra Foods was the beginning of my storied life with David. Over the years, David and I have learned many things about one and other and we have shared many experiences together.

Just as it is with Doug and Don, 'what David knew first' is important to him. He was born in Scotland and reports that he came over 'on the boat' when he was a baby; he feels a connection with his “hometown”, never shy to tell someone he is “a Scotty boy”. However, his most vivid memories and stories of place come from a different locale. On its website, *Moose Jaw*, a small prairie city just 70 kilometers west of Regina, invites visitors to experience the ‘surprisingly unexpected’ through sporting and cultural events, the mineral spa, walking trails, and ‘good old-fashioned friendliness’. However, Moose Jaw is also known for its history of warehousing many of Saskatchewan’s “less fortunate,” specifically those with “mental handicaps” (Wickham, 2012, p. 9). On the outskirts of Moose Jaw sits Valley View Centre, an institution which, at one time, housed over 1500 people despite its 1100 person capacity. Although developed out of Tommy Douglas’ desire to help those less fortunate, the Saskatchewan-based father of universal health care could not foresee the unfair, maltreatment of Saskatchewan’s most vulnerable citizens.

At one time, a younger David was a resident of Moose Jaw’s Valley View Centre. In the early days when I met David, his response to his time living in the institution was similar to Carl’s (whom I spoke of earlier): No one could even mention the name ‘Moose Jaw’ without him yelling out, “Don’t ever say the name of that place!” in an attempt to avoid any discussion of his time there. Nowadays, he is more tolerant; perhaps he is now able to make sense of his time there or he has chosen to forget – or forgive it – entirely. However, he is still not prepared to talk about his time in Valley View. Thus, I do not have the details of his early life in Saskatchewan. I do not know when he arrived at Valley View, what he did while he was there, or how old he was when he left. These are stories that David carries with him everyday, stories that he is not ready, willing, or able to share. David’s presence in my life often reminds me that the stories that are not told are just as important as the ones that are.

Taylor Field at Mosaic Stadium

I open the truck door and the burst of summer heat hits my face and pours out onto my bare legs and sandaled feet. I lay the backpack full of iced drinks in the cab of the truck, put the key in the ignition, and start the engine. I crank the air conditioning to its maximum and question my decision to place the backpack in the truck for now, as the ice in the drinks will melt fast and ultimately leave us with piss warm Gatorade. I leave the truck door wide open, thinking the AC will push the hot air outside. Not very 'green' of me I realize, but it's so stinking hot. I can't imagine sitting in that terrarium. I return to the house deciding to take the backpack with me hoping that the AC in the house will keep the drinks cool for a bit longer.

Ian is inside gathering the required items for the day. Seat cushions? Check. Sunflower seeds? Check. Sunglasses? Check. Jerseys? Check. It's game day at Mosaic Stadium, home of the Saskatchewan Roughriders. It's a beautiful prairie day. The weather is perfect; it's hot and the sky is clear. There's a light breeze that, with any luck, will caress us throughout the afternoon. I see that it's 12:25 pm. We need to be at the practice field by 1 pm and we still have to pick up David.

As I wander through the house checking to ensure we have all the game day items, I think back to the beginning of our time volunteering with the Rider organization. Several years ago, a Kinesiology student double majored in Adapted Physical Activity and Sport and Recreation Management. She was determined to do her fieldwork experience with the Roughriders. I recall helping her with the proposal required by the Fieldwork Coordinator, who wasn't convinced that she could meet the objectives of both 'disciplines' with a pro sports organization. He, a loyal follower of Therapeutic Recreation, saw her best fit to be with a government funded care home. Despite his prejudice, Karen convinced him that her fieldwork objectives could be met. Her plan was to have people with disabilities (and other economically disadvantaged community members) volunteer for odd jobs during pre-game activities in exchange for game-day tickets. She believed this would allow her to gain experience developing inclusive programs while gaining the public relations and marketing experience she also needed. Karen was successful and, for one summer, her program provided opportunities for several disadvantaged community members to regularly attend CFL games.

Karen's fieldwork placement turned into a permanent position with the team organization. Her program was successful for the three seasons she worked for the Riders. After she left for a different job in another community, we were concerned about our continued involvement with the team. Were we a package deal; if Karen left did that mean we had to leave, too? Thankfully, Karen insured we could stay involved when Kelly, a new employee of the Rider organization, took over the program. Karen left specific instructions for Kelly informing her that David, Ian, and myself were to continue to be involved with pre-game activities, regardless of the direction of the organization. Kelly agreed, despite the decision of the Rider organization to have Scotiabank employees and their families volunteer for all pre-game activities. David, Ian and I were the only 'community members' who kept our volunteer positions.

Ian and I finish loading the truck and jump in the cab to head for Regina. It's so hot, even with the AC on; we roll down the windows and quickly pull out of the driveway to get some air moving inside the cab. Once we hit the highway we roll up the windows and let the AC cool us down. There's a lot of traffic going into the city. Several vehicles have Saskatchewan Roughrider window flags flying and ... oh, shit.

“We forgot to put our flag on,” Ian says. “I don’t even think it’s in the truck. David will give us hell!” I agree; David *will* give us hell. I think about the Rider license plate we bought at last year’s end-of-season locker room sale that we still haven’t put on the front of the truck. We know it’s in the garage somewhere... but where? Every week David offers to come to our house to find that damn plate!

We drive through the city and it’s obvious it’s game day. Traffic is backed up on Victoria Avenue, Saskatchewan Drive, and on the Lewvan. There are Rider flags, car stickers, and game jerseys everywhere. It’s a bit ‘redneck’, I’d say, with giant flags on hockey sticks haphazardly fastened to truck tailgates and car bumpers. As we stop at red lights, I look at the faces of the people in the vehicles. From adults to infants, they’re all painted green. I wonder what visitors, just passing through the city, think when they see all this. Do they drive out of town as fast as they can or does it spark their curiosity to stay for a while? Regardless of how it looks, I thoroughly enjoy game day, regardless of my lack of knowledge of the sport. There’s something about 30,000 people coming together for a shared purpose that gives me goose bumps.

We’re lucky enough to hit most of the green lights as we come through the intersections. Turning the corner onto David’s street, we can already see him standing on the sidewalk. As we pull up beside him, he’s already talking, but of course we can’t hear him as the window is still rolled up; don’t want to risk letting out too much cool air. “What’s that you said?” I roll down the window as Ian thrusts the gear shift into park. I throw open my door.

“Where’s the flag? That one for the window,” David asks. He has this way about him that is gruff, but, at the same time, sweet and endearing. He’s dressed in his ‘uniform’; black dress pants, a green undershirt, a Roughrider windbreaker and his Rider ball cap.

“We forgot it, David. Sorry!”

“Next time bring it!” His words say, ‘That’s an order!’ but his tone says, ‘Just a suggestion.’

“Where are we meeting our boss today? What time?”

As usual, those are the two questions David always asks. Ian begins to drive away and, as usual, I say, “Just a minute, Ian” and remind David to put his seatbelt on.

"The usual today, David. We meet at the goal posts at 1 o'clock."

"What are we doing today?" David asks.

"Not sure. We'll have to see when we get there," I respond.

Thanks to David, we park in the 'Austin' lot, one of the most coveted parking lots at Mosaic Stadium. At the beginning of the season, he asked Kelly if we could have a parking pass close to the stadium so we wouldn't have to walk very far. It did not take much convincing, as David sometimes walks with a cane due to the break in his ankle he suffered a couple of years ago. Kelly *loves* David. If he asked for the moon I'm sure she'd find some way to give it to him.

We gather our items and navigate our way through the 'Sea of Green' towards the goalposts in the 'Family Fun Zone'. Ah, the 'Family Fun Zone. The paradise where parents happily unleash their kids so they can play the football toss game, get 'inked' with temporary tattoos, and recklessly wrestle in the dreaded Dino Bouncers. Of all the jobs we've had on the practice field, which has included everything from tattoo application to handing out cupcakes, the worst job is supervising the Dino Bouncers...

Described as 'room-sized, giant inflatable bouncers... a combination of a ride, game, playroom, and trampoline', they are a nightmare for volunteers. Please take a moment to imagine an inflatable room with trampolines for walls that is designed to see how high you can make yourself, and others, bounce into the air by using your body as projectile. It turns into a war of 'big beings' versus 'little beings' (of course the little beings never win). And the parents of all 'the beings' take the opportunity to get into the beer line while their children, regardless of age or size, eventually come tumbling out ass over teakettle with tears streaming down their faces. And now imagine being the person who is responsible for letting people in and out of this bone-busting vortex. I do my best to negotiate a balance between participants (i.e., no 13 year olds in the space with small 5 year olds) but in the end, it's uncontrollable. Of course Ian and David are there to help, but let's be honest, David isn't going to act as a disciplinarian, and Ian, a 12 year old trapped in a 40 year olds body, wants to run his own experiment to see how many kids we can fit into the Dino Bouncer at once, despite the rule of 8.

We see Kelly and, as always, she squeals, "David!" as we approach. I smile, all the while thinking, 'Dear God... *Please*. Not the Dino Bouncer.'

"There she is! There's my boss!" David says. He never uses her name. To David, she is "his boss". Sometimes we ask him, 'What's your boss's name?' but he can never answer that question without a prompt from one of us. I'm not sure if it's because he can't remember her name or if it's because he doesn't feel comfortable calling her by her name. Regardless, his "boss" greets him with a hug and it's always a good one because she *hugs like she means it*.

Now we wait to hear what our assignment is for the day. Please God, let it be a good one.

"Can you guys clean up the tables and chairs today? That's all I need you to do. Just stack them up so my guys can move them once everyone leaves."

Thank you, Jesus!

Kelly is so patient with David, sometimes more so than I am. I know she has a lot of work to do. She's in charge of everything that happens on the practice field. It's always busy and today will be even more crowded as thousands of fans will come early to enjoy a cold beer (or two) and take in the pre-game excitement. But David has so many newsy items to share with Kelly; he talks about his doctor's appointment, his leaky roof, the neighbor across the street he doesn't like, and the argument he got into with a fellow downtown last week. Kelly quietly listens, nodding and commenting where appropriate. She always takes the time to talk with David and engage with him in a way that is meaningful to him. Kelly's presence in my life reminds me to engage with people in a meaningful way.

Our work will not start until 30 minutes prior to game time; we have 90 minutes to kill. We wander around the practice field. We aren't allowed to have a beer while we're working, so we each have a cold pop. David likes Sprite. Often, when we're wandering the field, David gets distracted by all the fans and goings-on around him and he stops for a few seconds to take it all in. In those moments with him, I am reminded to embrace the moments that make up my life and appreciate the festivals and parades which surround me.

Church

It's 4 o'clock on a warm Wednesday afternoon in July and I've just picked David up from his house on York Street. We are heading to his church just a few blocks away. Today David is showing me around his church and helping to prepare the Wednesday supper that is offered prior to the church band sing-a-long. David is an usher on Sunday mornings at church and he has invited me to see where he works. As I understand, there are two Sunday morning services in the summer, 9 o'clock and 11 o'clock, and only one service in the fall, winter, and spring at 10 o'clock. Usually, David walks to church but if the weather is inclement the church minister will give him a ride.

We pull into the parking lot and David points to the area where I should park. He is sure to remind me that I cannot park where the minister parks. “Don’t park at that sign that says *he* can park there!” David says. “Don’t worry,” I reply, “I won’t!” From the outside, one can see that the parish is very large. As we walk through the front doors, we enter the foyer which has a cloak room off to the side. The wall in front of us has several mailboxes. This is the first stop on our tour; David walks me to the mailboxes to proudly show me his.

“Here’s my mailbox” he says, proudly pointing to the label affixed under the slot that holds his name.

“Very nice! Do you get mail everyday?” I ask.

“No. Just sometimes. Like the church newspaper or something like that. Let’s go.”

We continue past the mailboxes and he takes me in to the chapel. It is beautiful. Several tall stained glass windows catch my attention, and then I see the impressive altar up front on a large stage area. It is apparent that there is a sing-a-long tonight as there are several instruments on stage. David and I take a moment to talk about his role in the church and the significance of this place in his life. He sits in a pew at the back of the church and we talk…

Brenda: What a beautiful church, David.
David: This place is good for me. I like this church.

[I notice that all the books in the pews are spine-side down.]

Brenda: Tell me why the books have to be placed that way?

[David picks up a book, and places it page-side down.]

David: Every Sunday, everybody puts their books like this. Right? Theys don't know what they're doing. Right? You do it like this.

[He picks up the book to reposition it, throwing it back into the shelf spine-side down. It makes me laugh as I note that his meticulous attention to detail regarding book placement is more important than how one treats the books! Regardless, he tells me that placing the books in their proper positions is important and is one of his jobs at church. "We do that. We start at the front and go all the way to the back… after the service."]

Brenda: Are you more busy in the winter or the summer?
David: We're busy every winter and summer…
Brenda: Cause, is there always two services?
David: We only have one service. A 10 o'clock service.
Brenda: Every year? All year?
David: No, no. Winter time we have two services, summertime

we only have one service. At 10 o'clock. I have to get there by 9:30. I get the bulletin board and put it [at the front door] and my boss puts the names on that [pointing to the hymn board]. And on Wednesday's we have a band here. And Sundays. This is a good church.

Brenda: And you said someone gives you a ride here in the winter time?

David: Yeah. [Looking off in the distance, he says, under his breath] What's that guy's name? [Looking at the floor.] He was a firefighter. *Wayne!* Wayne is my boss. He phones me in the winter times and gives me a ride. I know his mother.

Brenda: Oh! You know his mother?

David: He phones me. He goes to my house. He picks me up and goes to church with me. I can't walk all the way here to church in the winter time.

Brenda: Well it's a good walk in the summer but not a nice walk in the winter I guess.

David: Not in the winter.

[Visiting with David in the chapel, I notice that his usual gruffness is gone from his voice. He has become soft-spoken... respectfully quiet... and I struggle to hear his words. This church is important to him, and so is the congregation that he assists every week. I decide to ask him about Joe, his neighbor and friend who lived across the street from him. They met at church...]

Brenda: So I have a question for you. Is Joe's funeral going to be here?

David: Who?

Brenda: Joe's. Is Joe's funeral going to be here?

David: Who...Joe?

Brenda: Yeah.

David: No... Joe's gonna be... We'll have his funeral on the 12th.

[Silence. David looks towards the altar.]

David: At 1 o'clock, Joe's gonna be right there [pointing at the altar].

Brenda: Oh, okay.

David: His ashes are going to be up there.

Brenda: So will you help with that? Will you be an usher?

David: No. I'll be there. I'll be going to the funeral. And after the funeral's over we're gonna have lunch after... up the stairs.

Brenda: And what will you wear? You were telling me last week what you were going to wear...

David: Clean clothes. Clean clothes for Joe.

Brenda: Ah.... clean clothes.

[David stands up. That is my cue to move on from our conversation.]

As I think about David's connection to Joe, I note the significance of David's comment about 'wearing clean clothes' to see Joe for the last time. I think about all those times that I used to pick David up when I was his SILP worker – and all those times when his previous SILP workers would pick him up to run weekly errands – and how it was such a big deal to them/me that he 'smelled good' and 'looked clean'. Perhaps we were not such a big deal to him… not important enough nor significant enough in his life for him to bother with 'clean clothes'. Perhaps David perceived himself to be walking in our parade, rather than us walking in his. Truthfully, that's how it would have been arranged. As a SILP worker, the professional knowledge/sacred stories that I carried with me told me that David had to live up to my expectations; that he had to follow the rules of my parade in order to be with me. There was no expectation for me to follow his rules in his parade. Now, as I reflect on that time, I realize what a gift it is that David has invited me to walk in his parade today and for the past number of years. I'm left to wonder 'when was the moment that the leader of the parade switched'?

The Move to 'Drugstore Street'

The years that I supported David in the SILP program, he lived in the run-down apartment building on 10th avenue. I never felt safe waiting in my car for him, so I always wondered how he felt safe walking through the neighborhood, across busy Lewvan Drive, to attend Pats hockey games during the winter. Maybe he didn't feel safe but loved sport so much that he couldn't stay away from 'The 'Dome' when the Pats were on the ice. During my time supporting him, it seemed as though we were always in search of a new apartment for him. Unfortunately, as soon as a building manager found out that the rent payment would come from the Department of Social Services, they mysteriously remembered that they had already promised the room or apartment to someone else. I was never able to succeed in finding him a new place to live. A handful of years after I left the SILP program and my role in David's life focused on friendship rather than 'service', he moved into a rental house on York Street. Although it was run-down as well, the street was lined with families, all of them low-income, who worked hard to ensure the streets were safe for their children to play. David became friends with the family who lived next door to him. Often when I would stop by to pick David up he was stepping over toys and bicycles that the neighbor children had left in his yard... and on his step... and in his porch. He didn't seem to mind being surrounded by the youthful energy.

One afternoon, I received a call from David, frantic about something 'happening to his house'…

"Hello?"

"Brenda, I don't know what to do!"

"About what, David?"

"That sign they put up. He told me people are gonna come and see my house!"

"What sign? Who put it up?"

"Oh, Brenda, what am I gonna do?"

“Did you talk to your worker, David? Does your worker know? Do you need me to come over?”

“He told me I gotta go somewhere else! I don’t know those new people!”

“Who told you that you have to go somewhere else? What people?”

“That sign... it says... *FOR SALE*!”

“What?! Call your worker and Ian and I will come over later. We have to come in to get groceries so we’ll come to your place first. We’ll be there around 5 o’clock. That’s in an hour and a half. Is that ok?”

“Hurry!”

And with that, he hung up the phone.

Ian and I arrived just before 5 o’clock, and sure enough, there was a ‘For Sale’ sign on David’s lawn. And there was David standing on the sidewalk waiting for us. As we drove up, he waved frantically and pointed at the sign. I thought about the challenges I had faced years ago when trying to find him a new place to live; I knew this place wasn’t easy to come by either. Regardless, he had told me that in recent weeks his worker had mentioned something to him about moving out of his current home. Although he didn’t spend much time upstairs in the traditional one half story house, he did have to walk up the stairs into his porch and walk downstairs to the dingy basement to do his laundry. (The ‘half-story’, the upstairs space designed as a loft with no attic, only housed a small table with an unfinished jigsaw puzzle.) The advice to move was understandable, as David was instructed to walk with a cane in the months following his accident. He was still recovering from last winter’s fall on the ice.

Ian barely had the truck in park and David was opening up the passenger door to talk to me.

"It's okay, Brenda. I talked to my worker and she said we'll find somewhere for me to live." I was relieved to hear how calm he was.

"Good! Well, it looks like you're moving! When do you get to go house shopping?"

"Did you see the sign? It says, 'For Sale'."

"I see that! When are you moving?"

"My worker says as soon as we find something. We'll go looking this week."

Finally, David stepped away from the door so I could get out of the truck. He invited both Ian and I inside so he could show us "everything that has to be packed." He pointed out the Regina Pats paraphernalia on the walls and on shelves, his Saskatchewan Roughrider player pennants, and photos of his family. He also showed me the funeral card from Joe's service that he attended just a few weeks earlier.

"Joe's wife doesn't know I'm moving. She's in the hospital."

Joe and his wife lived across the street from David. About a year ago, once he learned that they lived just across the way, he began having short visits with them, noting their departure and arrivals from their home so he could help them with groceries and the like. He took great pride in helping his neighbors. I think this is also why he didn't mind the neighborhood children leaving their belongings on his doorstep as he often commented that he was "watching their stuff".

After a short visit, Ian and I left. Later that week, David called me again, but this time with exuberance.

"Guess what! I'm moving!"

"Really? Did you find a new house?" I asked.

"Yeah, we went and saw this place and it's nice! The bus stops right out front. And there's new carpet. And I'm way up high and I can see the Roughriders! An apartment!"

"You sound excited! Where is it?"

"It's close to that drugstore! That drugstore street!"

"Which drugstore? Do you know the street?" I tried to recall the drugstores in the city and which ones were closely situated to residential areas, specifically apartment buildings.

"I have the address. *The drugstore street!* I'll show you when you come for football on Saturday!"

The following Saturday, we picked David up for football a half hour early so we could drive by his new place. As usual, he was waiting for us outside of his house when we turned the corner onto York Street. As we approached, I could see he had a piece of paper in his hand. When we pulled up, I rolled down the window to greet him. Before I could even open my mouth, he handed me the piece of paper through the window.

"There's my address," he said as he climbed into the backseat of the truck.

"It's on Lorne Street," I read. "Now I know which drugstore you're talking about!"

Lorne Street. I knew the location, just north of College Avenue. But I couldn't recall the housing on the street. As we turned north onto Lorne, David excitedly said, "There it is! It's my new house!" He leaned forward from the back seat with his arm stretched out pointing at the large building just down the street. His fingers were nearly touching the windshield.

We pulled up to a large apartment building. "There's my neighbors!" David said, referring to the people sitting on the benches out front.

"Do you know them?" I asked.

"Nope. But they live there, too. I'm scared… I don't know them people…"

"It looks like a big building! You're going to have lots of neighbors... and lots of new friends I think!" The apartment building provided affordable housing for older adults. It was perfect for David.

We sat out front for a few minutes in the truck just 'watching'. We watched residents come and go from the building, we watched guests wait to be buzzed in through the security door, we saw others get on and off the bus. All the while, David was commenting, "I don't know that guy… Who is that lady?" I tried to reassure him that he would get to know them, but it would take time. David told us he would be moving in at the end of the month which, at the time, was less than two weeks away.

Over the coming days, I stopped in at David's a couple of times to see how the packing was going on York Street. He packed two or three boxes a day, but explained that many of his possessions were going to be thrown in the trash. I was not surprised to hear him say that and honestly I was glad to hear it. Everything he owned was second-hand and was moved from the filth of the 10th Avenue apartment he lived in when we first met into the old, mildew-scented wartime home on York Street. 'It's about time he got *something new*,' I thought.

Moving day came quickly. Ian and I were away on vacation and we could not be with David to see his new home on the day of possession. Once we returned, we made sure to call him to arrange a time to come and visit. On that day, when we parked out front of his building, we could see him watching for us from the large foyer windows. He proudly greeted us at the front door where he showed us the button we need to press to be 'buzzed' into the building. He toured us around the foyer which housed game tables, bookshelves full of donated books, and two large tables that were set up for people to work on jigsaw puzzles. When we approached the elevator, he told us about how he has to use his credit card style 'key' to access the elevator floors. He swiped his card and pushed '6'. When the elevator door opened, we turned right out of the door and began our walk down the long hallway. His apartment was at the end of the hall. Once again, he swiped his key in the door, and invited us in. When the door swung open, I nearly burst into tears.

I had never, ever seen David's home so clean. The beige carpet was... well... beige! The windows were large and full of sunshine. Ah, the furniture! He had *new furniture*! And wait... the smell... there *was no smell*! The kitchen counters were clean and free of clutter, the bathroom was fresh, and his bedroom was bright and tidy. David showed us everything, from the closets to the light switches, with great, great pride. I was so happy for him. I could not imagine his excitement... a beautiful new home that was safe and clean.

Over the next few weeks, I began to learn just how beneficial the move was for David's well-being. He was able to spend time with other people without leaving the comforts of his building which meant he now had choices about with whom and when to visit; he began "working" (i.e., volunteering) in the small tenant-run store in the foyer, and he developed new skills as he learned how to take the elevator from floor to floor so he could access his storage locker or do his laundry in the basement. He also began to feel a lot safer reporting that he was "now sleeping at night" because he knew someone would come check on him if he failed to put out his 'I'm O.K.' door hangar on his doorknob every morning. But perhaps the most outstanding thing to happen to David occurred on a Tuesday afternoon in the laundry room. Below is my recounting of the experience, as David shared it with me:

[Ring! Ring! Ring! My cell phone rings. I see that it is David calling.]

Brenda: Hi, David! How are you?

David: Ooh.. ooh [sounds like he is crying.].

Brenda: Are you okay?

David: Oh, Brenda! Guess what happened to me?

Brenda: I don't know, David. Can you tell me? Are you okay?

David: [Sniffling into the phone.]

Brenda: What's wrong? Are you happy or sad?

David: I'm happy! I'm happy, that's all!

Brenda: Well what's made you so happy that you're crying? Can you tell me about it?

David: I went downstairs to do my laundry... [sniffling]... and someone was putting their clothes in that big dryer there.... [sniffling]....

Brenda: And...?

David: And this girl... she's old now... this girl turned around and looked at me!

Brenda: And...?

David: She says, "Hi, David!"

Brenda: Was she someone that you met since you moved in there?

David: No... but I knew that girl! I said, 'David, you know that girl!' And guess who she was?

Brenda: I don't know... someone you used to work with?

David: Nope! Someone else! Guess who!

Brenda: I don't know... Just tell me! I'm too excited!

David: *My sister*! My sister lives in that building with me! On number twelve! I'm on number six and she's on number twelve! We're close!

Brenda: *WHAT?!? Your sister*???

David: Yeah, my sister! She's old now!

Brenda: When was the last time you saw her?

David: She was younger. I used to see her downtown sometimes. Her and my nephew. Now I can see him, too! My family is here!

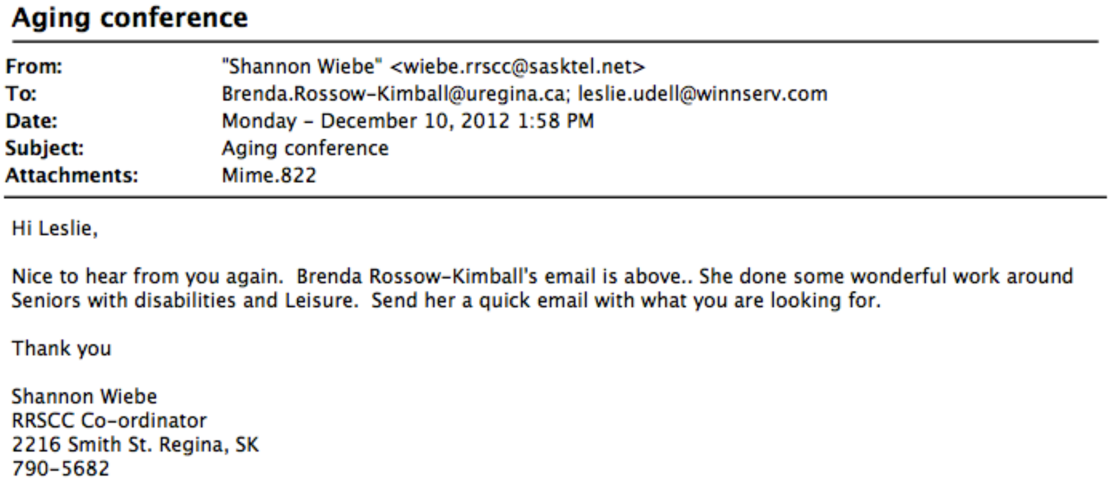
Now, in that moment, I was not sure if I should be happy, angry or sad for David. In all my years working with him and being his friend, he only spoke of his sister a handful of times. In fact, the last time he spoke about her was years ago. At the time, she was fuming mad at him because he did not show up at her house for Christmas dinner as he usually did. Apparently, they used to see each other every Christmas Day. She would call him Christmas morning to tell him what time her husband would be coming by to pick him up and drive him to their home for turkey dinner. Well, one Christmas a few years ago, David was invited to spend Christmas Eve and Christmas Day with his SILP worker's family. When he was not home Christmas morning to answer the once-a-year telephone call from his sister, she became very, very concerned. When her husband drove over to David's house to check on him, they called the police once they realized he was not there. A search began for David, one which garnered much attention when his family claimed they had not heard from him for a year. When David's SILP worker learned about the search through local media, she contacted the police and David's family to let them know that he was alright. Regardless of the miscommunication, David’s sister told him that he was no longer welcome at their house for Christmas dinner. He had not been to her home since.

But, despite the ‘Christmas incident’, apparently time healed the wound his sister felt she incurred. Now David’s attendance at Christmas dinner would be much more convenient.

Chapter 7

[My Own] Coming of Age

Email received December 10, 2012 (via cc) from Shannon Wiebe in Regina:



Aging conference

From: "Shannon Wiebe" <wiebe.rrscc@sasktel.net>
To: Brenda.Rossow-Kimball@uregina.ca; leslie.udell@winnserv.com
Date: Monday - December 10, 2012 1:58 PM
Subject: Aging conference
Attachments: Mime.822

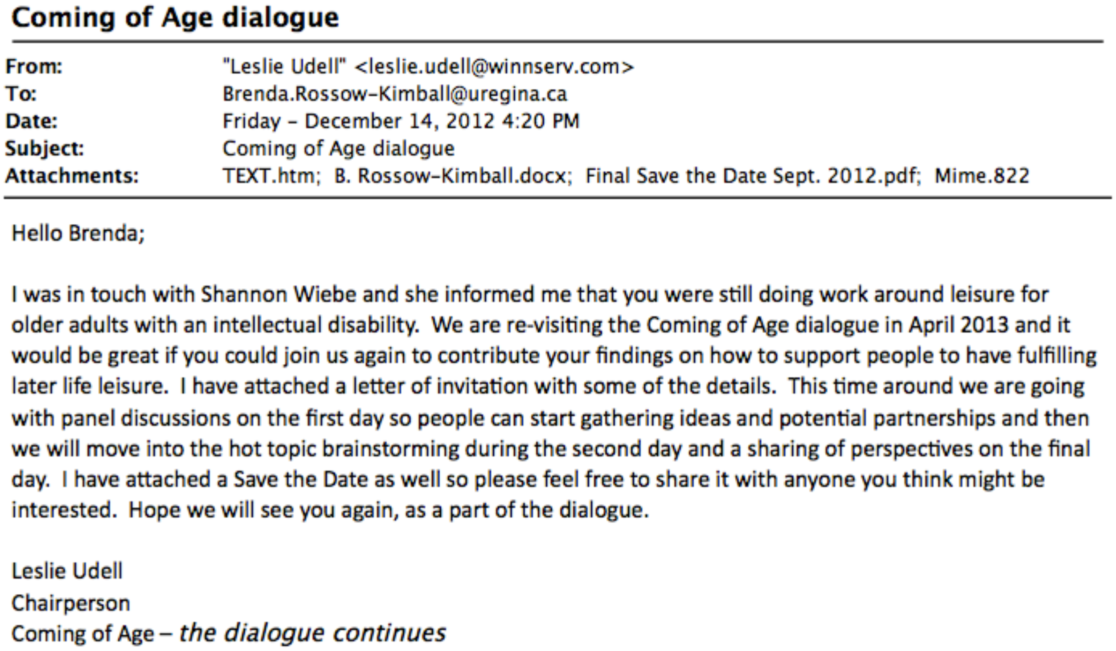
Hi Leslie,

Nice to hear from you again. Brenda Rossow-Kimball's email is above.. She done some wonderful work around Seniors with disabilities and Leisure. Send her a quick email with what you are looking for.

Thank you

Shannon Wiebe
RRSCC Co-ordinator
2216 Smith St. Regina, SK
790-5682

Email received December 14, 2012 (direct) from Leslie Udell in Winnipeg:



Coming of Age dialogue

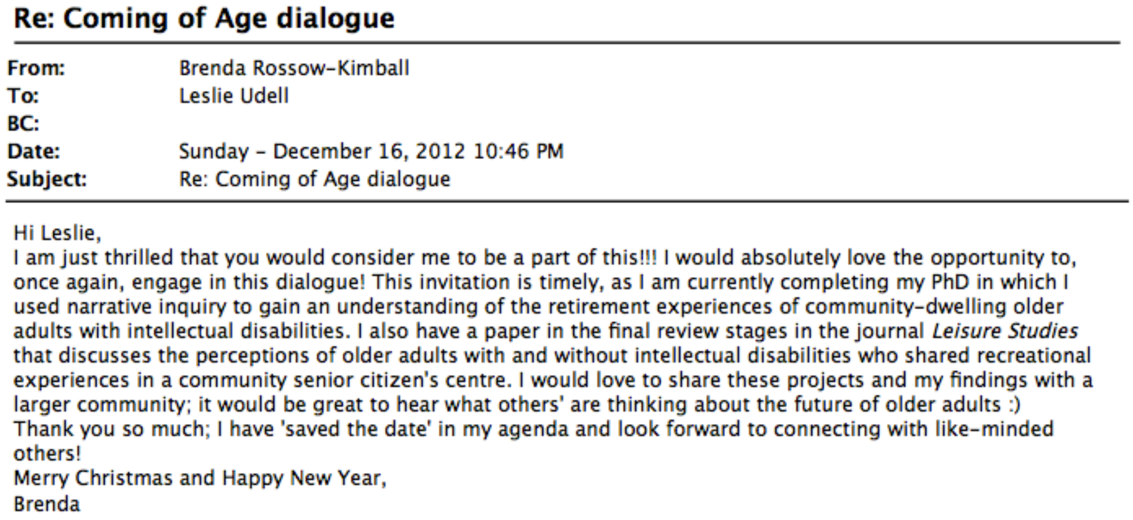
From: "Leslie Udell" <leslie.udell@winnserv.com>
To: Brenda.Rossow-Kimball@uregina.ca
Date: Friday - December 14, 2012 4:20 PM
Subject: Coming of Age dialogue
Attachments: TEXT.htm; B. Rossow-Kimball.docx; Final Save the Date Sept. 2012.pdf; Mime.822

Hello Brenda;

I was in touch with Shannon Wiebe and she informed me that you were still doing work around leisure for older adults with an intellectual disability. We are re-visiting the Coming of Age dialogue in April 2013 and it would be great if you could join us again to contribute your findings on how to support people to have fulfilling later life leisure. I have attached a letter of invitation with some of the details. This time around we are going with panel discussions on the first day so people can start gathering ideas and potential partnerships and then we will move into the hot topic brainstorming during the second day and a sharing of perspectives on the final day. I have attached a Save the Date as well so please feel free to share it with anyone you think might be interested. Hope we will see you again, as a part of the dialogue.

Leslie Udell
Chairperson
Coming of Age – *the dialogue continues*

Response from me December 16, 2012 to Leslie Udell in Winnipeg:



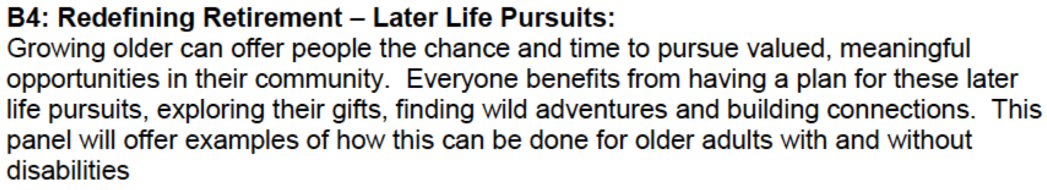
Re: Coming of Age dialogue

From: Brenda Rossow-Kimball
To: Leslie Udell
BC:
Date: Sunday - December 16, 2012 10:46 PM
Subject: Re: Coming of Age dialogue

Hi Leslie,
I am just thrilled that you would consider me to be a part of this!!! I would absolutely love the opportunity to, once again, engage in this dialogue! This invitation is timely, as I am currently completing my PhD in which I used narrative inquiry to gain an understanding of the retirement experiences of community-dwelling older adults with intellectual disabilities. I also have a paper in the final review stages in the journal *Leisure Studies* that discusses the perceptions of older adults with and without intellectual disabilities who shared recreational experiences in a community senior citizen's centre. I would love to share these projects and my findings with a larger community; it would be great to hear what others' are thinking about the future of older adults :)
Thank you so much; I have 'saved the date' in my agenda and look forward to connecting with like-minded others!
Merry Christmas and Happy New Year,
Brenda

I was thrilled to receive an invitation to participate in this event! In 2004 at the initial 'Coming of Age' Dialogue (and the only one until now), David and I traveled to Winnipeg to talk about the new and exciting program called Retirement for All that was just beginning in Regina. Nine years ago we spoke with excitement about the potential of fostering new relationships with community partners and providing new opportunities for older adults labelled with intellectual disabilities in the city. At that time, we were incredibly hopeful.

When the chair of the conference sent me the final description of my session it read:



B4: Redefining Retirement – Later Life Pursuits:
Growing older can offer people the chance and time to pursue valued, meaningful opportunities in their community. Everyone benefits from having a plan for these later life pursuits, exploring their gifts, finding wild adventures and building connections. This panel will offer examples of how this can be done for older adults with and without disabilities

I was advised to 'just come and talk' as it was hoped that, just as the conference title suggested, a dialogue would emerge as I shared the storied history of the Retirement for All Program. I felt confident that I would be able to ‘just talk’ about the program as I have been involved with it for such a long time. It was also beneficial that the paper my advisor and I had been working on over the past couple of years had just been published. I made several copies and took them along with me to hand out at my session in case anyone should anyone be interested in learning more.

The first day of the conference included a panel session in which self-advocates spoke about their experiences of work and transitioning into retirement. As I listened, I took notes of the significant things that they had said. During lunch, as I prepared for my session at 1:15 p.m., I made a list of talking points:

Who am I
10 years ago – Retirement for All
Now – Retirement for All
Project – CCDS – what are the experiences like for people in this program?
  - *mainstream older adults*
  - *SR participants*
  - *Staff*

How program has changed; what’s the same
What’s next
  - *why don’t some access program*
  - *now able to exercise autonomy, self-det*
  - *‘broke the mold of the day program’*
  - *segregated or inclusive program? Choice is important*
  - *Gladys and Jane say that what is important is right place and the right people*
  - *Gord says confidence to make decisions is most important; has changed his life*

I included take-home messages that I had heard earlier in the day from other speakers. Jane, speaking on behalf of her non-verbal sister Gladys, talked about Gladys’ transition from a day program into retirement. Jane believed that a successful retirement experience for Gladys was dependent on spending leisure and recreational time in “the right place with the right people" (for example, Gladys was able to spend time at the mall with support workers who enjoyed shopping with her). Gord had worked in a sheltered workshop for years and spoke of the confidence he had gained in his ability to learn new skills due to new found opportunities to make his own choices for leisure and recreation since leaving work. I thought I might be able to incorporate these two points into my presentation.

For my own benefit, I thought it would be a good idea to clearly lay out what has changed about the Retirement for All Program over the past years and what had not. I made more notes:

What has changed

- *Executive director; 3 different ones; changes culture of centre*
- *# of participants increased*
- *program coordinator (changed 4 times)*
- *membership at senior centre; decreasing, not getting younger*
- *what we contribute to the centre – depends what they let us contribute (contribute $ towards activities but won't let us develop new inclusive ones)*
- *who attends the SR prgm; not who it was initially designed for*

What hasn't changed

- *caregiver involvement (still no one volunteers or helps out)*
- *funding (still applying for same seed funding year after year; only $10,000/year*
- *activities (what we can access; still only dances and floor curling)*
- *locality and proximity in the centre – still sitting in the corner away from general membership*
- *culture of the centre – still not inclusive*

I walked into my assigned session room at 12:50 p.m. I wanted to get there early to make sure I was comfortable and prepared for my presentation. Just after 1 p.m. people started to make their way into the room and by 1:15 p.m. there were about 30 people sitting in their chairs waiting for me to begin. Once I got the nod from a conference volunteer, I introduced myself to the group and began my presentation. I provided a history of the Retirement for All program and spoke of my varying roles as a program coordinator, committee member, and researcher. I spoke of the research project that was conducted and its findings. Finally, to summarize, I looked at my list of what-has-and-hasn't changed and shared my thoughts on the future of the program. I indicated that I was not sure how much, or if, my presentation would change if I were to come and speak 10 years from now. I indicated that I could not assume that program participants would be more included at the centre, especially since the centre membership itself did not demonstrate diversity. In fact, I specifically pointed out that there are no Aboriginal older adults or other people of visible minority who attend activities and events. I even went so far to suggest that the concept of a traditional senior centre may not exist in the future, as younger retirees seem to be bypassing the senior centre experience for more exciting and diverse opportunities. I made sure to incorporate the points that Gladys, Jane, and Gord had made earlier, all of whom were in attendance at my session, and reiterated that it takes "the right people in the right place" to create a satisfying retirement and the "confidence to be able to make choices" and embark on new adventures.

"What's interesting," I added, "is that the fellows we designed this program for don't access the program to its fullest. In fact, they have significantly decreased their participation over the years." Of course, I was thinking specifically about Doug, Don, and David.

"Well... what're they doing?" an attendee asked.

"Spending time in their community. They always seem to be out and about doing something."

"Do you feel that you have had many successes in the program since it began?" someone else asked.

I thought for a moment. I looked down at the piece of paper in front of me and skimmed the notes I had made earlier. I looked at the column of 'what has changed' and then at the column of 'what hasn't'. A wave of frustration came over me as I realized that when David and I spoke nearly 10 years ago, we presented the same challenges yet felt great pride and hope when sharing our successes in the program. The only difference from that moment to the current one I was experiencing was that I realized I did not feel pride and hope. In fact, I was not feeling very proud at all because I felt that somehow we had let the participants down, let the centre down, let the membership of the centre down because things had not improved in the program or the centre itself. In that moment, it really bothered me to think that we have to sit across the auditorium out of contact with the general membership at the centre, that we have to get our coffee before the 'official' coffee break and miss some of the dance because we 'take up too much time dilly dallying around with the cream and sugar', and how the participants who have been there for a number of years still do not have friends outside of our program group. In the midst of the tensions I was secretly unpacking inside my head, I responded, "No, I don't think I can say we've had much success." My heart sank as soon as the words left my mouth. I felt sick to my stomach… embarrassed and frustrated. Truthfully, I couldn't tell if I was frustrated and embarrassed for the program or *myself*. My sacred story of professional knowledge should have told them that 'we're doing a great job'. Unfortunately, it was my secret story of practical knowledge that poured out of me as I told them it wasn't going very well. I wished I had a cover story that would have 'fit' on the professional knowledge landscape, a story that would have saved my ass!

At that point, a young woman, about the age of 20, slowly raised her hand.

"Hi!" I said, acknowledging her with a smile, hopeful that I was not wearing my current emotions on my face.

"Well... I don't know if you've thought about this..." she quietly began, "But maybe those three gentlemen you spoke of... the ones who don't come to the centre as much anymore... maybe they *are* the successes."

Before I could respond or even contemplate what she had suggested, someone else asked, “What do you mean?”

“Well,” she continued, “maybe the program gave them the confidence to try new things in their community. Maybe the program is another piece of their transition to retirement. If they’re not taking part in the program, maybe it’s not because they don’t want to, but because they *don’t need to*. Your program helped them to succeed.” I took a moment to pause and think about what she had just said.

“You know what... you could be right,” I said. “Thank you for pointing that out. I never really thought about it like that.”

Chapter 8

[Trying to] Making Meaning of Stories

There have been several times over the past few months since my daughter has been born that I have intended to come in to my office for the day and write. In my mind, I believe that it is possible to pick up where I left off days... weeks.... months ago... and just jump back into the 'unpacking', the reflecting, the writing, etcetera. Yet, the few times I have made it to the quiet solace of my office have been seemingly unproductive. And today, December 28 2012, I sit in my office in the vast silence of the building, and I experience the same issue. I peruse the notes that I have made over the past months during the visits with my inquirers, and the thinking I have done around their/our stories and I see at one point I made the following notes regarding Doug and Don:

Place	Personal/Social	Temporal
Cemetery	Family	Remembering life with; now without
Farm	Family	Working; youth
Smitty's; the mall	Connect w community	Retirement; girlfriends
senior centre curling	"boss"; their peers	Work; structure
Home? House?	Connecting w mom	Time w parents
Buffalo Days; Farm Progress Show	Connect w farmers	Time back on farm
Southey Restaurant	Father & mother	Funeral; time of loss
Downtown	Connect w community, family	

- replaced workplace c senior centre work (tension?); created place of work

At the bottom of the page is a green sticky note on which I have written the following:

1) list stories
2) unpack stories (write them down)
3) make sense of stories (weave together)

It seems simple enough; if one follows the above recipe for narrative inquiry research, one must surely experience success! But why then am I having so much difficulty with this exercise in writing?!?! I flip to the other side of the page and I see several notes I have written about the process, the methodology, the tenets of narrative inquiry:

- tensions; bumping up against grand narrative
- meaning of lives
- my idea of retirement; their idea of retirement; shifting story of retirement; make sense of my meaning making
- how/do I shape their retirement (professional knowledge and practical knowledge)
- NI is methodology; not method – we think with stories
- think with stories; don't analyze stories
- narr [narrative] works on us; don't think of narrative as working with/analyzing stories as this objectifies
- engage with people in relational ways
- relational is key
- difficult to pick up methodology – you can't just step into narrative; you live stories; you don't fall asleep. It's exhausting to always live this way but this is how we are

Finally, at the very bottom of the page, many lines below the rest of the notes, I wrote:

- ~~deconstruction~~ 'unpack' stories

Perhaps this was my way to remind myself to simply tell the story, rather than to disassemble it or take it apart; a reminder to not objectify the experiences of others. I'm not sure. I'm reminded that I frequently find it difficult to explain to others just what narrative inquiry is. When asked, I often say that it's about understanding how peoples' lives fit together and how our presence and the presence of others can shape how we perceive the experiences from our past, our present, and our future. It's about 'waking up' or recognizing that we share our lives and stories with others. I am always sure to say, however, that 'narrative inquiry is more than just telling stories...' As I read the notes I've made, I realize that it's difficult to explain a phenomenon that one lives, just as it is difficult to explain 'who' one is or perhaps 'why' one is. Thus, there is no recipe for narrative inquiry, for one must *live it* and *write as one lives*.

I see more notes:

- engage with people in relational ways
- relational is key

These two points help me think about why I am unpacking stories or perhaps tell me what to do with them. It helps me to realize that Doug and Don live their stories in relational ways, just as I do. Talking about the farm and sharing stories of their time spent there helps them to, literally, go back to the land. I am honored that they allowed me to walk alongside them on that journey. I know that they look forward to attending events in the community such as the Farm Progress Show every summer and Agribition in the fall; it allows them to reconnect with the farming community and recall their own experiences on the farm. They are able to relive their stories with others who have an appreciation for their experiences. Having dinner at the Homesteader Restaurant helps them to reconnect with their roots and remember the small community who supported them during a time of grief and sorrow. Spending time at the senior centre and "working for their boss" every Tuesday and Thursday morning to set up floor curling helps them to re-establish purposeful and meaningful activities within a new group of peers. Finally, their time spent downtown visiting with others may replace the network they lost once they retired from the workshop.

More notes:

- Perhaps I can't relate to everything...?

I think of my own experiences and stories and whom I select to walk alongside me in the parade. I am quite particular about who I let into my life and with whom I share my stories. It's quite simple really… it's because I don't want everyone to be a part of everything I do and live. (This is the reason why I have never joined Facebook!) I think about the people I invite into my parade and I realize that Doug and Don are particular about their parade, too, as I have been honored to walk alongside them in a few aspects of their lives. I am welcome with them anywhere in the community but they have chosen to keep me outside of their home and that is something I need to accept. I am not quite certain if it is my positioning as a friend or my positioning as an advocate that is most bothered by the lack of invitation into their home. Regardless, it is my duty to respect their wishes.

Finally, as I continue to think about my writing, I return to my Bible, *Narrative Inquiry: Experience and Story in Qualitative Research* and I read and reread the text and read and reread my pencil marks in the margins, all the while trying to keep this precious book together in my hands as it's literally falling apart at the seams. I am reminded that narrative inquirers "make themselves as aware as possible of the many, layered, narratives at work in their inquiry space. They imagine narrative intersections, and they anticipate possible narrative threads emerging" (Clandinin & Connelly, 2000, p. 70). As I flip through the book for more guiding nuggets, I find a piece of paper tucked in the pages that reads:

What similarities are there?
What resonates across stories?
What tensions do they share?

This is helpful.

Similarities, Resonations, Tensions

As I continue to think and try to make sense of what it all means… to understand how my positioning may have shifted… to become awakened to new possibilities…. I imagine my hypothetical positioning as a social worker in the Community Living Service Division of Social Services. I imagine I am tasked with finding supports for older adults labelled with intellectual disabilities. To do this, I think specifically about my inquirers. My first question would likely be "Do they meet our mandate?" (i.e., is their IQ below 75?). If they do not meet our mandate, I am able to simply wash my hands of them and assume that some other entity in the system will take care of them. If the gentlemen do meet our mandate, my second question would likely be, "Who are these guys? Whose caseload are they on?"

I suppose on paper, I might assume that these three gentlemen would require similar needs as they have had similar experiences over the majority of their lives. They each spent over 30 years working at Saskatchewan Abilities Council, they are retired and have been introduced to the Retirement for All Program, they have little to no involvement with family members and seem to be doing 'ok' with the natural support networks they created or have available to them in their community (i.e., friends, each other, support worker, etc.). The one exception is that David is supported by an agency that provides an Independent Living Worker for him, albeit on their terms (i.e., they are only available between the hours of 9 AM – 5 PM Monday to Friday, if you don't get the errands completed within the 1-1/2 hours allotted to you each week you have to wait until the following week to finish them; if you have a crisis outside of business hours you are instructed to call Mobile Crisis because no one will answer your call at the office on the weekends, etc.). Regardless, these three gentlemen would likely be viewed to have similar needs to one and other, and it is probable that they would be grouped or 'lumped' into a one-service-fits-all kind of program.

I believe that all three of the inquirers have a personal desire to (a) *belong* to 'something', (b) to *contribute* to 'something', and (c) to maintain/continue to develop an *identity*. Although 'retired', all three gentlemen have sought out opportunities to return to 'work' and have found security and enjoyment identifying a new 'boss' in their life. Opportunities to connect with others who can guide them in the development of new skills and help them take on new challenges appear to be important. This is similar to mainstream older adults who choose to 'unretire' in search of skill upgrade or to address their need to fill what is missing in their life since they left their job or career (Schlosser, Zinni, & Armstrong-Stassen, 2012).

Thinking back to my stepping onto the professional knowledge landscape, I relive a sacred/cover story I lived by/forced upon my friends at the senior centre. I had all the Retirement for All Program participants engage in age-appropriate activities because that is what the grand narrative told me is 'right'; engaging in activities and appearing to be age-appropriate is a way for people with disabilities to experience a normal life (Forster, 2010). My attempt to write a cover story telling 'mainstream' older adults that our group was just the same as they were because we enjoyed the same activities in the same context, was not only a lie but proved to be no fun for anyone. Writing a cover story to fit onto a sacred landscape is difficult and exhausting. I fear that the story I may have told the participants is that their time at the senior centre, and ultimately their retirement, may be stressful and confusing; wrought with unhappiness and anxiety; controlled by others who do not really know what they want.

I think about my inquirers and the cover stories, secret stories, and competing stories they are composing in their lives. Specifically, I wonder if Doug and Don are attempting to live a *counterstory* that suggests 'although we are labelled with an intellectual disability, we do not need the supportive programs that are suggested by the grand narrative. We can take care of ourselves, and each other.' They have expressed many times to me over the years that they do not have a ‘support worker’, nor do they need one. Perhaps the sacred story they are living by is not authored by an expert in the field of disability but rather by the community in which they lived and grew up. For example, planting and nurturing a garden is not a common activity that people labelled with intellectual disabilities engage in. In fact, even within the supportive structure of a group home you do not see the employees tend to a garden. (From my experience, many group home agencies contract others to tend to their lawns because the staff do not have time nor the interest to cut the grass, pull weeds, tend to foliage.) In fact, for others with a disability, planting a garden may be a novel idea, perhaps even a ‘pilot program’ created by a therapeutic recreation specialist as way to enhance skills. Yet for Doug and Don, gardening is an activity common to farm life and a history of living off the land; a story they lived with their family and rural neighbors. They are engaging in a life of normalcy, without having experts normalize them. Now, I cannot help but wonder if they experience tensions as they live out a counterstory; are they satisfied with the quality of their horticultural work? Perhaps they do not even notice, nor care.

As I continue to reflect on the time that Doug and Don and I spent in their garden, my professional knowledge leads me to think that they must have wanted, or *needed*, help. I cannot imagine that their mother’s garden was planted in several small pockets of soil surrounded by weeds and dense prairie grasses. Yet they made the most out of what was available to them and they continue to plant a garden season after season. What, if any, is the cover story they are living? And what is the secret story they are keeping to themselves? Is this why they do not let people – specifically me - into their home? What would one find upon opening the door? Is the house tidy with everything in its place or are items strewn about and cluttered amuck? Are the floors and furniture clean or dirty and soiled? Is the food in the fridge fresh or rotten with rancidity and mold? Is the laundry folded and put away? Are they living a secret story or is it just that they prefer their privacy?

When I think of other tensions that my inquirers may experience, I immediately think of place and temporality... and I think about loss. Doug and Don experienced a loss of land and closeness to nature, a loss of shared family experiences on the farm, a loss of connections with neighbors and the helping out with one another that is so familiar to rural life, a loss of opportunity for physical labor, and a loss of parents and family. Perhaps David's tensions with place and loss are experienced differently; a loss of freedom and rights in the walls of the institution, a loss of family and land (Scottish soil), a loss of the opportunity to experience the normalcy of childhood and adolescence in a community shared with other children, and a loss of feeling safe and secure in one's home and community.

I reflect on how my perceptions of living on the farm have changed over the years, even in the past months in which I have been engaged in this inquiry. During my time in the midst of farm life, I experienced stress. There is so much uncertainty with farming… the weather can affect one's livelihood to the point that entire crops can we wiped out in a flash… the health of the animals can be jeopardized with one bad bail of hay… and the resiliency of a farmer can solely depend on a machinery part that is 'in stock'. But walking alongside Doug and Don in their parade led me to reflect on my storied farming life. I cannot say that I have a better understanding of what occurred during my time there, but I can now reflect on the tensions and relive them in more educative ways. It is my time with Doug and Don that has helped me to realize – and remember – what it is that I loved so much about what I knew first.

Time changes *everything*.

Chapter 9

To What End Are We Programming?

"Somewhere along the way we developed a mistrust of idle time."

(MacGregor, 1996, n.p.)

In a recent conversation with a colleague, she was telling me about the heated discussion that ensued amongst her students in a 'Current issues in Sports and Recreation' class. They were talking about the benefits and drawbacks of organized sports for children and youth. One student claimed "If it wasn't for organized sport I would have been a mess when I was a teenager! It gave me somewhere to go, people to spend time with. It kept me out of trouble!" A mature student, a mother of two pre-teens, indicated that, "Organized sport has too many rules about who can play and when they can play! And it takes a toll on the parents who are driving their kids from A to B then back to A the next morning! There's nothing for my kids to just go play sports without all the rules or meddling parents! They can't even think on the field because there's so many people yelling at them telling them what to do!" My colleague was very pleased with the mother's comments which suggested that programmed activities could, in some ways, be detrimental to the development of youth. As she spoke, my mind wandered slightly as I reflected on the time I spent observing leisure activities in group homes. *The home with the less structured programming created more independence in the residents* (Rossow-Kimball & Goodwin, 2009). I wondered if parallels could be drawn between the youth sport movement and the programming narrative for people labelled with intellectual disabilities. Thus, I began to investigate and I soon discovered there are some similarities. (Please note that I am not making this comparison to suggest that adults labelled with intellectual disabilities are *like* children and youth. Rather I am making a comparison of the progression of the youth sport movement and the paradigmatic similarities to service provision for people with disabilities.)

The History of Organized [Sport and Disability] Programs

Jay Coakley and Peter Donnelly have spent much of their careers researching and writing about the experiences, philosophies, politicization, and culture of sport. In recent years, one question they have put forth to the sporting community, particularly to those who are involved in creating, facilitating, managing, and monitoring youth sport, is "Is there sufficient evidence to show that organized youth sports are worth all the time, money, and effort put into them?" (Coakley & Donnelly, 2004, p. 114). Through a critical lens, they recount the history of organized youth sport, originally crafted as a means to assimilate 'deviant' individuals or groups (i.e., First Nations people, immigrants, the unemployed, etc.) into society; organized sport was an attempt to address a social problem through social control. As time progressed, the purpose of organized sport was no longer for social control, but rather recognized as a valuable vehicle to generate character and life skills within the youth of the day. Today, participation in organized youth sport is commonplace. It is expected that parents will enroll their children into one type of program or another as a means to immerse them into a venue and experience which they believe – and society believes as a whole – will bestow values, enhance development, teach socialization, and strengthen character. Engagement in organized sport and activities is a thread commonly found in the grand narrative of today's youth.

It is relatively easy to draw parallels between the development of the youth sport movement and the history of services provided to individuals with disabilities. As a way to control the social deviancy generated by people with disabilities, institutions were developed to warehouse the population (Polloway et al., 1996). Eventually viewed as a potential benefit to the social economy, the development of groups homes and sheltered workshops replaced the institutions in hopes that newly skilled and 'normalized' laborers could contribute to society (Rosen, Bussone, Dakunchak, & Cramp Jr., 1993). Today, I see in my own community, programs abound to address the social, vocational, educational, recreational, intellectual, spiritual, hygienic, etcetera, needs of people with disabilities. It seems that the 'programming plot' runs thick throughout the grand narrative for people with disabilities. Just as youth sport exists, it is commonplace and expected that a person labelled with a disability will enroll in or enter into a facility that houses some kind of character/skill/growth-enhancing program. In fact, in my community, an individual labelled with an intellectual disability cannot access the services of a residential services agency (i.e., move into a group home or approved private service home) without having a day program placement (i.e., a spot or assigned seat in an activity centre or sheltered workshop). Essentially, if you do not have somewhere to go between the hours of 8 AM and 4 PM every weekday, you will not have a place to live.

Further exploration into the culture of youth sport reveals other common threads shared with the philosophy of service provision for people labelled with intellectual disabilities. Parents enroll their children into organized youth sport programs for many reasons, including (a) to demonstrate that they are "good parents... who account for the whereabouts and behaviour of their children twenty-four hours a day" (Coakley & Donnelly, 2004, p. 116), (b) as a means of social order to keep children active and "constructively occupied, out of trouble, and under the control of adults" (p. 117), (c) to protect children and youth from the dangers of the outside world where 'hanging out' or engaging in informal activities can be dangerous without adult supervision, and (d) their ability to readily access information and research which touts the benefits of engagement in sport for children and youth. Similarly, we 'program' for people with disabilities because (a) it is our duty as caregivers and professionals to be accountable for opportunities that will insure that people with disabilities experience optimal growth, assimilation, and a satisfactory quality of life (American Association on Intellectual & Developmental Disabilities, 2010; Bullock, Mahon, Killingsworth, 2010), (b) it is expected that their time should be kept busy and filled with 'things to do' (Rossow-Kimball & Goodwin, 2009; Stancliffe, 1997), and (c) parents and caregivers tend to overprotect individuals labelled with disabilities (Sanders, 2006).

What Value Lies in Programming?

Coakley and Donnelly (2004) suggest that proponents of organized youth sport should ask themselves some serious questions about the value of 'programming'. Specifically, while parents recognize the value of physical activity, their children continue to engage in sedentary behaviours even in the context of organized sport where they spend time sitting on a bench waiting their turn, or even worse, not playing at all because their skill is not up to par for the big game. Additionally, parents may feel that they are spending quality time with their child during organized activities, yet some youth have reported that they "grew to dread those times, which they remember as endlessly directive and judgmental" (Coakley & Donnelly, 2004, p. 120). Third, Coakley and Donnelly suggest that parents should consider if they are diluting the experience for their child, particularly when there is always someone present to tell he or she "Great job!" or "It's okay" that you lost/missed the ball/got hurt, etcetera.

Correspondingly, asking similar questions might be a valuable reflective exercise for the experts who endlessly program the lives of people labelled with intellectual disabilities. The research continues to report that this population tends to engage in sedentary activities, yet caregivers still fail to encourage a more physically active lifestyle (Dixon-Ibarra, Lee, & Dugala, 2013). The quality of the time that ‘programmers’ spend with individuals in a structured, contrived setting tends to be focused on the management of the environment, rather than on the experiences of the individuals (Rossow-Kimball & Goodwin, 2009). Finally, ‘helicopter’-caregiving and a tendency to overprotect may cause people with disabilities to internalize a sense of underachievement while failing to experience self-regulation and self-esteem in specific activities and in other aspects of their lives (Sanders, 2006).

A Bold Proposal

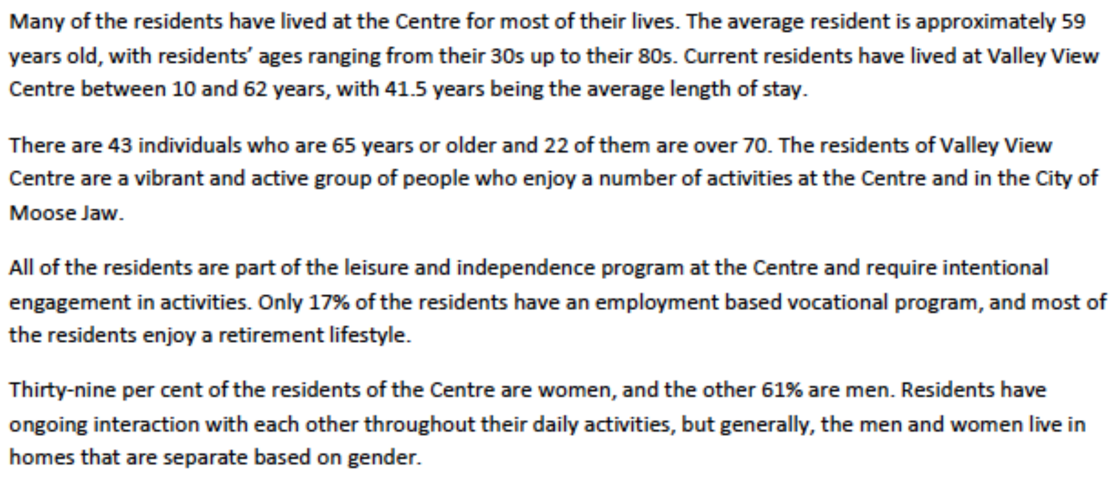
Is it too bold a suggestion to propose that the experts might do best by leaving well enough alone? That perhaps community-dwelling older adults labelled with intellectual disabilities do not require our expertise to program their retirement experiences? The problem that we would be faced with in the event we decided to relinquish our control is similar to the challenge in dismantling the adult-organized youth sport movement: the programming structure is too well established, too well rehearsed, and too far gone (Coakley & Donnelly, 2004). It is impossible to stop the momentum of a moving train, especially when academics, community leaders, caregivers, families, advocates, and self-advocates have spent decade upon decade fighting to address the disparities experienced by this marginalized group. I often joke to my students that “Every day we should be attempting to work ourselves out of a job!”... But what if we actually did?! I suppose it does sound preposterous to suggest that we stop asking for money and retract funding proposals to government bodies by declaring, “We’ve decided that we no longer desire or need social service to support people with disabilities in the community. Don’t worry, we’ve got this…”

However, the idea may not seem so preposterous when one considers the lack of funding provided to community agencies and self-advocates in supporting older adults labelled with intellectual disabilities to pursue or develop a meaningful retirement experience. Since 2007, the Government of Saskatchewan has provided over $202 million dollars to social services “to support the inclusion of people with disabilities in social and economic life” (Government of Saskatchewan, 2013, para. 1). This funding has aimed to meet diverse needs in many areas, including infrastructure (e.g., building of group homes), training (e.g., intensive autism treatment programs, mental health first aid to address the needs of those with a dual-diagnosis), human services (e.g., respite for families, increased wages and benefits for front-line workers to address recruitment and retention), health (e.g., FASD prevention programming, therapeutic programming), workforce development (e.g., job shadowing, skills training), and income support (e.g., increased daily living and food allowance).

Not typically one to look a gift horse in the mouth, I am disappointed to see that none of this funding has been specifically earmarked for aging adults labelled with intellectual disabilities. I do recognize that this population does reap some of the benefits of increased government funding, but despite annual proposals submitted to the Minister’s office - proposals which clearly outline the need for funding for retirement programs, education, and supports - the issue is not being addressed. In fact, for the last four years, I have had the honor to be selected as the delegate from the community to have an audience with the Minister of Social Services to discuss the challenges of supporting an ever-growing population of older adults labelled with intellectual disabilities to experience a meaningful retirement. Although I do feel that the Minister has an understanding of the problems facing the semi-/retired population (e.g., barriers to inclusion, lack of community capacity, ill-prepared and fatigued caregivers able/willing to assist with planning, etc.), there has been no indication that the government will support any kind of ‘programming’ to assist older adults labelled with intellectual disabilities to experience a meaningful retirement. Perhaps the community should be looking to the older adults themselves for answers.

Institutionalized 'Retirees'

In addition to the already-existing older adult community, I feel it is important to consider the needs of the aging population residing within the walls of the Valley View Centre in Moose Jaw, Saskatchewan. On February 24, 2012, the Minister of Social Services announced that the government would begin consulting with the residents of Valley View, their families, and other key stakeholders to "replace the current Valley View program... [to] develop services that better support the inclusion of people with disabilities in our communities..." (Valley View Centre Transition Planning Steering Committee, 2013a). To most, the announcement was thought to be timely and progressive; the last institution in Saskatchewan will finally close its doors. In February 2013, one year after the announcement, the Valley View Centre Transition Planning Steering Committee (2013b) provided a report to the Minister's office outlining recommendations to meet the needs of the 198 residents who would be transitioning out of the institution and into the community. It was decided that instead of creating one large transition plan, 198 individualized plans would best meet the needs of those who would experience the move. Within the report, the steering committee also provided information on the current Valley View Centre residents:



Many of the residents have lived at the Centre for most of their lives. The average resident is approximately 59 years old, with residents' ages ranging from their 30s up to their 80s. Current residents have lived at Valley View Centre between 10 and 62 years, with 41.5 years being the average length of stay.

There are 43 individuals who are 65 years or older and 22 of them are over 70. The residents of Valley View Centre are a vibrant and active group of people who enjoy a number of activities at the Centre and in the City of Moose Jaw.

All of the residents are part of the leisure and independence program at the Centre and require intentional engagement in activities. Only 17% of the residents have an employment based vocational program, and most of the residents enjoy a retirement lifestyle.

Thirty-nine per cent of the residents of the Centre are women, and the other 61% are men. Residents have ongoing interaction with each other throughout their daily activities, but generally, the men and women live in homes that are separate based on gender.

(Valley View Centre Transition Planning Steering Committee
Interim Report of the Transition Steering Committee, 2013b, p. 8)

Although the aging residents of Valley View Centre are enjoying a "retirement lifestyle", the experience of retirement will likely become quite different once transitioned into the community. Although not considered to be the community-dwelling older adults I spent time with during this journey, it is still important to question quality of the retirement lifestyle they are living. Regardless of the caregiving supports that will be available to assist/guide/develop retirement activities, I suspect the experience may *feel* very different once one leaves the confines of the walls in and around the institution and is no longer allowed to return. I am also left to wonder about the nature of 'intentional engagement' activities, particularly if the activities are created and facilitated by a staff member at the institution. How can one be sure that the activities are meaningful and not a contrived social construction of what retirement should be?

A Suggested Step-by-Step Program to Eliminate Programming

With a lack of social funding to address the creation of meaningful retirement experiences (or 'programs') for older adults labelled with intellectual disabilities, one may question how much longer we can or should advocate for support. Perhaps our energy may best be directed towards other actions. Looking again at the literature on organized youth sport, Coakley and Donnelly (2004) make the following suggestions to resolve some of the challenges in programmed sport opportunities, some of which could be applied to address the 'programming narrative' of the disability-sector (I have renamed them in parenthesis to be applicable to the programming in the disability community):

Increase action *(i.e., exercise self-determination)*. Organized sport, just as the nature of programming aimed to serve people with disabilities, emphasizes rules for standardized, contrived, and predictable conditions. In these circumstances, action is guided and often prevented rather than stimulated and self-regulated. Researchers have shown that when individuals labelled with intellectual disabilities are left to their own accord to identify, pursue, and experience personal leisure interests, they can do so successfully while reinforcing the likelihood that self-determined behaviours such as independence, spontaneity, autonomy, self-regulation, and choice-making will occur again (Rossow-Kimball & Goodwin, 2009; Wehmeyer & Sands, 1996). For the inquirers of this study, being in charge of their own 'programming' (i.e., choosing what to do, when to do it, whom to involve, etc.) helped them to exercise behaviours of self-determination; experiencing success when executing those behaviours reinforced them to engage in the activity again (e.g., Doug and Don meeting new people and making friends with individuals at the mall; David seeking out and finding a new 'boss' and 'job' at the church). It seems as though they flourished in the absence of a structured program simply because they had room to do so. (Again, my mind wanders back to Doug and Don's garden as I remember the corn growing amongst the weeds and grass; *if the organism has room to grow, it will!*)

Increase personal involvement *(i.e., encourage personally-meaningful skill development)***.** In organized sport, the individuals who are the most skilled tend to be offered the most 'play' time, leaving the unskilled participants sitting out of the activity. By maximizing involvement for all individuals, a greater variety of skills would be learned by a larger group of people which would allow everyone to participate. For people labelled with intellectual disabilities, opportunities to identify and pursue leisure interests should be provided to all, regardless of their assessed or *perceived* ability. Now, if one assumes that people labelled with intellectual disabilities prefer to be involved in choice-making when it comes to issues that will personally affect their lives, we may be able to further assume that Doug and Don's quality of life was likely enhanced because they were able to make personal and meaningful choices about what to do during their retirement. For instance, regardless of the availability of a 'programmed' retirement experience, they chose to forego activities within a structured context and create their own personally meaningful opportunities of engagement. This supports the idea that the subjective nature of leisure participation (i.e., indicating preference and choice) is most important during retirement, rather than engaging in programmed activities just for the sake of engagement (Badia, Begoña Orgaz, Verdugo, Ullán, & Martínez, 2013).

Create close scores *(i.e., reinforce successful experiences)***.** In youth sport, individuals report 'good games' as those which are close in score; when the opportunity for success is perceived to be attainable, even in the last seconds before the buzzer. "Since motivation partially depends on how people perceive their chances for success, a close game usually keeps players motivated and satisfied" (Coakley & Donnelly, 2004, p. 141). Providing opportunities for individuals labelled with intellectual disabilities to experience success in their pursuits will help them to stay motivated to continue engaging in those pursuits. For example, when David moved into his new apartment, he was concerned at the thought of not knowing anyone in the building. However, upon meeting his neighbors, spending time with residents in the common area, and realizing his sister lived in the building as well, he was encouraged to overcome his fears and it motivated him to volunteer and spend time in new contexts (i.e., work in 'the store' of his building) where he would imminently meet even more people!

Maintain friendships *(i.e., embrace opportunities for friendships)*. Coakley and Donnelly (2004) write that "organized sports may provide useful contexts for making friends, but players need more appropriate opportunities to nurture relationships [with others]" (p. 141). Through *self-enforcement*, individuals engaged in the game or activity will naturally come to understand the rules for engagement and be able to self-regulate to adhere to those rules. In other words, through observation, proximity, and the motivation to be engaged with others, individuals will learn how to successfully participate. The idea of self-enforcement takes me back to my time when I was working at the Autism Centre. In addition to my task of force-feeding a sandwich to Raymond (do you recall that story?), I was enlisted to work in the 'Socialization Group'. Once a week, I would work alongside five individuals with autism as they rehearsed a contrived 'coffee and chat' scenario. They would all sit around a table with empty coffee cups in front of them and read text or images from a script or Picture Exchange Communication System and 'visit' about weather, sports, or current events. The goal of the program was to increase the socialization skills of the participants. I often wondered about the effectiveness of such a program when each participant was practicing socialization skills with another individual who was equally – or less – socially skilled! Sure, there was self-enforcement, but of incorrect and contrived behaviours! For the inquirers of this journey, perhaps the time spent at the senior centre when they initially retired helped them to recognize and understand the dynamics and intricacies of socializing with others which ultimately provided them with the confidence to spend time with people in new contexts (i.e., at the mall, at church, etc.).

Prospect for change *(i.e., question change)***.** Organized programs typically make changes which "reflect a concern for the needs and well-being of [program participants]" (Coakley & Donnelly, 2004, p. 142) which ultimately results in focusing on efficiencies, tighter management, and increased organizational levels. In programs which support people with disabilities, program changes occur for similar reasons (Stancliffe & Lakin, 2005). However, in my experience, changes may also occur to address an adjustment in funding (e.g., increase or decrease in amount, the structure or how it is made available, the mandate of the funding agency and to whom the money can be provided to), the number and/or type of participants, a change in agency policy, or new anticipated outcomes. Regardless of program changes and the reason(s) for such changes, most often there is talk about 'measurable outcomes'; how can we be sure that the changes we are making are of benefit to the participants and how can we objectively assess their success?

Additionally, training and education come in to play in which the people supporting individuals in structured programs are required to learn more about leisure education, supported decision-making, functional assessments, and so on in order to prepare individuals to experience *something*. However, the inquirers of this study experienced success despite not participating in specialized training (i.e., learning how to make choices about what to do, how to use the bus, how to behave, etc.). When the inquirers needed to know how to take the bus somewhere they had never been, they simply asked the bus driver. When learning about events going on in the community, they paid attention to marketing on television, in newspapers, and billboards. When interacting with others they used social cues to engage. There has been no assessment of measurable outcomes, no educating of staff to work towards measurable outcomes, and no strategically planned program to address the needs.

It is apparent that ‘retirement success’ for the inquirers has occurred, for the most part, without intended, structured programming. Now, I want to understand *why*.

Chapter 10

Putting the Stories into Perspective: Searching for Cohesion

> It is far more important to set one's gaze toward a better future, to traffic in possibility, than it is to obsess about the disappointments and injuries of a dank, dark past.
>
> (Saleebey, 2006, p. 78)

Recently, I was invited to talk about my experience with narrative inquiry methodology to students enrolled in a graduate-level qualitative methods class. I have been an invited lecturer in this class for the past three years, and I always get the same question from the students: *But how do you analyze the data?!?* They ask as though they are looking for a recipe; a 'how-to' to help them make sense of what to do with stories. Clandinin (2013) suggests that narrative inquiry is "…fluid inquiry, not a set of procedures or linear steps to be followed but a relational inquiry methodology that is open to where the stories of participants' experiences take each researcher" (p. 33). Again, as a narrative inquirer, it is not my role, nor my right, to analyze or interpret the stories of my inquirers. My job is to understand the *relational*; to help them, myself, and the audience of this inquiry make sense of how their/our storied lives have come to be and exist alongside one and other. The theoretical framework for this inquiry *has been* the methodology of narrative inquiry.

My continued reading and learning into narrative inquiry has taught me that there are no answers to my questions; only more questions! What I need to work towards is coherence; to make sense of the stories. I need help to make sense of *why* and *how*. *Why* do Doug and Don seemingly thrive in the absence of immediate family support and no 'support worker' or ‘program’ to navigate their retirement; *how* does David continue to connect with others and develop new friendships despite leaving his entire network behind when he left the sheltered workshop? These gentlemen are living a competing story and I need more help to make sense of this. It is coherence that I am searching for; I need things to ‘make sense’ (Clandinin, 2013).

In February of 2013, I attended the National Aboriginal Physical Activity conference in Vancouver. I was listening to a researcher talk about ‘a new approach to sport and recreation for Aboriginal people in Canada’ (Paraschak, 2013). She spoke of the ‘deficit perspective’ and how it has dominated physical activity research in the Aboriginal population, reinforcing ‘a sense of hopelessness that things can/will get better’ and how it tends to ‘reproduce attention on problems’ (e.g., suicide rates, chronic health conditions, substance abuse, etc.). She suggested that a ‘strengths perspective’ be a lens through which to view physical activity experiences of marginalized groups. The strengths perspective highlights the strengths of the Aboriginal community (e.g., strong cultural identity, already existing positive qualities and values found within cultural practice, being holistically balanced, family and community oriented, etc.), and should be used to focus on what is *possible*. By assuming that this marginalized group holds ‘the inherent capacity for transformation’, current and future physical activity patterns and health behaviours can be changed resulting in better overall health outcomes.

Immediately, I could see the parallels between the Aboriginal community and people *with* disabilities. I could see how the focus on deficits was being used to situate the dominant story of retirement for older adults labelled with intellectual disabilities. I decided to further investigate the strengths perspective, as I hoped it would help me make sense of the *why* and *how* of my inquirers’ stories. Again, it is not my intention to apply this perspective to analyze the stories of my inquirers; rather it is my hope that it will help me make some meaning and sense out of this inquiry into their storied lives. To begin, I will share the history, development, and philosophical underpinnings of the strengths perspective with you.

The Strengths Perspective

Historically, the dominant narrative in fields such as social work, disability studies, and medicine have taken a 'deficits-based' approach; a professional assesses an individual's problems and creates an intervention to 'deal' with their inadequacies, illness(es), deficits, lack of achievement or functioning, and so on (Anderson & Heyne, 2012). The nature of the 'helping work' which is ultimately undertaken by professionals is situated in a negative state and defined by one's problems. Saleebey (2009) writes that the incentive to develop a strengths perspective is a response to "our culture's continued obsession with psychopathology, victimization, abnormality, and moral and interpersonal aberrations" (p. 2). The strengths perspective is an attempt to write a counterstory of possibility, hope, expectation, and independence in response to a dominant grand narrative of inadequacy, hopelessness, underachievement, and dependence. For example, a deficits approach sees the person as a 'case' or 'diagnosis' whereas the strengths perspective sees the person as unique with talents and resources; the deficits approach creates an intervention that is problem-focused whereas the strengths perspective will create an intervention that is possibility-focused; the deficits approach sees the professional as the expert whereas the strengths perspective sees that individuals, families, and communities are the experts; finally, the deficits approach aims to eliminate illness or dysfunction whereas the strengths perspective aims to enhance one's well-being and quality of life (Anderson & Heyne, 2012).

The strengths perspective (hereafter abbreviated SP) has been building with great interest in social work over the past two decades (Saleebey, 2009). Philosophically, the strengths-based approach puts the lens of focus on "what people want their lives to be like, and what resources and strengths they have or need to get there" (p. 12). Practically, practitioners of this perspective turn their eyes to possibility and work to "rally clients' interests, capacities, motivations, resources, and emotions in the work of reaching their hopes and dreams, helping them find pathways to those goals..." (p. 1).

The principles of the SP are based on the ideas of (a) liberation and empowerment, and (b) alienation and oppression. "Liberation is founded on the idea of possibility: the opportunities for choice, commitment, and action whether pursued in relative tranquility or in grievous circumstance" (Saleebey, 2009, p. 7). Saleebey contends that people have an inherent craving to be 'heroic' and move past current conditions in hopes of greater opportunities for achievement. The capacity to realize this does not exist only in times of adversity or crisis, but rather can also be experienced in the day-to-day occupations of individuals as they try new behaviours, engage in new ways of thinking, develop new relationships, or take on the challenge of new activities to change the routine existence of their lives. Individuals become empowered once the facets of the dominant narrative (i.e., institutions, community, etc.) recognize one's strengths and resources by responding to and accepting one's new ways of thinking and doing.

Alienation and oppression can manifest themselves through hatred, racism, prejudice, and intolerance in contexts of relationships, institutions, and community. Being subjected to these experiences can make us feel inadequate, scared, and hopeless. However, "at times our fear and trembling is best handled by taking matters into our own hands, individually or collectively, and dealing the instrumentalities of fear and loathing onto others" (Saleebey, 2009, p. 9). This is when the human spirit is aroused as one attempts to move on from a negative experience and engage in new opportunities to flourish and grow. The strengths perspective is a "focus on the future - through the dreams and goals of the [individual] - and the generating of new possibilities for [him or her] (Dybicz, 2011, p. 248).

Finding Coherence with Strength

I cannot help but wonder if the strengths perspective is the best window from which to view the stories of retirement that the inquirers are living. In my Master's thesis which explored the self-determined leisure experience of women living in group homes (Rossow-Kimball & Goodwin, 2009), I discovered that it was likely that the women in the Cairn Group Home which had little to no support staff to help them engage in leisure activities were in fact more self-determined and in control of their leisure experiences than the women who lived in the Elm Group Home which staffed a 'recreation worker' each day to guide (and ultimately eliminate opportunities for) self-determined leisure. Thus, fewer opportunities to access supportive and structured leisure programs essentially *forced* the women of Cairn Home to become more independent and self-determined in their leisure, a facet of their lives that they quite enjoyed! The Elm Home women were required to engage in contrived leisure experiences guided by a staff person and thus were more likely to be unhappy and engage in behaviours that would remove them from leisure situations that they did not enjoy (e.g., middle-aged 'homebody' Daria would yell profanities at strangers during community outings so she would be sent back to the group home). It could be that the lack of structured retirement programs, or at least having the choice whether or not to access a structured program, provided an opportunity for growth for the inquirers. At the very least, perhaps the structure provided by a retirement program acted as a vehicle for skill enhancement, a building block for confidence, and a familiar blanket of security when necessary. The inquirers of this journey had a desire to move past stable conditions, take matters into their own hands, and experience a fulfilling retirement.

Fortigenesis: The Continual Development of Human Capacity

As I continue to reflect on my time with the inquirers pre-during-post this inquiry, I am still amazed at their continued growth as individuals. They have developed the confidence to exercise new skills in new places with new people. They have surpassed the expectations laid out by the grand narrative. At one point during my thinking about this research puzzle, I thought that perhaps the inquirers were *resilient*; they were able to 'recover' from a difficult situation (i.e., leaving the familiarity and security of the sheltered workshop for a retirement experience in the community).

However, it is difficult for me to suggest that these gentlemen are resilient or if they thrived or flourished in spite of this significant change in their lives because I do not have knowledge of their previous life experiences outside of the last 10 years or so. Perhaps David was resilient when he was able to leave the walls of the institution for the freedom in the community; perhaps Doug and Don were resilient when leaving the peacefulness of farm for the complexities that city life can offer. However, in my time walking in their parades, I cannot recall witnessing a regression in which they were required to 'bounce back'; they have always demonstrated *fortigenesis* or a continual building of strength, competency, and capacity (Strumpfer, 2006). Strumpfer writes that people are able to continually develop fortigenesis because they have an innate need to (a) achieve subjective well-being, (b) create meaning and develop a sense of coherence in their lives, (c) optimize opportunities to experience personal growth and wisdom, and (d) feel they belong to a group or be able to develop interpersonal relationships *when they are needed*.

Thus, it could be that the inquirers, upon recognizing that the 'meaning-making' or coherence that they were most familiar with in their lives was gone, chose to pursue opportunities for engagement and relationships with others to address their innate need to continue personal growth, to feel that they belong, and to have a sense of well-being in their lives. Furthermore, it could be that their engagement in self-directed leisure activities helped them to reconstruct a [meaningful] life story that was continuous with their past (Kleiber, Hutchinson, & Williams, 2002). For example, Doug and Don quite enjoyed attending farm-related events in the community such as The Farm Progress Show (an annual farm expo in Regina) and Agribition (a trade show which includes livestock sales, educational exhibits, agricultural technology and services). David found his involvement with the Saskatchewan Roughriders team provided him with the opportunity to 'work' for a 'boss' in a context in which he felt he was needed. I expect that all three gentlemen will continue on a path of fortigenesis as long as their health, energy, and spirit allows them to do so.

Chapter 11

Finally, as a way to mark the completion of this journey (and perhaps to consider potential new beginnings), I have written three letters: one for Doug and Don, one for David, and one for me. The letters reveal my thoughts about our independent/shared storied lives and how we have/and will continue to/come together to live in educative ways. The writing is candid and sincere; open and raw; reflective and heartfelt. I feel this writing was necessary so I could "rethink moments of tension and the educative promise these moments hold" (Clandinin, 2013, p. 76). Here, I reveal my vulnerability.

It is not my intention to share this writing with my inquirers, rather I have used this as an exercise to help me to continue to make sense of what it all means… our stories… our lives… and our relational being.

Dear Doug & Don,

As I write this letter to you, I laugh at the thought of dropping it off or even mailing it to you; I don't think you'd be home long enough to read it!

What a long winter! Thankfully, this afternoon the weather feels different as the sun is shining; you can actually feel the warmth it has to offer. Spring is upon us! Today I've come to my office to write. I look out towards the campus green for inspiration and I notice one tree that stands out from the others simply because it hasn't leafed out yet. I wonder if the long winter has taken its toll on the young sapling's development. I hope the light spring rain and warmth from the sun will nurture it back to health. I cannot help but think of your garden; I am hopeful that you will be able to plant a crop of vegetables this year to enjoy throughout the summer and early fall.

I am writing to you today to say 'thank you' for making space in your parade for me to walk alongside you. Many years ago, when we first met, you warmly greeted me at the senior centre on my first day of work. The senior centre is a place where we both began to learn 'what we knew first' about retirement; the two of you were learning new skills, making new friends, and establishing your roles in that space. I, too, made new friends, worked to establish my role in that space, all the while trying to figure out what retirement looked like/should look like for you and your friends who were leaving the woodshop.

I have a question for you... Did you know that the Retirement for All program was designed specifically for the two of you? Yet you never seemed interested in spending time with the group as a whole. I always wondered if it was because you were only interested in floor curling or maybe you were too busy as you preferred to keep your daily appointments with your acquaintances in the community. I wondered if you ever really identified yourselves to be a part of the Retirement for All group. The advisory committee always asked me to encourage you to attend more activities at the centre, specifically the dances. And I remember asking you several times, 'How come you don't come to the dances? They're lots of fun!' and you would always reply, 'Nah, we don't want to.'

I think that one of the things we both learned during our time there together is that for some individuals, the senior centre is not necessarily the best place to experience retirement. Reluctantly, I admit that my stepping in and out of the professional knowledge landscape - all the while negotiating back and forth between my secret stories and cover stories - took my energy away from making that realization sooner. I spent so much time trying to please the mainstream older adults so they would accept the Retirement for All program that I failed to focus on the wants and needs of the Retirement for All participants. I wonder if I disheartened them by pointing out their inability to cope (Norman, 2000). For that, I am embarrassed and – at times – ashamed.

I recently spent some time with representatives from the self-advocacy group People First of Canada. One of the major goals of the People First movement is deinstitutionalization. They define an institution as:

> … any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size. (People First of Canada, 2006).

As I sat and listened to their members speak, I reflected on my time on the professional knowledge landscape. I thought about all of the institutions I had worked in... I thought about the group homes that I worked in under the guidance of policy, the community programs in which community-inclusion theory determined our scheduled activities and outings, and the behaviour modification programs I was required to follow in an attempt to normalize my 'clients'. And then I thought about Retirement for All, a program in which...

- People congregate together based on their label of intellectual disability
- The congregation is isolated and segregated from the general membership due to their label
- They are not allowed to exercise control over some aspects of their experience in that place, for example choosing when to get a refreshment

I thought about the original intent of the Retirement for All program. The aim was to provide an opportunity for a 'normalized' retirement experience as older adults left the institutional setting of their sheltered workshop. Now, I question if we have been obliviously creating an institution of retirement. Sometimes I wonder, Doug and Don, if this is one of the reasons why you chose not to be a part of the Retirement for All group. Did you feel that we were trying to 'institutionalize' you? Did you have the foresight that the we, the experts, failed to see?

I hope that the two of you recognize your successes and take pride in your achievements. Please know that I do not mean this in a condescending way. Your resistance to receive structured support is intriguing to me. You mentioned that your neighbors help you out when you need it and you call your brother once a week to talk, but you do not have any formalized supports in place. You have even refused the simplest of offers for help from me: a car ride. Do you remember that incredibly cold day in January when we met at Classic Buffet for lunch? It was minus 40 degrees Celsius with the wind-chill and I offered to give you a ride home so you would not have to wait at the bus stop. You told me that you did not need a ride; 'We like taking the bus.' I couldn't believe that you would rather stand outside in the cold and wait for a bus than ride in a warm car! Anyone else would jump at the chance for a ride, yet you chose to wait for the bus. I realize now it was likely so you could visit with the bus driver or other passengers. I wonder if, for the two of you, it's not about reaching the destination, but rather your preference to experience the journey.

During our time on this journey, and since our last visit, I have thought a great deal about your parents. I wonder what the experience was like for them to raise you in the early 1950s, a time when it was socially expected that the two of you would be best served in an institutional setting. I wonder if they were pioneers in their community as they chose to raise you at home, send you to the local school, and ensure you were a daily part of their lives and the lives of others. I wonder if because they had expectations for you to experience a 'normal' life is why you are doing so well on your own now? You never had to be *integrated* into something because you were never *segregated* to begin with!

I want to thank you for reminding me of 'what I knew first'. I will always remember the days we spent wandering and exploring your old farmyard. I did not realize how much nor why I missed the prairie until I stepped back into the stillness of it all ... the rustling of grasses and leaves, the song of the meadowlark, the smell of sage, and watching the wheat dance like waves on the ocean... these are just some of the things I took for granted in my youth, a time when I couldn't wait to leave the farm for the big city. Now, my heart aches for those moments... and for the people who will never experience that stillness nor have an appreciation for it. It makes me realize how important it is for my daughter, Wilder, to experience the same knowledge… how important it is for me that she knows *what I knew first*.

Speaking of Wilder… Now that I am at home with her, I don't get in to see you as often at the senior centre. But you have my telephone number if you ever need to get a hold of me. I still remember the day – years ago now - that I gave you my phone number. I have secretly hoped that someday you would call me. But you never have! Perhaps I need you more than you need me. Sometimes I wonder if the stories we tell people with disabilities about themselves – that they require assistance from the 'experts' – is just the 'experts' telling themselves a story that they need to be needed.

I suppose I should go; I've been in the office for most of the day. Ian and Wilder are at home and are expecting me soon. I am thankful that the two of you have each other… I hope you will always have each other.

I just noticed out my window that in the few hours I've been here, the young sapling has begun to leaf out. Perhaps the warmth from the sun and spring showers today were the perfect combination of nourishment. Or maybe the sun was able to peak through the clouds at just the right moment to show me that although small, the tree *is* continuing its growth. It looks like it is going to be okay… everything is going to be okay.

Perhaps it's all about perspective.

With sincere thanks,
Brenda

P.S. I’m going to leave you with some of the lyrics from a 2005 Neil Young song, *Prairie Wind*. I listen to the lyrics and I think about what I knew first; perhaps this is what you knew first, too.

Prairie Wind

Trying to remember what my daddy said
Before too much time took away his head
He said we're going back and I'll show you what I'm talking about
Going back to Cypress River, back to the old farmhouse

(Prairie wind blowing through my head)
(Prairie wind blowing through my head)
(Trying to remember what Daddy said)
(Prairie wind blowing through my head)

I tried to tell the people but they never heard a word I say
They say there's nothing out there but wheat fields anyway
Just a farmer's wife hanging laundry in her back yard
Out on the prairie where the winds blow long and hard

Late at night, lights dancing in the northern sky
Like the Indian spirits trying to show me how to fly
You can see into the future but it may be a mirage
Like a new car sitting there in your old garage

There's a place on the prairie where evil and goodness play
Daddy told me all about it but I don't remember what he said
It might be afternoon and it might be the dead of night
But you'll know when you see it 'cause it sure is a hell of a sight

(Prairie wind blowing through my head)
(Prairie wind blowing through my head)
(Trying to remember what Daddy said)
(Prairie wind blowing through my head)

Dear David,

Many years ago, on the day that we met, I drove to your apartment unsure of whom I was going to meet that morning. I remember the uncertainty I felt when I pulled up to your building. I reflected on the meetings I had with my co-workers earlier that week (some, your previous SILP workers). I was warned about you; I was told that you were grouchy, you played your Playboy videos too loudly (so loud the neighbors would complain), and you often smelled badly. In fact, I was told that you smelled so bad on occasion your previous worker refused to take you to the bank, out for coffee, and declined to help you get your weekly groceries. She told me that on more than one occasion she had "kicked [you] out of the car before the seatbelt was even buckled" because you "fucking stink".

To be honest David, on some days, you *did* seem grouchy, I *could* hear your Playboy channel when your apartment window was open, and… you did *smell*. But I did not refuse to support you. The sacred story that was shared with me by my mentors told me that – in your best interests – I should 'manage' your behaviours and your 'being' in a way that would make you more acceptable by those with whom you share a community… to make you 'socially invisible' if you will. And David, there were times when I attempted to manage you… and in fact, I still do. Specifically, it's usually when you walk out of your way to talk to a complete stranger simply because he or she is wearing a Pats Hockey hat or a Saskatchewan Roughrider t-shirt. My professional knowledge tells me, "Follow David and help him manage this conversation so he doesn't look foolish in front of a complete stranger!" or "Stop David before he gets this random person trapped in a conversation they don't want to be in!" My practical knowledge tells me to let you be and let the stranger decide if he or she wants to be engaged with you. Ultimately, I always find myself in the midst of a cover story as I walk up and say, "Hi!

Another Rider fan, hey David? They're everywhere!" and join in on the conversation. I know that I do this for protection, David. I think I am doing it to protect you from awkwardness, although now I wonder if I am trying to protect *myself*. Regardless, I need to remember that while I am walking alongside you in your parade, I need to respect your leadership.

When I reflect on our time together, David, I never would have imagined that those weekly trips to the grocery store would have sown the seeds to establish the well-rooted friendship we now have. I think about the sacred story that my mentors told me about best support practices; a tale of relational disconnectedness necessitated by normalization. Yet the only sacredness to this story is found in the adoration we have for one and other. I do adore you, David. You have and continue to be a gift in my life. I am thankful that we have both had the courage to continue our friendship beyond our 'SILP duties', despite the tensions we may face as I/we traverse the professional landscape together.

I am most thankful that you have welcomed my family into your life. Ian has learned a great deal from your presence and he has become a role model to his friends, whom by the way, quite enjoy your company. Sometimes, I see them gaze at you and it looks like they are trying to 'figure you out' as though they are confused about who you are and why you are a part of our lives.

David, I will never forget the day we told you that we were expecting a baby. No one showed more genuine happiness than you! The tears that ran down your face as you embraced me and said, 'My girl's going to have a little baby!' are forever etched in my mind. I think your elation tossed me into the potentially joyous reality of what was about to happen to us. I had spent weeks in a state of shock and dismay about our miraculous, medically-unassisted conception despite a lengthy history of infertility and failed IVF cycles. I remember telling both of our families about what a miracle it was that we conceived naturally, finally revealing to them the emotional, physical, and financial strain we endured for years. Yet they both reacted with a similar response: ‘Well at least you’re *finally* having a baby! Neither of you are getting any younger!’ David, it felt like you understood the significance of this baby in our lives when no one else did.

And on the day Wilder Grace was born, when Ian phoned you to tell you the good news, he cried when he could hear the tears of joy in your trembling voice. When you met Wilder for the first time you cried… you cried again a few weeks later on the day you got to hold her and feed her a bottle… and you cried again just last week when she wrapped her tiny hand around your finger when you sat on a bench beside her stroller at the park. You certainly love our little girl, David, and I hope we are all together long enough that she will get to know you and how much you care for her. I know she will love you, too.

During the moments we share with Wilder, David, I think so much about your life and the experiences you have not yet lived. I wonder if you have ever been in love and if so what ever happened to your ‘other’; I wonder what kind of father you would have been and what lessons would be most important for you to teach your children. I wonder if the potential for these life experiences were storied out of you by other professionals. Normalization, intended for people with intellectual disabilities to “establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” (Wolfensberger, 1972, p. 28), has been spouted to service providers/support workers/caregivers for decades. Yet, as Wolfensberger noted, at times “human managers endorse the principle readily while engaging in practices quite opposed to it” (p. 29). How could we impose the idea of normalization in some circumstances (i.e., wear clean clothes, get your own groceries, don't stink in public) but not, at the very least, encourage it in other aspects (i.e., fall in love, experience intimacy, discover companionship)? It makes me wonder how *I* storied you in the past.

Sadly David, there will be a day when our time together will end. It will be an unwelcome yet necessary continuation of our 'being-ness' as our souls must move onto other worlds to embark on new journeys and tasks. There is no certainty that we will be together again, but at this time, in this place, we are together. Again, I'm reminded of one of my favorite songs, *Just Breathe* (Pearl Jam, 2009). For some, this song is an appropriate reflection of their love for one and other. For us, I believe it is a message of reciprocal respect, teaching and learning, awareness of the human condition, and humanity's need for relational connectedness. The lyrics are a suitable tribute to our friendship, shared stories, and the mutual respect we have for one and other. It is my voice 'coming clean', stepping onto the professional landscape to reveal that it is ok to care for and about the people I have/continue to support.

Thank you so much for allowing me to walk in your parade and for leading me with gentleness and patience.

With great adoration and respect,

Brenda

Just Breathe

Yes, I understand that every life must end, uh-huh
As we sit alone, I know someday we must go, uh-huh
Oh I'm a lucky man, to count on both hands the ones I love
Some folks just have one, yeah others they got none, uh-huh
Stay with me... let's just breathe...

Practiced all my sins, never gonna let me win, uh-huh
Under everything, just another human being, uh-huh
Yeah I don't wanna hurt, there's so much in this world to make me bleed
Stay with me, you're all I see...

Did I say that I need you?
Did I say that I want you?
Oh, if I didn't I'm a fool you see
No one knows this more than me
As I come clean...

I wonder every day, as I look upon your face, uh-huh
Everything you gave and nothing you would take, oh no
Nothing you would take,
Everything you gave.

Did I say that I need you?
Oh, did I say that I want you?
Oh, if I didn't I'm a fool, you see
No one knows this more than me
As I come clean, ahhh...

Nothing you would take
Everything you gave
Hold me till I die
Meet you on the other side...

To Whom It May Concern:

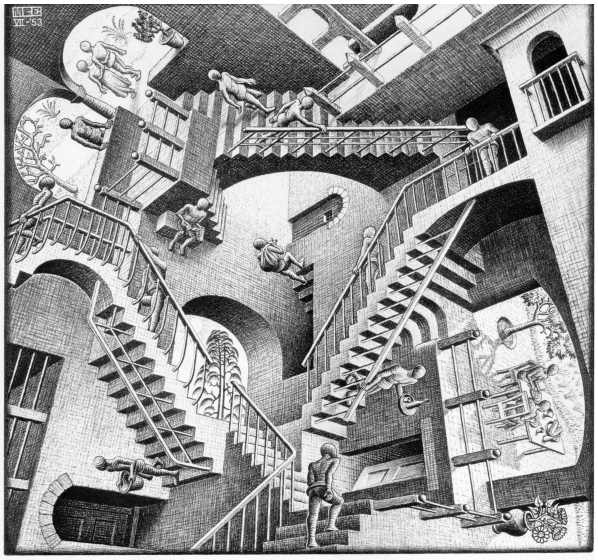
I have never written a letter to myself although I have heard that it can be a useful, therapeutic task. I thought that it is only fair that I write to myself as an inquirer in this journey, as I have written to the others (David, Doug & Don). However, as I reflected on my writing, I realized that this letter could be addressed to anyone... myself, my committee members, other narrative inquirers, students, etcetera. Thus, I have written this to 'Whom It May Concern'.

My first thoughts drift to my storied life on the professional knowledge landscape. I think about where I have lived my stories alongside others in a context of support. It is not so much *place* that comes to mind, but rather *people*. People like Raymond, Carl, and my inquirers. As a young woman negotiating her way through the midst of sacred stories (stories that were told to me by my supervisors and other 'experts') I did not realize until just recently how 'tension-filled' my time on the landscape was. I experienced many struggles with people, but the struggles were seldom with/between the people I supported. Rather, the struggles were with the authors and narrators of the sacred stories whom I was living alongside on the professional knowledge landscape. I wonder if there is room in narrative inquiry to distinguish between 'authors' and 'narrators', for those telling me 'how to behave/think/relate' were not necessarily the ones *authoring* these stories of ideal practice, but rather they were simply *retelling* the story to me as it was told to them (i.e., the grand narrative).

As an instructor, I have the privilege of working alongside young men and women who intend to make a career of walking alongside people with disabilities, whether it be in the context of a school, a group home, a clinic, or in the community. I must remember to be wakeful to the 'whys' and 'hows' of the stories I share with them, for I have gained some coherence of my storied past during my time in this inquiry. I suppose that one of the most significant things I have learned about my time on the professional knowledge landscape is that I, too, am an author. I am composing a life. Yet it is not just my life that I am composing but it is also the lives of others whom I have chosen to spend time with… and those who have chosen to spend time with me… in our respective parades.

I can recall times in my life when I had great fear about losing someone… a good friend from high school who I cannot relate to anymore, co-workers at previous jobs, reputable students who have moved on from our undergraduate program, my grandfather. I feared losing the day-to-day opportunities to be near or with them, particularly when our time together was filled with laughs, thought provoking conversation, or teaching moments. What I have come to realize is that regardless of the lack of proximity to others, there continues to be the prospect to live in *educative ways* through our shared stories. The challenge I have is to ensure that I am always mindful of these opportunities.

On the cover of Dr. Clandinin's 2013 book *Engaging in Narrative Inquiry*, there is an image of MC Esher's 1953 lithograph print entitled *Relativity*:



Prior to viewing this image in the context of narrative inquiry, I really never gave much thought to the meaning of this particular piece of work. Described as ‘a world in which the normal laws of gravity do not apply’, The National Art Gallery in Washington, D.C. suggests it is “a fine example of Escher's focus on unusual, and often conflicting, points of view” (National Art Gallery, 2013). As I continue to study the image it begins to make sense.

While we live our storied lives on storied landscapes, we seamlessly transcend our being-ness into the day-to-day experiences of others, often unaware of the influence we may have on how we live our lives. As I look at the faceless individuals going about their what seems to be quite ordinary business such as dining, shopping, and reading, I am reminded of the words of John McGee who said that a person labelled with an intellectual disability often views caregivers as ‘a faceless, anonymous, average of the other 120 people who have come into his life’. The caregivers who enter their parade, often without an invitation, may be unaware of how their presence can either enhance or negate one’s feelings of personal value, confidence, engagement, and security. However, just as in Escher’s Relativity, our worlds are drawn together through experience often without our knowing. It is only when we choose to become awakened to each other’s presence will we come to understand the significance we have in other’s lives.

Finally, I will leave you with the following story which I feel illuminates the possibilities of relational being; a story of awakening and the coming together of lives; a story of living in, and appreciating, the moments...

‘Grandpa’ Ray

As I carry Wilder down the bridge to get on the plane for the next leg of our journey to Abbotsford, I look into her big blue eyes then whisper into her tiny ear, “You be a good little goose! Not a silly one! We have to sit quietly on the plane... It’s only an hour. Okay?” With her soother plunked deep in her mouth, she gazes into my eyes with indifference. The 6 a.m. flight from Regina to Calgary was not near as bad as I thought it was going to be. She just started walking a week ago and I know how hard it is for her to sit still. I only wish the people on the previous flight could know that the whining she serenaded them with for the past hour is so unlike her. But she just wants and *needs* to move. When I was pregnant with her, she was always moving. There were days that I would be in meetings and people would comment on how ‘busy’ my baby was as they could see the movement coming from within my belly through my shirt. I still remember the guilt I felt one afternoon when Ian came home and I was crying my eyes out because it felt like she had been doing somersaults and cartwheels all day. “I know I should be enjoying this! I know it’s a sign of health and vitality! But I wish she would just relax and stop wiggling around so much!” I often wondered what she would be like as an infant once she was able to crawl, scoot and walk. Would she be a busy body always needing to be in motion? The answer is a resounding *yes*.

We step onto the aircraft. As we wait for other passengers to get to their seats I reflect on the logic of airlines to offer pre-boarding to parents with small children. Why on earth would any parent take advantage of such a perk? Just as I did in the Regina airport, I choose to be the last passenger on the flight. The less time we trap ourselves on the plane with others, the happier everyone will be! Finally, we slowly move down the aisle and I look for my seat. I notice that my arm is getting tired. My ‘little goose’ is not so little anymore. Although tall and skinny like her father, she still weighs nearly 20 pounds and I’ve been holding her with one arm for the last 10 minutes. “This could be a long week,” I think to myself. “Am I crazy for going to Vancouver Island all by myself with her?” I know Ian’s parents are going to meet us on the ferry at Horseshoe Bay this afternoon and I know they are going to be of great help during our trip but I still wish Ian was here. I feel like there’s only so many tasks I can ask his parents to help me with. After all, this is their end-of-summer vacation, too.

Usually I like to sit beside the window when I fly so I can rest my head against the wall. However, for this trip, I’ve booked all aisle seats so I can make an easy get-a-way to the bathroom for a change table when needed. As a new parent, I find myself asking previously unthinkable questions like, “What are the chances she will have her 10 a.m. poop at 8 a.m.?” Slim to none I hope. I find row 8 and awkwardly sit in the last empty seat on the plane. I try to hold Wilder upright while placing my bag under the seat in front of me. At this point, I realize just how much I’m sweating. I think it’s pretty obvious that I look like a new mom; I just hope it also looks like I’ve got it together, somewhat.

I am afraid to look into the face of the poor soul sitting next to me. If he looks anything like the fellow I sat beside on the previous flight, I won’t even get a “I’m-tolerating-you-but-know-I-don’t-like-you-sitting-here” smile for the next hour. Before I can look, I need to get settled and get this seatbelt on. Suddenly, I hear a voice:

“And isn’t she lovely? Let me hold her! I just love children!”

I look to my left and beside me sits an older gentleman dressed in a nice navy suit and matching tie. His hair is thick and gray and coiffed in a retro kind of way, like he just stepped out of the 1950s. He is smiling at Wilder with his hands open reaching towards her.

Immediately, he feels friendly to me and without much thought I hand my daughter off to this complete stranger.

"Thank you so much! I'm going to apologize in advance for any disruption we may cause. She's such a busy girl and she's going to want down to cruise around in a few minutes. She'll probably whine a bit when I have to hold her. Fortunately this is a quick flight and..."

"You know what? You don't worry about it," he interrupted. "I have 8 children. Three of my own and five we adopted. And I've got 10 grandchildren! You don't worry! We'll have a great flight! I'm Ray."

"Hi! I'm Brenda. And this is Wilder."

"Wilder? Like Laura Ingalls Wilder? She's beautiful! How old is she?"

"She will be one year in two weeks!" Ray has no idea how much my mother will love to hear that he referenced Laura Ingalls Wilder, the author of the Little House on the Prairie books. My mom was not too keen on the name 'Wilder' for her granddaughter. However, when I told her that Wilder's name came from memories I have of her reading and sharing the Little House series of books with me when I was younger, she has come to love the name. The name *Wilder* reminds me of nature, the prairies, wilderness, and landscape. Although it is usually recognized as a boy's name, Ian and I felt it could be a lovely girl's name, too.

"Is she walking yet? I bet she is! She's strong! Look at how she's pushing against the seat in front of me!"

"She just started walking last week!" I look into Wilder's eyes as she gazes into mine, still with indifference, her soother plunked deep into her mouth, and her legs stretched out with her little feet pressing against the seat in front of her. She doesn't seem to mind being in the arms of this stranger. Thankfully, she's never been one to 'make strange'. I credit my involvement in the community for her ability to adapt as she has been attending meetings with me since she was a handful of weeks old. Tons of people have held her in their arms and she's never minded once.

The flight attendant comes by to give me the spiel about takeoff and landing and to be sure that she is facing me with her body pressed up against mine. What's interesting is that she is talking to Ray, too, as though we are travelling together. I suppose it does look like we are a team as we are conversing about Wilder as she looks so comfortable in his arms. Ray and I both go along with it and smile to one and other. The flight attendant leaves, the pilot comes on the PA system to tell the crew to 'prepare doors and cross check for departure'. We begin to taxi down the runway.

"I can take her now..." I offer.

"I'm okay! No sense in disturbing a content baby!"

Wow! That's what *I* always say! Sometimes I wonder what others think about my parenting. I have surprised myself over the last year with how comfortably I fell into this role. I've never been anxious about anything; I believe it's best to take things as they come. Embrace the moments that are good and withstand the moments that are bad because *nothing lasts forever*. I never interrupt her independent play because I feel she needs to learn to be comfortable being by herself. And I never talk 'baby talk'; what's the point of teaching her words that we're going to have to correct in a few months? I let her explore on her own, fall when it's safe, and rarely clear an area so she'll always have a path of least resistance. To some, I wonder if I look lazy or unengaged in my daughter's development. I often need to remind myself to stop worrying about what other people think.

As the plane moves faster and faster, I can feel that we are almost ready to lift off. Wilder is sitting quietly on Ray's lap facing the seat in front of her. None of us are concerned that we have not heeded the instructions for take off from the flight attendant. The nose of the plane picks up and we are in the air. Wilder, again, seems indifferent to what is going on around her. She is so much like her father. I am thankful for this. Once we reach the desired altitude, the seat belt light is turned off and Ray stands Wilder up on his knees. She is peering over the seats and trying to see the faces attached to the people in front of her. Then, Ray open his tray table and lets Wilder stand on it. She is in her glory! I'm expecting the flight attendant to come and tell us to behave ourselves, but Ray keeps a close eye on who is watching; he quietly and carefully sits Wilder down when it is necessary. He plays this game with her throughout most of our trip to Abbotsford.

During our flight, Ray and I visit about our lives. He is inquisitive about my work, my family, where I grew up, my schooling, and our plans for our trip to Vancouver Island. I ask similar questions, although he has much more to tell me as he has lived a longer and more storied life. I learn that he has been married for over 50 years. He and his wife adopted several Aboriginal children after having three children of their own, and he loves spending time with his grandchildren. He is a musician, mastering several instruments, but playing the piano is his favorite. He comes from a family of musicians. He tells me that his mother spent a lifetime composing songs to sing to her children and he carries these songs with him wherever he goes. He begins to sing to Wilder and she looks into his eyes *longingly*. Before long, she is fast asleep on his lap.

Time passes quickly on the flight. We will soon begin our descent and I find myself somewhat sad at the thought of leaving 'Grandpa Ray', a name he coined for himself over the last hour. He invites me to bring Ian and Wilder into his music store in Edmonton where he will play the piano and sing for her. He writes his contact information on a piece of paper and I agree to contact him when I come to Edmonton for my PhD defense.

I take a moment to ask Ray why he is traveling so early in the morning in his perfectly pressed navy suit. "Are you going to Abbotsford for work?"

"No, dear. My sister is dying of cancer in Langley. My four brothers, two sisters and I are all meeting today to spend the weekend with her. My brother will pick me up at the airport this morning and we will go to the hospital."

"Oh... I'm sorry, Ray..."

"Don't be, dear. We are going to have a nice weekend. I'm going to sing some songs to her, songs that my mother wrote for us when we were children. Just like the songs I sang to Wilder this morning... I think she liked them! She's still out!"

"Yes, Ray, I *know* she liked them."

"You have a good baby here. I hope you know that." He looks at her face as she lays in his arms sound asleep. He runs his finger over her cheek. I notice how perfect her skin is, how peaceful she looks, and how perfect a moment this is for all three of us.

"I know it, Ray! I'm really lucky! She is a great baby..."

"And you're a good mom, Brenda. You're doing a great job! Look at how happy and relaxed she is!"

"Thanks, Ray."

"And your husband... I bet he's a good man. Take care of him. I want to meet him when you come to Edmonton. I'll sing to him, too!" he smiles and winks at me.

I smile at Ray and take a moment to think of my grandpa. I wonder if my grandpa would be thinking and feeling the same as Ray; that I'm a good mom, that Wilder is a good baby, and that Ian is still a good man. My mind wanders briefly to the image of a grain truck sitting in a field... I see myself and my grandfather sitting in the cab as we wait for the combine to finish its round so it can unload. It's quiet and I enjoy the stillness of the prairie as I look over the golden sea of wheat. I love being with my grandpa. I miss him dearly.

I look at Ray and wonder if my presence today has affected him the way his presence has affected me. Will he share the story about his time with Wilder and I with his sister the way I will share our story with others in my life? I realize that Ray and I were meant to meet today, to remind each other of what is important, and to relive *what we knew first*.

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